AN EXPLORATION OF STORIES OF OLDER PERSONS AND FAMILY MEMBERS LIVING WITH DEMENTIA

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A submission presented in partial fulfilment of the
requirements of the University of South Wales/Prifysgol
De Cymru for the degree of Doctor of Philosophy

April 2021

“The dominant narrative is a horror story. People with Alzheimer's are perceived as zombies, bodies without minds, waiting for valiant researchers to find a cure. For Alice and me, the story was different. Alzheimer's was a time of healing and magic. Of course, there is loss with dementia, but what matters is how we approach our losses and our gains. Reframing dementia as a different way of being, as a window into another reality, lets people living in that state be our teachers — useful, true humans who contribute to our collective good, instead of scary zombies.”

(Dana Walrath, Alzheimer’s Through the Looking Glass, pp. 2)

Abstract

The aim of this study is to explore the lived experience of older people living with dementia and their family members. Exploring both perspectives of dementia can offer a deeper understanding into the lived experiences as they are equally important. There are many guidelines and policies that state what the standard of care, information and support should be for people affected by dementia, yet the literature suggests these resources are not satisfactory.

This study is qualitative and used descriptive phenomenology and life story work to explore participants' journey with dementia. Ten older people with dementia participated in this study, along with 12 family members, who were all video recorded whilst sharing their stories of life both before and after a dementia diagnosis. All participants were given the opportunity to amend their video recordings which were then returned to the participants as keepsakes. The narratives were analysed through a bespoke analysis method combining Colaizzi's (1978) descriptive phenomenology analysis framework and Burnard's (1991) framework for analysing interview data.

For people with dementia, key themes were identity and resilience, whereby their changing cognitive and physical abilities result in changes to their sense of self. Regardless of this adversity, all participants try to remain positive and optimistic. The family members experience ongoing loss as their loved one's condition deteriorates; despite this, they try to remain hopeful and make the best of their situation, but sometimes it can become overwhelming as they struggle to cope with the reality of living with dementia and the increasing responsibilities. All participants feel isolated from society as people will purposely avoid them or treat them differently. This segregation often results in them having to remain independent and deal with things alone as there is no one to turn to for support. For those with dementia, they desire social acceptance, which they often struggle to find outside of dementia support groups.

The contribution to new knowledge includes findings that are not supported by the literature, such as a couple's intimate relationship diminishing as the dementia progresses and the reaction of family members to their loved one’s diagnosis. Furthermore, an original element of this study is the use of video recorded life stories as the data collection tool. Recommendations from this study include researchers using alternative methods of data collection to explore different elements of life with dementia. Areas where education and additional funding may be beneficial are suggested to help those feeling isolated by dementia to remain mainstream members of society, with ample support networks.

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Author’s Declaration

This is to certify that, except where specific reference is made, the work described in this thesis is the result of my own research. Neither this thesis, nor any part of it, has been presented, or is currently submitted, in candidature for any other award at this or any other University.

Signed AWalker

Candidate

Date …………30/10/2020…………………………......

Funders

This project was funded by KESS 2 (Knowledge Economy Skills Scholarship) and conducted in collaboration with Hafod Care Association, Aneurin Bevan University Health Board and Cwm Taf Morgannwg University Health Board. KESS 2 is a pan-Wales higher level skills initiative led by Bangor University on behalf of the higher education sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys. The scholarship for this study covered October 2017 to October 2020.

Confidentiality Statement

Pseudonyms have been used throughout this thesis to protect the identities of the research participants, the residential care homes and the NHS memory clinics that hosted the study.

Acknowledgments

This thesis would not have been possible without the assistance and support of many people, who are acknowledged here.

My journey began with Dr Anne Fothergill, who proposed this research project, attained the funding and appointed me as the student. More importantly, she believed in my ability to obtain a PhD and guided me throughout the journey. For all of this, and more, I will forever be grateful.

I have had supervision from Prof Joyce Kenkre, Dr Nicky Genders, Dr Rachel Iredale and Dr Philip Tyson, at varying points during my studentship. They have provided unique insight and skills to my thesis. Thank you all for your encouragement, support and constructive feedback.

I would like to thank Geraint Morgan, June Clark, Amanda Whent and Robert Richards for acting as my company advisors, granting me access into the services and ensuring that I had everything that I needed to complete my studies.

Thanks also to the care home managers and memory clinic senior nurses who identified and recruited participants to this study for me.

Special thanks are due to all the research participants, who gave up their time to share their personal stories with me. Their honesty, bravery and commitment to living well with dementia is inspiring. Without their contribution, this thesis would not exist.

This has been a learning experience which was further supported by KESS and USW's Graduate Research Office's training programmes. I also owe thanks to Toby Bradshaw (USW IT Department) for spending hours of his time teaching me how to edit the videos and burn them to DVD.

To the other PhD students in EM023, we began this journey as peers and finish as friends. Thank you for your companionship, humour and a never-ending supply of coffee.

Thank you to my family for their support, love and reassurance. Lastly, to my (now) husband, Thomas, thank you for putting aside your own career aspirations to allow mine to thrive, and for always providing exactly what I needed.

Key Terms

Carers Members of the family of patients, and friends of the patient, who are involved in their care.

Caregiving Proving care and support to someone who has physical, psychological or developmental needs.

Care Home A residential setting where a number of older people live, usually in single occupant rooms and have access to on site care services.

Care Provider An organisation or person deemed capable of providing health and social care services.

Charles Bonnet Syndrome Charles Bonnet Syndrome is caused when a person's sight deteriorates, they begin to hallucinate. While the hallucinations are not caused by the person's dementia, the dementia can make the hallucinations more bizarre (NHS, 2018).

Dementia Unit A section of a care home which provides care specifically to people with dementia. This care could include personal care, medication administrating, meals etc. For the residents' safety, these sections of the care home will have locked doors at all entrances and exits to prevent people from leaving and keep them safe.

Domiciliary Care Proving help and support to people within their own home in the form of personal care and household tasks.

Deprivation of Liberty (DoLS) A safeguarding tool that is applied when someone goes into a care home or hospital and cannot make decisions regarding their treatment (Mind, 2019).

DSM-5 A manual used by clinicians to diagnose psychiatric illnesses.

Early Onset Dementia Dementia that is diagnosed in those below 65 years of age (also known as younger onset dementia).

Family Caregiver Providing unpaid care and support to a family member who has physical, psychological or developmental needs.

Hits The number of articles generated by a database during a literature search that are relevant to the key words searched for.

Holistic Treating the whole person, including social and mental factors, rather than focusing on just the symptoms of their disease.

Humanistic Emphasising the value of human beings, individually and collectively.

ICD-11 A guide used by clinicians to classify and code diagnoses, symptoms and treatments.

Memory Clinic A medical clinic specialising in memory disorders.

Nursing Unit A section of the care home which provides continuous full-time nursing care from qualified nursing staff to the residents.

Older Person A person sixty-five years of age, or above as defined by the health and social care services in Wales.

Person Centred Care Focusing the care on the needs of the person in receipt of the care, not on the care providers.

Phenomenology A philosophical movement or a research method that studies the structures of experience.

Posterior Cortical Atrophy A subtype of Alzheimer's Disease that causes problems with vision, literacy and numeracy.

Primary Progressive Aphasia A neurological syndrome that impairs speech and language ability and is often caused by Alzheimer's Disease.

Qualitative Research Research that focuses on non-numerical data.

Quantitative Research Research that measures variables using numerical data.

Residential Unit A section of a care home which provides care for older people with a number of different basic personal care needs, for example, washing, dressing and meal preparation. Unlike the dementia unit, the residential units are not protected by locked doors, residents are able to come and go as they please.

Resilience Adapting well in the face of adversity.

TIA Transient ischemic attack, or “mini stroke”, is a temporary disruption in the blood flow reaching the brain. The symptoms are like a stroke but only last up to 24 hours.

Well-Being Well-being means a person is happy, healthy and is comfortable with their life and what they do.

Abbreviations

APA American Psychiatric Association

ASSIA Applied Social Sciences Index and Abstracts

DoLS Deprivation of Liberty Safeguarding

DSM-V Diagnostic and Statistical Manual, 5th edition.

GP General Practitioner

ICD-11 International Classification of Diseases, 11th edition

IRAS Integrated Research Applications System is a single online system for applying for ethical approval for health and social care research within the UK. Without ethical approval, a study cannot recruit participants from within a health board setting.

MAS Memory Assessment Service

NHS National Health Service

NICE National Institute for Health and Care Excellence

PCA Posterior Cortical Atrophy

PPA Primary Progressive Aphasia

SIGLE System for Information on Grey Literature in Europe

TIA Transient Ischaemic Attack

USW University of South Wales

WHO World Health Organisation

CHAPTER 1 Research Background

"Each person has come to be who they are by a route that is uniquely their own; every stage of the journey has left its mark"
(Tom Kitwood, 1997, Dementia Reconsidered: The Person Comes First, pp. 15)

1.1 Introduction to this Thesis

This thesis explores the experiences of those affected by dementia through narratives and storytelling. Dementia is a broad term and refers to a set of symptoms, such as memory loss and difficulty with thinking, which are caused when the brain is impaired due to disease, damage or injury (Alzheimer's Society, 2017). Alzheimer's Disease is an example of a disease which causes dementia. Damage to the brain may include a stroke or haemorrhage while injuries to the brain that can cause dementia, includes blows to the head (dementia pugilistica) (Zeilig, 2015). Dementia is organic and progressive in nature, causing cognitive functioning to deteriorate beyond what would be considered *"normal ageing"* (World Health Organisation, 2019). There are many forms of dementia (World Health Organisation, 2019) with some estimating that there are over 200 different types (Dementia UK, 2018). The four main types of dementia are Alzheimer's Disease, vascular dementia, Lewy body and frontotemporal dementia (Alzheimer's Society, 2017). These have differing symptomologies that interfere with the activities associated with daily living and furthermore, these symptoms will vary from person to person, and diagnosis to diagnosis (Mitchell and Agnelli, 2015). *"Thus, is it crucial to recognise that dementia represents more than a medical condition and that wider social, cultural and political context also influences the ways in which people live with the diagnosis"* (Zeilig, 2015, pp. 13). This is apparent throughout this thesis, whereby policy, cultural beliefs and social experiences may alter people's experience of living with dementia.

In this first chapter, the reader is presented with dementia prevalence figures, dementia costs and dementia care in the UK. Various dementia legislations, policies and frameworks have been considered throughout, but more so in this introductory chapter; the table below offers a brief summary of those referenced most throughout this thesis (Table 1). A timeline of all relevant policies, legislation and frameworks impacting upon people affected by dementia in Wales, can be found in Appendix A (pp 342). This chapter then goes on to outline the aims and research questions for this study, followed by an explanation of the importance of originality in PhD research, and concludes with the plan for the remainder of this thesis.

Table 1: Summary of policies, legislations and frameworks relevant to this thesis

Legislation, policy or framework	**Relevance to people affected by dementia**
National Dementia Strategy (2009)	This was the first national dementia strategy for the UK (GOV.UK, 2009). The strategy had 3 objectives; to drastically improve dementia services through earlier diagnosis and intervention, a higher quality of life and improved awareness.
Equality Act (2010)	Recognises dementia as a disability and protects disabled people (amongst others) from unfair discrimination. This was updated in 2015 and includes some minor amendments.
Social Services and Well-Being (Wales) Act (2014)	Imposes regulations on health boards, local authorities and Welsh ministers to ensure their work promotes the well-being of those who need care and support. The Act ensures that people have control over the support they need, assessments are focused on the individual, families have equal rights to support whilst they provide care and information and advice is easily accessible to all.
The Care Act (2014)	This act states that the wellbeing of people living with dementia can be preserved by involving the person with dementia in the decision making about their care, furthermore, the wellbeing of the family must be considered. Provisions need to be implemented to ensure the person with dementia remains a part of their community. People with dementia and family members should be granted access to a wealth of information and advice about services available to them.
Dementia Action Plan Wales (2018)	The Welsh Government is aiming to increase awareness of dementia as this will allow the community to support people affected by dementia and allow for more timely diagnoses. Once diagnosed, people affected by the condition will be granted access to formal information and support.

1.1.1 Terminology

This thesis explores the experiences of older people with dementia; the definition of an older person living with dementia is someone 65 years of age or above (Age UK, 2019) who has a confirmed dementia diagnosis. Dementia is not an inevitable part of aging and can affect younger people (World Health Organisation, 2017). Young onset dementia is used to describe cases of dementia that occur before the person is 65 years old (Chemali *et al.*, 2012) and is not the topic of interest for this PhD study. To further confirm how the health boards frame their services around older people, the steering committee members were asked to confirm that the "older person's services" were for those aged 65 and above; their email confirmation of this can be found in Appendix B (pp. 353).

Throughout this thesis, reference is made to "*people affected by dementia*"; this is shorthand for *"older people with a dementia diagnosis, their family members and friends"*. When making specific reference to older people with a dementia diagnosis, the terms *"older person with dementia", "person with dementia*" or "*older person living with dementia*" are used interchangeably. Similarly, the term *"family member*" is used interchangeably with caregiver, adult children and spouse. When making the distinction between family members who provide care and paid care providers, the term "*paid carers*" is used for the latter.

This study recruited participants with any form of dementia. Throughout this thesis, when discussing more than one form of dementia, the umbrella term *"dementia*" is used. When making specific reference to a certain dementia diagnoses, that diagnosis is named. This is more evident within the literature review chapter where studies have been conducted on specific types of dementia and this distinction is made.

1.1.2 Initial Reflexive Act

Central to qualitative dissertations is the process of reflexivity (Davis, 2020). *"If a researcher clearly describes the contextual intersecting relationships between the participants and themselves (reflexivity), it not only increases the creditability of the findings but also deepens our understanding of the work"* (Dodgson, 2019, pp. 220).

For this thesis, the research student's own reflective accounts are interwoven throughout and can be found after the summary of each chapter, in blue text. The aim of including such personal reflections is for the reader to understand the relationship between the researcher and the context of the research (Barrett *et al.,* 2020). This may offer a rationale for some of the decisions made and ultimately explain the narrative behind this PhD (Enosh and Ben-Ari, 2015). The final chapter of this thesis is dedicated to a more detailed personal reflection (pp 274).

Me, Myself and I

I feel it is necessary for me to introduce myself, briefly, to the reader so that they may understand this thesis better. My prior education, work experience and interests have all influenced this PhD. Chapter 10 is dedicated to reflecting upon this journey and is where you will find the in-depth explanations of the factors influencing this research. As we go through, I have highlighted some of the more poignant details at the end of each corresponding chapter. Naturally, some are longer than others but it is important to begin with a brief explanation of who I am.

I am Alex Walker, MSc, BSc. Both in Psychology. I have spent six years of my life studying psychology (including A levels) with great emphasis on the importance of quantitative data. Qualitative methods seemed to be put aside. This impacted upon my chosen methodology and analysis, but the reflection of this comes after Chapter 4.

My work experience is short. I dedicated four years to helping vulnerable adults remain in their own homes for as long as possible by providing whatever care and support they needed. Any carer will tell you, clients very quickly become friends and when they are let down or mistreated, you take it personally. I am no different. I have seen first-hand the way that older people with dementia are treated by support services and some family members. This is one of the reasons behind me choosing this topic of research for my PhD.

1.2 Context

This section delves into statistical information regarding dementia figures and a forecast for how these will increase in the coming years. It then discusses dementia in relation to disability, human rights, mental capacity and research. Relevant legislation, policies and frameworks are identified throughout.

1.2.1 Dementia figures forecast

There are roughly 50 million people worldwide with a dementia diagnosis (World Health Organisation, 2019) and 850,000 of these live within the UK (House of Commons, 2019). Globally, almost 9.9 million people develop dementia each year (Prince *et al*., 2015). However, a recent study by Ura *et al.,* (2020) found that a large proportion of older people with dementia go undiagnosed, leading them to believe that the dementia figures above only illustrate a fraction of the real statistics. One in fourteen people over the age of 65 will have dementia; this increases to one in six over the age of 80 (Mental Health Foundation, 2015). Due to the aging population, it has been estimated that 82 million people will have dementia by 2030 (World Health Organisation, 2019). This number is expected to increase, with an estimated 132 million people worldwide developing dementia by 2050 (World Health Organisation, 2019). In the UK, dementia is the second leading cause of death in over 65s; the first being coronary heart disease (Office of National Statistics, 2020).

This study was conducted in Wales, therefore, contains specific references to Welsh policy and Welsh statistics throughout. Within Wales, England, Scotland and Northern Ireland, there are distinct differences between the NHS and social services organisations due to devolution (National Audit Office, 2012). Devolution refers to the transfer of authority and funding from national (UK) to local (Wales) governments (Local Government Association, 2020), which creates, for example, Welsh policies and differences in spending between Wales and England. In 2018, 27% of the Welsh population were over 65 and by 2030, it is estimated that this will increase to 33% due to the aging population (Older People’s Commissioner for Wales, 2019), which will result in more people developing dementia. This makes dementia one of the largest health and social care issues in Wales (Welsh Government, 2017). There are

46,800 people currently living in Wales with a dementia diagnosis (Wittenberg *et al.*, 2019).

1.2.2 Disability and dementia

Dementia is a major cause of disability and dependence amongst older people and has a significant impact on their families and friends (World Health Organisation, 2017). Dementia is considered a long term medical disability; the Equality Act's (2010; 2015, pp. 15) definition of disability is *"a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day to day activities*". Furthermore, it states that no one is to be discriminated against due to race, gender, ethnicity, religion, sexual orientation or disability. The Equality Act (2010) protects disabled people from unfair discrimination and aims to use official regulations to benefit people with disabilities, including people with dementia (Mental Health Foundation, 2015).

It has been acknowledged that recognising people with dementia as *"disabled" "could place people with dementia, as self-advocates, at the centre of their own stories, and help provide an enabling identity"* (Shakespeare et al., 2017, pp. 2). They would be protected by disability legislations and be encompassed within the Disabled People's Movement of "*nothing about us without us"* (Dementia Alliance International, 2017). "*Whether individuals diagnosed with dementia actually come to self-identify as disabled people is an entirely different matter* (Thomas and Milligan, 2018, pp. 118)*.* For some, identifying as *"disabled"* can result in a loss of personhood and a sense of being controlled, they may also feel discriminated against and susceptible to domestic abuse (Brittain *et al.,* 2010; Boye and Yan, 2016).

1.2.3 Human rights and dementia

The first political initiatives to address the basic human rights of people with dementia were introduced in 1998; the Human Rights Act (HRA) and the European Convention on Human Rights (ECHR). Both the HRA (1998) and ECHR (1998) provide a legal framework that all health and social care workers adhere to, including the necessity to respect the dignity of people using their services. Policy and day to day practices of all health and social care workers are underpinned by, and should adhere to, the HRA (1998) and ECHR (1998). The HRA (1998) emphasises that everyone has the same civil and legal rights, and protects people from physical, psychological, financial, emotional and sexual abuse. It provides a legal framework for patients and their family members to challenge the "*professionals*" about what is best for them (Social Care Institute for Excellence, 2013). While the ECHR (1998) outlines sixteen fundamental human rights. Of these sixteen, three are particularly relevant to people with dementia and their family members. Article 3 states that no one shall be subject to degrading treatment. Article 5 says that everyone has the right to liberty and security. Article 14 declares that everyone is entitled to freedom from discrimination on the grounds of a disability (including dementia). Adherence to these articles should prevent people with dementia from feeling isolated and should enable them to believe that they are mainstream members of society.

The Worldwide Alzheimer's Report (2019) found that 60% of 70,000 people worldwide believe that it is important to remove all responsibility from a person with a dementia diagnosis; it has been argued that such an attitude will ultimately strip that person of their basic human rights (Dixon, Laing and Valentine, 2020; World Alzheimer's Report, 2019). This is further exacerbated by the negotiations regarding Brexit, whereby any EU laws will no longer apply to those living within the UK (UK Parliament, 2019) and henceforth, the ECHR (1998) and HRA (1998) will also be redundant.

The human rights approach to dementia places emphasis on the civil, political, economic, cultural and social rights of people living with dementia (Bartlett and O'Connor, 2010; World Health Organisation, 2016). It is central to the World Health Organisation's (2016) Global Action Plan on the public health response to dementia that encourages countries worldwide to cross check their legislation with the action plan. The human rights based approach has influenced legislation and policy within the UK and asserts that people living with dementia must be seen as a mainstream member of society, must be supported to live within their community as an independent individual and must be treated with respect and dignity (World Health Organisation, 2016). This emphasis on human rights relates closely to the social model of dementia which is discussed in depth in chapter 2 (pp 33) of this thesis.

Some claimed that the human rights approach has adapted and improved upon the social model of disability (Bantekas *et al.,* 2018). Lawson and Beckett (2021) found that the two are often used interchangeably as an opposing view to the medical model (pp 28), yet they are different. Degener (2016) suggests that the human rights approach is the most recent model of disability, with its' predecessor being the social model which, in turn, offered an alternative to the medical model of dementia (both of which are discussed in chapter 2). While the social model of disability solely focussed on anti-discretionary policies and civil rights, the human rights approach to dementia encompasses the civil, political, human, economic, social and cultural rights of the person (Degener, 2016; Lawson and Beckett, 2021). The human rights approach to dementia has therefore gained prominence and influence over the legislations and policies governing the lives of those living with the condition.

1.2.4 Mental capacity and dementia

For people with dementia, there is a pervasive belief that upon receiving a diagnosis, they become immediately and permanently labelled as incapable of making any independent decisions (Brooks *et al*., 2017). This is in violation of the Mental Capacity Act (2005) which states that everyone has assumed capacity until it can be proven otherwise, irrespective of a diagnosis (Department of Health, 2005). The Mental Capacity Act (2005) ensures that people are empowered to make their own decisions. Likewise, the Care Act (2014) states that local authorities must not make assumptions about a person with dementia (Article 1). If a person is no longer able to make decisions about their care and treatment in care/nursing homes or hospital, the Mental Capacity Act (2005) allows the carers of that person to apply for Deprivation of Liberty Safeguards (DoLS) to be implemented. These result in the person not being allowed to leave that facility (hospital or care/nursing home). The Mental Capacity Act (2005) ensures that the DoLS are appropriate for the person's circumstances however, they only apply to people living in England or Wales, and only those in hospital, care or nursing homes (Department of Health, 2005).

Amendments to the Mental Capacity Act (2005) in 2020 meant that the DoLS were no longer applicable. As of August 2020, the DoLS are being replaced by Liberty Protection Safeguards (LPS) which harness the same goals as DoLS but ensure more streamline procedures are in place (Gov.UK, 2020). LPS will be implemented if a person has a mental disorder and lacks capacity to consent to care arrangements; the care arrangements must be necessary and proportionate to that person's likelihood of causing harm to themselves or another (Gov.UK, 2020). Both the DoLS and LPS state that the person lacks capacity to consent to care arrangements but may still be able to consent to alternative tasks; for example, taking part in research.

The Mental Capacity Act (2005) was designed and intended for everyday use by anyone who works with a person lacking capacity. Its' purpose is to empower and protect vulnerable people who may not be able to make decisions for themselves (Legislation.Gov.UK, 2005). However, its' incorporation into the everyday routines of those professionals has not been successful, with most admitting that they do not have time within their daily roles to adhere to the Mental Capacity Act (Marshall and Sprung, 2018). When used correctly, the Mental Capacity Act (2005) offers protection for patients and practitioners, therefore, the House of Lords has strongly recommended that it becomes a part of daily practice (House of Lords, 2014). To achieve this, practitioners need to begin viewing it as a necessity, not an option, which requires a cultural shift and increased societal understandings (Marshall and Sprung, 2018).

The Mental Capacity Act (2005) offers a standard for assessing the capacity of a person on a regular basis (Department of Health, 2005). These guidelines can be used by many professionals, including researchers when conducting dementia research as fluctuating capacity is a common symptom (Trachsel *et al.,* 2014). These standards were incorporated into the research for this thesis (pp 100) and specify that the patient has to be able to understand, retain and reiterate information regarding the research study and provide an informed decision on their choice to participate or not.

1.2.5 Research into dementia

Despite the impact that dementia has on society, research into dementia remains desperately underfunded (Alzheimer's Research Trust, 2010) and there is a general dearth of research from the perspectives of people with dementia (Boer *et al*., 2007).

Existing research has historically focussed on the family members experience or asked them to offer a proxy account for what the person with dementia is thinking or feeling, but over the years, researchers have become more inclusive of those living with the condition and have begun exploring their experiences through one to one conversations. This may be due to the increased attention given to dementia research, as highlighted within several legislations, policies and frameworks.

The Social Care Research and Development Strategy for Wales 2018-2023 (Welsh Government, 2017) has identified three areas that research in Wales needs to target: home care, children in care and dementia. The emphasis on increasing dementia research is also evident within the National Dementia Vision for Wales (2011), Prime Minister's Challenge on Dementia (2012), G8 Dementia Summit (2013), Prime Minister Challenge on Dementia 2020 (2016) and the Dementia Action Plan Wales (2018). Researchers can often be discouraged from conducting research with those who have dementia as ethical committees can be reluctant to grant approval for studies using vulnerable populations, yet research to understand the experiences of these vulnerable groups is essential for building a strong evidence base for best practice (West *et al.,* 2017). The Prime Minister's Challenge on Dementia 2020 (2016) plan acknowledges that research into understanding and treating dementia is vital (Department of Health, 2016); however, currently, people are living with dementia. Equal effort needs to be put into researching support and services aimed at making life with dementia easier (Department of Health, 2016). Dementia care research needs to find new and innovative ways to support people to live well with dementia in both community and care environments (Department of Health, 2016). This next section outlines the different care settings available to people living with dementia, how common they are and any legislation, policy or frameworks concerning them.

1.3 Dementia Care

"Here in the UK, the cost of dementia [care and medication] is £23 billion and globally it's approaching $600 billion[1]… But the real reason to do something about dementia is not financial. The real reason is human. Everyone deserves to live their final years with dignity, respect and the support of loved ones".
(Jeremy Hunt, speaking at the 2013 G8 Dementia Summit)

The total global and societal cost of dementia care in 2015 was $818 billion[2] (World Health Organisation, 2019), this is likely to have increased in recent years and will continue to increase. *"If dementia care was a country, it would be the world's 18th largest economy*" (Alzheimer's Disease International, 2010, pp. 38). In 2015, the Welsh Government invested £7 billion into dementia care (Alzheimer's Society, 2015). Within the Dementia Action Plan Wales (2018), the Welsh government set out to invest a further £10 million a year into dementia care. Dementia care is a vague concept and covers 4 main areas: family members providing care, formal home carers, care or nursing homes and hospital care (Welsh Government, 2018). These differ greatly and are discussed individually below as they are all essential steps on a person's journey with dementia.

1.3.1 Family members providing care

A large portion of dementia care in the UK is provided by family members of the person with dementia (World Health Organisation, 2019). In 2015, approximately 700,000 people in the UK were caring for a loved one with dementia (Alzheimer's Research UK, 2015). These family members are often unpaid and save the government an estimated £11 billion per year (Alzheimer's Society, 2014). The experiences of these family members can vary from adapting well to their caregiving role, through to struggling to cope and having to find additional support; this is

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[1] Equates to approximately £460 billion

[2] Equates to approximately £650 billion

explored further within the literature review (pp 64). Over 50% of dementia caregivers report that their health has suffered as a direct result of their caregiving responsibilities (World Alzheimer's Report, 2019). Family members who provide care for their loved ones will often sacrifice their own wellbeing to ensure that their relative has the best quality care (Alzheimer's Research UK, 2015). They are often referred to as the invisible second patient as they experience physical and psychological ill-health, social isolation and financial hardship as a direct result of caring for their loved one (Brodaty, 2009). Yet a recent six year, longitudinal study found that family caregivers did not report that their mental or physical health had declined over the six year period; contrary to this, only the participants who were not caregivers at any point during the six years reported that their wellbeing had deteriorated (Wranker *et al.,* 2020). Wranker *et al.,* (2020) concluded that being a caregiver positively impacted upon the person's health although it is unclear why.

The first governmental legislation to specifically mention the wellbeing of family members of people with dementia was the National Service Framework for Older People (2001) which stated that health and social care workers need to *"recognise any psychological distress experienced by the older person, carer or their family"* (Department of Health, 2001, pp 26). Similarly, the Mental Health (Wales) Measure (2010) specified that carers of people with dementia should be given "*information and advice about the services available to them, to meet their reasonable requirements for such information and advice"* (Article 5). Further policies that make reference to the well-being of family caregivers are the Social Services and Well-Being (Wales) Act (2014) and the Care Act (2014); both of which state that caregivers have equal rights to support, information and advice as the person being cared for (Gov.UK, 2014). Their needs must be considered, and they must have joint control, along with the person with dementia, about the care and support they receive (Gov.UK, 2014). Furthermore, the Care Act (2014) states that family members must be protected from the challenging behaviours displayed by some people with dementia, particularly physical abuse (Article 14). The Nursing Vision and Strategy (refreshed edition) (2016) stated that all family members of people with dementia must be treated with respect and dignity (Department of Health, 2016).

Despite the guidance and law outlined above, literature suggests that family members providing care are not given enough information about their loved one's diagnosis, they are not directed to appropriate support services and often feel isolated when having to care for their loved one alone (Andrews *et al.,* 2017; Gorska *et al.,* 2013). When they feel that they can no longer cope with the demands of caring for their relative alone, they will seek out additional care. For some, they incorporate home carers into their daily routine to help with the strain of caregiving.

1.3.2 Paid home carers

The Dementia Action Plan Wales (2018) aims to improve care and support to ensure that people with dementia can stay in their own homes for as long as possible (Welsh Government, 2018). Staying within their own homes is only practical with the right support, therefore, the person may need outside carers to assist them with daily tasks; that is domiciliary care or home carers (Age UK, 2020). Approximately two thirds of people with dementia are living within their own homes (Mental Health Foundation, 2015) and roughly 25% of these receive formal care packages (Lewis *et al*., 2014). This equates to 75% of people with dementia living in their own homes are either cared for by a relative (as above) or without any support at all. As stated previously, many family caregivers do so without any monetary gain and when they need additional support, they have to pay for it. People with dementia are expected to pay for their own domiciliary care if they have over £14,000 in savings (Alzheimer's Society, 2018) and despite paying for their own care, three in five of the local council authorities in Wales found that demand for care packages outweighed capacity to deliver, leaving many service users without formal care and reliant on their relatives (BBC, 2017).

Article 4 of the Care Act (2014) states that care packages should no longer contain 15-minute visits; all visits must be longer, and the services should be tailored made to the recipient of the care (Gov.UK, 2014). From personal experience, 15-minute calls were still the norm in 2017. This could be attributed to the demand for home carers whereby 15 minute calls allow for more clients to be fitted into a working day, or could be due to the client having to pay for their own care as a 15 minute visit is cheaper than half an hour. Despite the Prime Minister's Challenge on Dementia

(2016) stating that there must be continuity of care for all service users with a dementia diagnosis and care plans must adequately represent what is needed by each service user and their families (Welsh Government, 2017), research suggests that this is not the case for most families accessing home care services. Greenwood *et al.* (2019) found that caregivers thought home carers to be unreliable, uneducated, untrained and unhelpful; they concluded that it would be less stressful for the family member to provide the care themselves. This may provide further explanation as to the low numbers of people with dementia who live in their own home with home care support. Instead, it seems to be the norm that the family member provides care until they are no longer able, and a residential care home or nursing home becomes the only care option (Schultz, 2016).

1.3.3 Care homes

As a person's dementia progresses, it is likely that they will become increasingly dependent on other people to provide care. This escalating level of care often results in admittance into a nursing or residential care home, especially for the last year of their life (Hennings *et al*., 2010). One third of people with dementia in the UK live within residential care homes (Mental Health Foundation, 2015). The cost of a residential care home can range from £600 to £1200 a week, which is paid for by the person with dementia or their families; unless that person has less than £14,250 in savings/property, in which case, the government will pay all the residential care home fees (Age UK, 2020). This highlights the huge economic cost of residential care for those in need of it. There is need for fair and efficient financial support leading to high quality care provided by the health and social care sector (Wittenberg *et al.,* 2019). There is already substantial demand for dementia care, which will increase with the rapidly rising aging population. By 2021, it is estimated that there will be need for an additional 40,000 dementia beds available within residential care homes in the UK to keep up with the increasing number of people being diagnosed with this condition (Alzheimer's Society, 2018).

Further residential care home improvements were promised by the Prime Minister's Challenge on Dementia (2016) which pledged to make all residential care homes within the UK dementia friendly by 2020. This means that there will be a safe environment, with good use of colour distinction to help those with visual impairment to distinguish between wall, door, handrail, toilet, plate, food, and so on. Furthermore, a dementia friendly care home will also have reminiscence furniture or artwork, for example, an old telephone box or photographs of familiar elements. The National Dementia Vision for Wales (2011) originally vowed to ensure that every paid carer working with people with a dementia diagnosis in Wales will have sufficient dementia training; this was further supported by the Dementia Action Plan Wales (2018) which aimed to have completed this by 2022. The British Psychological Society (2016) suggest that psychologists, who can offer appropriate psychological support and advice, should be tasked with training all staff working with people with dementia. Although other professionals would also be suitable to conduct the staff training, for example, mental health nurses or dementia leads. This is further supported by the 1000 Lives initiative which has developed a Welsh dementia training programme to enhance the skills of those working with people who have dementia (NHS, 2018). Unfortunately, a national audit conducted by Smith *et al.* (2019) on dementia training in the UK found that education programmes were not long enough to leave a lasting impact and they only contained 40% of the recommended topic areas as outlined in the Dementia Training Standards Framework (2018). This suggests that dementia training programmes are not successful when put into practice, leaving a workforce who do not understand dementia to the standard required by the Prime Minister’s Challenge on Dementia (2016) and the Dementia Action Plan Wales (2018).

In 2017, the Welsh Government’s new Directed Enhanced Services for Care Homes stated that one of their key aims is *“to enhance the care provided for residents in care homes through a proactive, holistic coordinated model of care”* (Welsh Government, 2017, pp. 2). Similarly, NICE (2006) guidelines emphasise the need to recognise people with dementia as individuals with unique experiences, personal histories and different experiences of their illness. Despite this, the Older People’s Commissioner for Wales (2018) found that, for people living within residential care homes, their personal histories, cultures, religious beliefs, likes and dislikes, future aspirations and prior achievements were not identified and were not made easily visible within their care plans. The Older People’s Commissioner for Wales (2018) also noted how there were very few examples within local councils whereby residential care home residents and family members were able to voice their opinions of the service provided, and, if they felt able to express their viewpoints, they were very rarely taken into consideration when improving processes or leading to change. As noted by the Older People's Commissioner for Wales (2018) *"they don't have good quality of life but aren't in a position to do anything about it"* (pp. 48). This highlights the importance of listening to the older people's voices and ensuring the issues they raise are acted upon as this is so very often highly linked with their quality of life. To achieve this, independent advocacy services should be made available to people living with dementia (Older People's Commissioner for Wales, 2018). This should apply in all settings: their own home, care homes, nursing homes and hospitals.

1.3.4 Hospital care

When a person with dementia has to go to hospital, whether this is for an outpatient appointment or being admitted onto a ward, it can cause family members stress and be detrimental to the mental health of the person with dementia (Hennings *et al*., 2010). John's campaign (Appendix A, pp 342) has been rolled out to hundreds of hospitals in the UK and allows family members to accompany people with dementia when they are admitted into hospital; the family can stay with the patient for as long as they are needed to help reduce the anxiety levels in the person with dementia (The Golden Standard Framework, 2015). Admittance as an inpatient is not the only time older people attend the hospital, day appointments as an outpatient can be equally as stressful for someone with dementia.

There are no specific policies referring to the treatment a person with dementia should receive whilst attending a generic outpatient's appointment, but several pieces of legislation and policy refer specifically to memory services. This is relevant to the current study as all participants would have been diagnosed within the memory service and have accessed the care and support offered by their local health board. In 2012, 94% of primary care trusts in England had a dedicated memory service for dementia (Gov.UK, 2012); this was attributed to the National Dementia Strategy (2009) which also aimed to improve the dementia services through early diagnosis and intervention. The Care Act (2014) also states that patients should receive timely diagnosis, information and support, yet literature suggests that those affected by dementia do not feel that they have enough information and support. In Wales, the dedicated memory service must have easily accessible advice and information for anyone affected by dementia (Gov.UK, 2012). This is also endorsed by The Care Act (2014). The Social Services and Well-Being (Wales) Act (2014) imposes regulations on Welsh health boards, Welsh local authorities and Welsh ministers to ensure their work promotes the well-being of those who access care and support in Wales; specifically, health boards within Wales must ensure that assessments and treatments are focussed on the individual (Gov.UK, 2014). The need for improved dementia care within Wales has been recognised through legislation, policies and frameworks since 2010 with the Mental Health (Wales) Measure and most recently, the Dementia Action Plan Wales (2018).

The National Dementia Vision for Wales (2011) outlines the plan for continual improvement for the future of dementia care in Wales. The plan involves enhancement of service provision, improved rates of diagnosis and interventions, better access to information and support for people affected by dementia and improved training for people delivering care to people with dementia and their family members (National Dementia Vision for Wales, 2011), all targets that have been set by previous frameworks and policies. This plan was accompanied by an increase in dementia service funding from the Welsh Government (Gov.Wales, 2011). Similarly, the Challenge on Dementia (2012) incorporated a financial reward to hospitals routinely screening for dementia in any admissions of over 75 year olds to increase diagnosis rates. In 2012, the diagnosis rate for dementia in the UK was 267,000, this has increased to 472,000 in January 2020 (Dementia Statistics Hub, 2020). To further improve dementia care, financial rewards were also offered to NHS staff who demonstrated innovative ideas for improving care (Challenge on Dementia, 2012). The Challenge on Dementia (2012) aimed to make the UK a world leader in dementia care. In 2016, the UK was the fourth best country for dementia care according to Botek (2016).

Prior to the release of the Dementia Action Plan Wales (2018), the Welsh Government had made several advances in dementia care for people living within

Wales (Welsh Government, 2018). With an increase in funding towards Welsh dementia care, the Welsh Government has implemented an initiative to provide dementia support workers, occupational therapists on older persons' mental health wards and specific dementia teams within district hospitals (Welsh Government, 2018). It is aiming to further improve dementia care by introducing support teams who work to the individual's needs and aim to keep them residing within their own home for as long as possible (Welsh Government, 2018). The Dementia Action Plan Wales (2018) aims to make services clearer to people within Wales so that a timely diagnosis can be obtained after symptoms begin (Welsh Government, 2018). For those with a diagnosis of dementia, the Dementia Action Plan Wales (2018) aims to facilitate planning for the future and provide flexible, person-centred care for all those who need it; this is to be accompanied by a further increase in the number of staff being dementia trained (Welsh Government, 2018). The Welsh Government have arranged for the Dementia Action Plan Wales (2018) to be formally reviewed by the Dementia Delivery Assurance and Implementation Group in 2021.

Dementia care within the UK has improved in recent years. The number of people with dementia remaining in their homes until their deaths has increased from 9% to 10% (Gov.UK, 2020); this may be attributed to improved support allowing them to remain in their own homes or could be due to the extreme costs of residential care. In 2019, the Care Quality Commissioner noted that the quality ratings of residential care homes within the UK has risen from 68% in 2018, to 73% in 2019[3] (Gov.UK, 2020). Since 2012, the number of people with dementia dying in hospital has declined (Gov.UK, 2020) whether this is down to palliative care at home improving or the insufficient number of dementia beds for the demand, is unclear. These figures highlight the improvements made in dementia care within the UK, but more can still be done to ensure that everyone lives well with dementia (Gov.UK, 2020).

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[3] Quality of the care homes is assessed through a checklist which outlines the fundamental standards that every resident is entitled to.

1.4 Summary and Reflection

This introductory chapter provided an overview of the contextual background for the research carried out in this thesis. Dementia facts were outlined regarding prevalence figures, the differing care options, and the costs for people living with the condition. Throughout this chapter, legislation, policies and frameworks were entwined to give a sense of the background agendas influencing the experiences of people with dementia within the health and social care systems in Wales. The remainder of this chapter outlines the aims, objectives and research question for this study. The essential ingredient for a PhD, original work, will be explored followed by the structure of the thesis.

Reflection on the Chapter

It is evident within the various legislations, policies and frameworks that governmental and international authorities recognise the importance of a person-centred approach to dementia care and support. Yet, Nursing Times recently published an article regarding the new methods of care that will be offered to people affected by dementia; *“information tailored to their individual needs, and having a clinically trained professional assigned as their single point of contact”* (Mitchell, 2020). Both of which can be identified within the National Dementia Strategy (2009), the Equality Act (2010), Social Services and Well-Being (Wales) Act (2014), The Care Act (2014) and the Dementia Action Plan Wales (2018) to name a few. I think that there are so many different rules and guidelines, from worldwide, European, British, Welsh, individual health boards and even individual memory services, that there is no way the staff can account for them all.

Nevertheless, from personal experience of caring for older people with dementia, their care plans are minimal and usually copied and pasted from someone else’s file. There is negligible support offered to them or their families, unless they source it themselves and there is no standard of services offered; they all differ and receive different amounts of funding and resources. Some offer brilliant resources, while others cannot afford to do so. I will admit that it is only since beginning this PhD that I have become accustomed with the legislations regarding people with dementia. The care company I worked for did not offer any training regarding legislation and I wonder if those writing the care plans and managing the front-line carers are aware themselves. Either way, there is room for improvement in the care sector.

1.5 Objectives, Research Question and Aims

The aim of this study is to explore and understand the lived experiences of older people and their family members living with dementia.

The research question is simply "*what is it like to live with dementia?*"

The objectives of this study are:

1. To explore and understand the lived experiences of older people with dementia.
2. To explore and understand the lived experience of family members of a person with dementia.

This study fits within the principles of descriptive phenomenology, and data collection followed a life story work approach. Participants were asked to share their life journey from the very beginning (childhood for the participants with dementia/ prior to dementia onset for the family members) through to the present day (life with dementia) and share their hopes for the future. Digital storytelling was incorporated within this study as participants were video recorded whilst narrating their stories and given the opportunity to edit their videos prior to data analysis. The study received ethical approval from the University of South Wales Faculty of Life Science and Education Ethics Committee (13th February 2018 and 15th July 2019) and Wales Research Ethics Committee 1 (17th October 2019). The participants for this study were recruited through residential care homes and memory clinics in South Wales. The data was analysed within Colaizzi's (1978) descriptive phenomenology framework and Burnard's (1991) framework for analysing interview data.

1.6 Originality and Contribution to Knowledge

"Originality is a major ingredient of doctoral research" without which, a doctorate cannot be awarded (Gelling and Rodriguez-Borrego, 2014, pp. 6). Original research should result in the production of new knowledge (Gill and Dolan, 2015). There are many key definitions of originality within a PhD (Phillips and Pugh, 2010); the most applicable to this study are making a synthesis of things that have not been put

together before, taking a particular technique and applying it to a new area. This study will contribute to new knowledge in three ways; firstly, this study has adapted the therapeutic method of life story work for people with dementia (Doran *et al.,* 2019; McKeown *et al.,* 2015) and applied it as a data collection method for those affected. Whilst this has been used for other groups of people as a data collection tool (Solomon *et al.,* 2011; Jensen, 2013), it has seldom been used for people with dementia. Secondly, by using video recordings, this study was able to comment on the non-verbal cues provided by the participants. Thirdly, the video recordings offered an opportunity for the research team to give something back to the participants whereby all participants received a copy of their life story on DVD, to keep. The final ingredient of originality within this study was several results that were without supporting literature, suggesting that they are hardly ever researched. A more in-depth discussion on the original contribution to new knowledge from this study can be found in the final chapter of this thesis.

1.7 Structure of Thesis

The structure of this thesis is as follows:

Chapter 2 contains a discussion on the different perspectives of dementia. This chapter begins by exploring the historical context of dementia and goes on to discuss the medical model of dementia, which focusses on the organic aetiology. The social model of disability that encourages social and environmental manipulation to make life with dementia easier follows. And lastly, the chapter discusses the biopsychosocial model.

Chapter 3 begins by detailing the search strategy employed to uncover relevant literature to this study. It then offers a synthesis of the findings followed by a narrative of the studies. The studies are divided into literature on the experiences of people with dementia, family members and joint perspectives, and are used to inform the methodology of this study and critique the results.

Chapter 4 explains the methodology for this study. Taking a chronological approach, the chapter initially explores the research methodology, descriptive phenomenology and digital storytelling as the data collection tool. The process of obtaining ethical permissions from University of South Wales and the NHS is then outlined followed by the sampling strategy, data collection procedure and ethical issues. The data analysis method used, and the process of analysis is then made explicit.

Chapter 5 is the first of three chapters that describes the findings of the study. Within this chapter, the reader will be introduced to the 22 people who participated. Their personal histories have been condensed and the dynamics of their interviews is explained. The aim of this chapter is to reveal the person behind the dementia and understand their life experiences (Holloway and Freshwater, 2007).

Chapters 6 and 7 provides an exploration into the themes found from using a descriptive phenomenology analysis framework, created from combining Colaizzi's (1978) descriptive phenomenology analysis framework and Burnard's (1991) framework for analysing interview data. Firstly, the themes for the person with dementia are presented (chapter 6) followed by the themes for the family members (chapter 7). Whilst their experiences are exclusive, there are some similarities that have been drawn together in the following discussion chapter.

Chapter 8 offers a critical discussion of the themes identified in the previous three chapters, drawing on the available literature and previous knowledge on life with dementia. This chapter begins with a discussion of the results from the persons with dementia, then the family member, followed by their joint experiences. Any observations made within the interview process are also discussed within this chapter as they offer additional insight into the participants.

Chapter 9 contains the conclusions made about life with dementia based on the results of this study. The essential element of a PhD, original contribution to knowledge, is specified. As with all studies, there are methodological limitations that are acknowledged within this chapter, followed by recommendations for policy, practice and research.

Chapter 10 is the final chapter of this thesis and offers a personal reflection, written in the first person, regarding the journey that this PhD has taken over the last three years. It explores my thoughts and feelings about various elements of this process, with anecdotes to accompany the narrative.

CHAPTER 2 PERSEPCTIVES OF DEMENTIA

"The study of dementia from the perspective of biology, psychology or sociology creates separate narratives, none of which hold the whole truth but all of which, combined in our journey of discovery, bring us nearer reality"

(Harry Cayton, 2004, pp. 9)

2.1 Introduction

This chapter critically discusses four differing perspectives of dementia. It builds on the previous chapter as the UK policies are impacted upon by the differing perspectives of dementia; this link is made clear throughout this chapter. The historical context of dementia is explored initially, as looking to the past allows a better understanding of the present (Boller and Forbes, 1998). This is followed by three models of dementia: medical, social and biopsychosocial model. Their origins and their implications for people living with dementia is discussed. The term "model" simply refers to the *"belief system utilized to explain natural phenomena"* (Engel, 1977, pp. 380). The varying models offer alternative methods of caring for people living with dementia. Exploring these is particularly important for this thesis as it mirrors the principles of the social model of dementia; focusing on what people can still do, not the abilities they have lost. This does not imply however that the other models of dementia do not have their worth.

2.2 Historical Context of Dementia

Medical historians have demonstrated that dementia has a unique history (Ballenger, 2006a; Katz, 2013) with usage of the word "*dementia*" dating back as far as 1381 (Lanteri-Laura, 1984) and the concept of dementia dating back as far as 2000 BC when the ancient Egyptians noted how old age could be accompanied by memory loss (Signoret and Hauw, 1991). Examples of this connection can be seen throughout history, particularly through the arts with literary writers and composers developing characters who often displayed many of the behaviours today associated with dementia. For example, Jonathan Swift's "*Gulliver's Travels*", published in 1726, offers a detailed description of the "*Struldbrugs of Luggnagg*" who can discuss their youth but do not remember anything that has happened recently. They have forgotten people's names, their friends and family members; furthermore, *"they have no remembrance of anything but what they learned and observed in their youth and middle–age, and even that is very imperfect; and for the truth or particulars of any fact, it is safer to depend on common tradition, than upon their best recollections"* (Gulliver's Travels, part 3, chapter 10, pp. 4). Ten years after the publication of this book, the author, Jonathan Swift, began to display the same cognitive problems as the Luggnaggians whom he had previously described in his book. Swift is believed to be the first recorded case of Alzheimer's Disease (Boller and Forbes, 1998). It is important to note that whilst people were historically diagnosed with dementia, some of the case notes of the person's behaviours, such as delusions, hysteria and attacks of excitement, reveal that they would not be considered to have dementia in line with today's diagnostic systems (Williams, 2018). Today, dementia diagnoses are made with the help of diagnostic tools such as DSM-5 (APA, 2013) or ICD-11 (WHO, 2019), both of which have evolved over time (Williams, 2018). These diagnostic tools are discussed in more detail shortly.

Approximately 50% of people living with dementia in the 19th century were cared for at home (Hill and Laugharne, 2003) as there was great emphasis on people being cared for by their families, but when their behaviour could no longer be managed at home, the family would seek out residence for the person with dementia within a workhouse or lunatic asylum (Suzuki, 2006). Occasionally, when an older person felt that they lacked the resources to obtain sufficient care for themselves, they would seek the care they needed within the workhouse (Hunter, 2005). It was however generally family members who made the initial requests for an older person with dementia to become a patient within the lunatic asylum as they had to prove their relative's "*insanity"* (Suzuki, 2006). It was generally social reasons that resulted in a person with dementia being admitted into a lunatic asylum or workhouse; primarily, the family's inability to manage their relative's behaviours (Mellett, 1982; Scull, 1980). Families often resorted to traumatising methods of dealing with the behaviour such as the use of restraints or family members providing constant surveillance

(Evans and Strumpf, 1989). Admission of a person with dementia into a lunatic asylum or workhouse was the result of environmental limitations or strains on their family, not on the severity of their dementia symptoms (Walton, 1988). This is consistent with data from recent years which shows that family members admitted a loved one with dementia into a care home because of an inability to manage challenging behaviours (e.g. aggression), emotional strains on the family members and safety issues (Johansson *et al.*, 2014).

The General Workhouse Rules (1842), issued by the Poor Law Commissioners states that *"persons of unsound mind, but not dangerous, could legally be kept in the workhouse"* (The Poor Law Amendment Act, 1834, section 45). Therefore, older people with dementia were initially offered residence within a workhouse (Green, 2002) as it was felt that they were "*easy to care for*" because they were only "*restless from old age*" or "*a little difficult to manage*", not dangerous (Commissioners in Lunacy, 1878 as cited in Andrews, 2017). Justification for a life in the workhouse instead of the lunatic asylum was based on the patient's physical state, not their mental state (i.e. being physically able to work) (Forsythe *et al.*, 1996; Suzuki, 1995). As a result of this, older people living with dementia struggled to reside within a workhouse as they were not able to "*fit in*" with the structure of the workhouse environment and doing as they were instructed (Andrews, 2017). When their behaviour (e.g inability to follow instructions) became problematic, they were moved into a lunatic asylum, where their behaviour would be contained within a secure building (Melling *et al.*, 1999; Smith 1999).

It is estimated that approximately 35% of people living in lunatic asylums had a diagnosis of dementia (Hill and Laugharne, 2003). The Commissioners in Lunacy (1881), as cited in Andrews (2017), noted the increase in aged people being admitted into the lunatic asylum with dementia symptoms and believed that this behaviour was caused by the natural decay of the aging brain, not insanity, therefore, they did not qualify to receive care from the lunatic asylums. Despite this, the number of aged people with dementia symptoms being admitted to the lunatic asylums still increased as their admissions process was based on the "*manageability*" of the person's behaviours, not on the medical definition of their condition (Scull, 1999). Many older people living with dementia did not meet the inclusion criteria for either a lunatic asylum or a workhouse as their mental state excluded them from admission to a workhouse and their physical state excluded them from admission into a lunatic asylum (Murphy, 2002). This suggests that a social model of dementia was being followed by the lunatic asylums whereby the manageability of the person's behaviour was the reason for admittance, not the organic structure of the disease; more on the social model of dementia can be found in Section 2.4.

During the first half of the 19th century, *"dementia*" was considered to be the last stage of the only recognised mental illness, insanity (Caixeta *et al.*, 2014); hence why people with dementia were admitted into lunatic asylums after their "*insanity*" was proven (Suzuki, 2006). In 1880, medical professionals came to realise that dementia was a condition in its own right, not a stage of insanity; furthermore, it was decided that the dementia diagnosis could be divided further (Albou, 2005). In 1838 France, dementia was divided into three types by Esquirol (1805); acute, chronic and senile with senile dementia being closer to today's definitions of dementia as it was associated with old age, memory difficulty particularly with recent memories and attention deficit, and progressively worsened. Esquirol's book, *"Esquirol on Mental Disorders"* (1839), states *"chronic dementia is seldom cured…dementia senilis is incurable"* (Esquirol, 1839, pp. 41). This indicates that Esquirol believed that only senile dementia was incurable, but chronic dementia can occasionally be cured.

Guislain (1852) noted that there were other forms of dementia which would affect younger people; *"there are two varieties of dementia… one affecting the elderly (senile dementia) the other, younger people"* (Guislain, 1852, pp. 10). One of the first 19th century medical professionals to attribute dementia to an organic disease was Georget who also noted the irreversible process associated with dementia (Georget, 1820; Caixeta *et al.*, 2014). The link between the dementia process and a loss of brain tissue was noted in 1860 by Morel but difficulty arose when Morel tried to distinguish between brain tissue loss as a result of normal aging or brain tissue lost as a result of the dementia process (Morel, 1860; Caixeta *et al.*, 2014).

Many significant discoveries in dementia occurred in the 19th and early 20th century (Boller and Forbes, 1998). These initial discoveries were primarily by psychiatrists;

including Pick, Esquirol and Pinel but later expanded to neuroscientists such as Kreapelin, Lewy, Fisher and Alzheimer (Berrios, 1987; Boller and Forbes, 1998; Caixeta *et al.*, 2014). Despite discovering that the causes of dementia were organic and could be located within the brain, the treatments for dementia in the early 1900s did not reflect this (Berrios, 1987; Boller and Forbes, 1998). Many people living with dementia were restrained to prevent them from "*wandering*" while physicians would often prescribe remedies such as a hot bath to alleviate the behavioural symptoms of dementia (Toodayan, 2016). Nevertheless, members of society were beginning to recognise the organic nature of dementia and located it within the brain; this would consequently lead health professionals to take a medical approach to understanding and treating dementia symptoms, hence the emergence of the medical model of dementia, which is discussed next.

The thesis is centred on the premise that the past needs to be explored and understood to fully appreciate current experiences. Delving into the historical diagnoses, treatments and care for older people with dementia can shed light on some of the current misconceptions, particularly around insanity and institutionalisation, which can accompany life with dementia. This is explored further in Chapter 8 as some of the findings from this study resonate with historical understandings of dementia (pp 232). It is interesting to note how dementia care in the 19th century was mostly provided by family members, and this mirrors today's dementia care (World Health Organisation, 2019; Hill and Laugharne, 2003). When the 19th century families could no longer cope, they sought institutional care for their loved one (Suzuki, 2006). Nowadays, residential care is the norm for those struggling to provide care at home (Hennings *et al.,* 2010). Similarities such as these highlight the way that dementia understanding has evolved but still echoes the past.

2.3 Medical Model of Dementia

There are three main characteristics of the medical model of dementia as described by Innes and Manthorpe (2012). Firstly, dementia is an abnormal, pathological condition. Secondly, dementia progresses through stages and has an organic aetiology. Thirdly, dementia can be diagnosed through biomedical assessments. Exploring the organic aetiology of dementia allows for a distinction to be made between a "*normal brain*" and a brain affected by dementia (Innes and Manthorpe, 2012).

Noting the physical alterations in the brains of people living with dementia can be dated as far back as the 19th century. Whilst many believe that Alois Alzheimer, a German psychiatrist, was the first to identify and study the organic changes within the structure of the brains of deceased people who had displayed the symptoms of dementia (Toodayan, 2016), this is not true. Alzheimer was the first to study a specific type of dementia in 1906, later named after himself, Alzheimer's disease. The team of psychiatrists led by Arnold Pick, a Czech psychiatrist, made the initial discoveries about the biological causes of dementia in 1892 (Boller and Forbes, 1989). There are over fifty different forms of dementia (Stuart-Hamilton, 2014), each caused by varying alterations in the brain structure. These various forms include Alzheimer's Disease, vascular, frontotemporal dementia, dementia with Lewy bodies and mixed dementia (WHO, 1993). Since all the dementias have varying structural alterations within the brain, as originally described by Pick's team, it is understandable that they fit within the medical models. Prior to these discoveries, the behavioural traits associated with dementia were deemed to be a natural symptom of old age (Downs, 2000).

Within the medical model, the dementias are referred to as a *"disease*" (APA, 2013; Mental Health Foundation, 2015); for example, *"dementia is an incurable, progressive neurodegenerative disease with no effective treatment to reverse or cure it"* (Australian Institute for Health and Welfare, 2012, pp. 1). Similarly, Sotolongo-Costa *et al.* (2017) described dementia as a "*decline in mental ability, caused by damage to brain cells, that interferes with daily living"* (pp. 87). Within DSM-5, dementia has been called a "*neurocognitive disorder*" as the brain disease will cause problems with the person's cognition (APA, 2013, pp. 591). DSM-5 defines dementia as *"the umbrella term for a number of neurological conditions, of which the major symptom is the decline in brain function due to physical changes in the brain. It is distinct from mental illness"* (APA, 2013, pp. 591). Similarly, ICD-11 has listed the diagnostic criteria for dementia within the "*organic mental disorders*" chapter, yet the diagnostic criteria are based largely on behavioral alterations, not organic evidence (World Health Organization, 2019). It can often be difficult for health professionals to distinguish between a "*normally aging brain*" and a brain affected by dementia (Downs, 2000), therefore the diagnosis is usually based on the symptomology (Gubrium, 1986; Innes and Manthorpe, 2012).

The medical model of dementia dominates western society. It has been argued that there are vested interests in maintaining this approach to dementia, from the training of medical health professionals, to the drug production organisations (Baldwin and Capstick, 2007). The medical model of dementia played a crucial role in the societal focus on accurate and timely diagnosing, along with doctors prescribing appropriate drug-treatments to slow down the progression of the dementia and treat the behavioural symptoms (Cahill, 2018). This is apparent within the Dementia Action Plan Wales (2018) which aims to increase the rates of timely diagnosis after dementia symptoms begin (pp 342). Utilising the medical model of dementia allows medical researchers to find alternative treatments for dementia and may eventually lead to a cure (Stokes and Goudie, 2002). The increase in medicalisation of dementia resulted in more refined diagnostic criteria, more precision with diagnosis labels and increased research into treatments (Bartlett and O'Connor, 2010). Furthermore, Brown and Hillam (2004) found that people affected by dementia prefer to view the diagnosis in terms of the medical model, whereby dementia is a biological disease; this allows them to attribute the behaviours to external factors (i.e. *"it's not her, it's the dementia"*; Bartlett and O'Connor, 2010, pp 18). Additionally, a medical diagnosis of dementia will allow the person to access additional support, often social care support (Bartlett and O'Connor, 2010).

The medical model is reductionist, whereby disease can be explained in simple terms such as "*a body is a machine, a disease is a breakdown within the machine and the doctor has to repair it*" (Engel, 1977, pp. 131). This is partly applicable to dementia as the organic changes can be identified within the brain of the person with dementia however, there is currently no *"repair"*. A further claim to support the reductionist criticism was by Katz (2013) who says that dementia is viewed via the medical model as a diseased brain that needs to be treated, instead of seeing a person with a brain. Reducing people with dementia to their diseased brains will increase the stigma associated with the diagnosis by isolating the person and marginalising them from society (Katz, 2013). The medical model disregards individuality, which leads to a generalisation of symptomology, decline rates, and care and support needs. This generalisation may be the cause of inflexible, task orientated care packages for people living with dementia (Cahill *et al.*, 2018). The medical model has been deeply criticised for ignoring the remaining capabilities of people living with dementia (Katz, 2013; Stokes and Goudie, 2002; Kitwood, 1997; Engel, 1977) and the Mental Health Foundation (2015) claims that the medical model of dementia *"maintains oppression, exclusion and passive dependency of the person"* (pp. 14). This was demonstrated within government funding, whereby there was a clear increased level of funding towards care homes for people living with dementia and early institutionalisation of people living with dementia was being encouraged (Donnelly *et al.*, 2016). For example, within the UK, government funding towards care homes has increased by 4.2% from 2018-19 to 2019-20 (Gov.UK, 2020) and The Care Act (2014) states *"if their [person with dementia] needs can be met in a care home, that is what should be arranged"* (Legislation.Gov.UK, 2014, pp. 8).

A set of organic alterations may be present within an individual, but it is only when these alterations become problematic (i.e. causing behavioural, psychological, emotional or social problems) that the person may accept their "unwell" status and seek help. This is contradictory to the medical model's definition of a disease whereby someone is "*diseased*" if they deviate from the norm (Engel, 1977). Additionally, research has suggested that older persons can have the physical alterations (neuritic plaques and neurofibrillary tangles) within their brain that are associated with Alzheimer's disease but not experience any of the behavioural symptoms (Iacono *et al.*, 2009; Snowdon, 1977). Further criticism of the medical model is that over-reliance can result in the over prescribing of medication, unnecessary hospitalisation and excessive surgery (Waitzkin, 2000; Holman, 1976). This has been highlighted within the Banerjee Report (2009) which found that antipsychotic medication was being overused to control the behaviours of people living with dementia in the UK. The report suggested that access to psychological therapies could be used for most people with dementia, with drug therapy being used as a last resort (Banerjee Report, 2009).

During the 1970s, debate by medical professionals focused on examination of the models being followed. One such debate within dementia care occurred at a Rockefeller Foundation Seminar in 1977, where Engel noted that some professionals were urging for "*medicine to concentrate on the real disease and not get lost in the psychosociological underbrush*" (Engel, 1977, pp. 129). Another had argued for a clear distinction between the organic disease and the psychosocial elements (Engel, 1977). Utilising the medical model of dementia does not recognise the individual's diverse background that may have led to them developing the condition, nor does it offer any advice on how to care for someone with dementia effectively; it suggests that life with dementia cannot improve until a medical breakthrough occurs (Kitwood, 1997).

The medical model of dementia is purely interested in the physical alterations within the brain that deviate from the "*normal brain*" (Katz, 2013). It leaves no room for the social, psychological or behavioural elements of dementia (Engel, 1977). Addressing such issues falls under the psychiatry discipline. At the Rockefeller Foundation Seminar, Engel (1977) noted how one attendee stated that psychiatry should be removed as a medical discipline as it only deals with *"problems of living*", not diseased entities; "*problems of living*" meaning mental illness (Szasz, 1960). This suggests that psychiatrists should be concerned with the social and psychological effects of dementia whilst other medical professionals work with the "diseased" brains (Engel, 1977; Katz, 2013).

As discussed in section 2.2 of this chapter, the symptomology of dementia has not changed historically, suggesting that the societal changes that have occurred have had no influence over the development of dementia (Berrios, 1987). Similarly, dementia has affected people in both developed and non-developed countries, which further supports the idea of society and environment having minimal influence (Kua *et al.*, 2014). Currently, healthcare spending is aimed at biomedicine; pharmaceutical treatments (69%) and medical goods (9%) (Office of National Statistics, 2020), yet research has demonstrated that psychological therapies have been more beneficial for people living with dementia in terms of improving their quality of life, the course of their dementia and coping with the diagnosis (Fava and Sonino, 2008). Despite the Banerjee Report's (2009) influence over dementia legislation encouraging the use of psychological therapies for those with dementia and drug therapies being offered as a last resort, there remains a lack of specialist psychological services for those living with dementia (Birtwell and Dubrow-Marshall, 2018) which maintains an over reliance on pharmaceuticals for treating the psychological symptoms of dementia. Thus, while the organic links for dementia cannot be disputed and the medical model of dementia functions well as a reductionist model, it has been suggested that the experiences of dementia need to be responded to within a social model of disability (Bowling, 2007; Innes and Manthorpe, 2012).

2.4 Social Model of Dementia

Whilst the biological elements of dementia are addressed within the medical model, the psychosocial elements are addressed within the social model. The social model of dementia is sometimes termed the "*psychosocial*" model of dementia as its founder, Tom Kitwood, was a social psychologist and many of the ideals of the social model of dementia fit within social psychology (Stuart-Hamilton, 2014); for example, the concept of personhood (Kitwood, 1997) and enablement (George, 2010), both of which are discussed later in this chapter. Walrath and Lawlor (2019) believe that *"dementia's stigma stems from its resistance to cure and its closeness to death. Biomedicine, after all, excels at curing. It views death as treatment failure instead of as a natural part of life. No cure has been developed in more than a century since Alois Alzheimer first described the histology characteristic of the form of dementia bearing his name… Restoring personhood and hope even in the absence of a cure can benefit people living with dementia and their families by helping to improve quality of life and supporting the function of people living with the condition"* (pp. 1002). The social model of dementia emphasises that, with the right interventions or support, people living with dementia can have a good quality of life (World Health Organisation, 2012). The social model of dementia has offered an alternative definition for dementia; whereby *"dementia is the decline in memory and other cognitive functions in comparison with the patient's previous level of function as determined by a history of decline in performance…dementia is a diagnosis based on behaviour and cannot be determined by brain scan, EEG or other laboratory* *instruments, although specific causes of dementia may be identified by these means"* (McKhann *et al.*, 1984, pp. 942).

The social model of dementia is an adaptation of the social model of disability (Bond, 2001); dementia is recognised as a disability under the Equality Act 2010 (Mental Health Foundation, 2015). The Equality Act's (2010) definition of disability is *"a person (P) has a disability if (a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities*" (pp. 4). The social model of disability has a mission to *"dismantle the barriers that blocked disabled people's participation in society…to pull down the walls of the custodial existence that had marked and marred the modern disability experience and replace it with freedom and opportunity" (*Goodley *et al.,* 2012, *pp. 310).* This is of relevance to this thesis as the inclusivity of people with dementia was central to all decisions made regarding this study. This is discussed more in the following chapters where the modification of the methodology is discussed. Subsequently, the overarching theme of the social model of dementia is the improvement of the person's quality of life through social (attitude) and physical (environmental) manipulation (Cahill, 2018).

The premise of the social model of dementia is that the person is not restricted due to their disability but is restricted as a result of their environment and social barriers (Oldman, 2002). The social model of dementia has five primary aims in the UK; (1) everyone has the right to make decisions about their lives, (2) human rights standards need to be monitored, (3) all forms of discrimination are prohibited, (4) individuals with dementia should be supported by their communities and (5) recognition of the person with dementia's legal rights (Mental Health Foundation, 2015). Governmental policies highlight these points too; within the Human Rights Act (HRA) and the European Convention on Human Rights (ECHR) (1998), the Mental Capacity Act (2005) and the National Dementia Strategy (2009) to name a few (pp 342), thus demonstrating that the social model of dementia has been a powerful political tool (Thomas and Milligan, 2010; Ballenger, 2017). The aims of such policies can be met through dementia friendly communities (environmental alterations), ensuring the person with dementia is considered the expert of their situation with their needs being carefully listened and attended to (social alterations) (Bond, 2001).

Dementia friendly communities can be created by ensuring people within the community understand dementia and know how to support people living with dementia, providing clear signposting and having good links between care homes and the wider community (Alzheimer's Society, 2014). The concept of "*dementia friendly"* has recently come under scrutiny, being accused of using inappropriate and patronising terminology in reference to people living with dementia (Thomas and Milligan, 2018) as society would not use the term "*friendly*" for other excluded groups (Shakespeare, Zelig and Mittler, 2017). Furthermore, Owens (2014) suggests that dementia friendly communities do not alleviate the difficulties faced in everyday life for people living with dementia.

As previously illustrated in section 2.2, concepts from the social model of dementia care were present within British society dating as far back as 19th century (Andrews, 2017), whereby community support for people with dementia was encouraged (Bosco *et al.* 2019). This encouragement is still present within the UK today, with 700,000 family carers providing dementia care within the home for 850,000 people with dementia in the UK (Alzheimer's Research UK, 2018) and psychiatric beds within hospitals quickly diminishing (Bosco *et al.*, 2019). There is a clear focus away from institutionalised care towards community care for people with dementia (Lewis *et al.*, 2014) as illustrated within the Dementia Action Plan Wales (2018) which states *"we understand the importance for people with dementia to remain in their own home for as long as possible"* (Welsh Government, 2018, pp. 23).

Despite this, in 1992, social psychologist, Tom Kitwood noted that there was a remarkable absence of a social model of dementia care (Kitwood and Bredin, 1992). Tom Kitwood was one of the earlier academics to apply a social model to dementia care. He initially began working on this alternative model of dementia care in 1985, and since then his work has been highly influential (Kitwood, 1997). He aimed to provide *"an approach to care that looks far more to human than to medical solutions"* (Kitwood, 1997, pp 2). Kitwood and colleague, Kathleen Bredin, coined the phrase "*person centred care*" and established the Bradford Dementia Group whose main concern was the implementation of person centred care in all environments, including hospitals, care homes and the family home (Kitwood, 1997). Central to the social models of dementia is the concept of "*personhood*". Kitwood defined personhood as "*a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable*" (Kitwood, 1997, pp 8). The introduction of the "*person with dementia"* rather than a "*dementia sufferer*" has encouraged individuals to view the whole person with dementia, rather than the "*tragic victim of a progressive disease*" (Bartlett and O'Connor, 2010, pp. 4).

There are some academics (Gilliard *et al.,* 2005; Palfrey and Harding, 1997; Woods, 2001) who reject the medical model of dementia in support of the social model and believe that "*people develop dementia as a means of escape from facing the reality of the end of their life*" (Gilliard *et al.*, 2005, pp. 574). Additionally, they argue that the "*challenging behaviours*" displayed by people with dementia are caused by emotional reactions rather than the pathological element of dementia (Woods, 2001). Despite health professionals acknowledging that they should address the social elements of a person's dementia to provide holistic care, in practice, this is rarely the case (Gilliard *et al.*, 2005).

An over-reliance on the social model of dementia has some drawbacks; particularly the societal misconception that dementia is a normal part of aging (Bosco *et al.*, 2019). As a direct consequence of this, some people do not recognise dementia as an organic disease and therefore, do not seek medical advice (Henningsen, 2015). For some forms of dementia there are medical treatments that can slow down the progression of the disease; for example, the cognitive decline associated with Alzheimer's Disease can be effectively halted (for a certain time period) with the use of cholinesterase inhibitors such as donepezil or memantine (Howard *et al.*, 2012) but if people are not aware of the organic nature of dementia, they will not seek medical intervention for their symptoms. Alternatively, some religious groups (namely Catholicism and Sikhism) preach to their followers that dementia is a divine punishment for sinful acts; it is something to be ashamed of which prevents them seeking help (Radde-Antweiler *et al.*, 2018; Katholisches, 2015). This is supported by the principles of "*seva"* which state that "*if you have dementia, you have to repent for your sins"* (Botsford and Denning, 2015, pp 279). While some African countries believe that people with dementia are witches and suffer physical abuse because of it (Age International, 2018).

The social model of dementia fits in closely with the Enablement Philosophy of Dementia which emphasises the strengths, abilities, independence and control for people living with dementia rather than focusing on all the loss (George, 2010). This has been highlighted through several governmental policies; for example, the Mental Capacity Act (2005) states that everyone has assumed capacity and society should empower people with dementia to make decisions for themselves (Department of Health, 2005). The support offered to people living with dementia should concentrate on maintaining relationships and encouraging the person with dementia to use their abilities to experience enjoyment and variety in their lives (Kitwood, 1997). The enablement approach to dementia has three implications for the person with dementia; maintaining functioning for as long as possible, adapting for the loss of function that cannot be regained and regaining the lost functions where possible (Poulos *et al.*, 2017). The Enablement Philosophy of dementia fits with The Social Services and Well-being (Wales) Act (2014) as it emphasises that assessments and support are completely focused on the individual receiving care. Furthermore, the Care Act (2014) states that local authorities must implement strategies to prevent or delay the progression of dementia (Department of Health, 2014).

The first indication that the British government was in support of the social model of dementia came in 1986, when they supported the King's Fund publication, the "*Living Well into Old Age"* document, which emphasised that people living with dementia have the same values, same rights and same needs as everyone else; this, in turn, led to more focus on the "*real lives*" of people affected by dementia (King's Fund, 1986). The social model of dementia is still present within today's practices whereby people living with dementia are encouraged to share their personal preferences and are given every opportunity to be included in meaningful, social and dignified interactions (Brooker, 2004; Bartlett and O'Connor, 2010). The Care Act (2014) states that local authorities have to ensure that people living with dementia remain active members of the community through social activities within their community (pp 2). Despite governmental policy alterations beginning to reflect a more psychosocial model of dementia in the 1980s, psychological therapies were being offered to people living with dementia twenty years prior; this included reminiscence therapy (Butler, 1963).

Critical social gerontology offers a differing viewpoint within the social model of dementia. Gerontologists have proposed the idea of "*successful aging*" which began with Havighurst (1961) who proposed that "*successful agers*" were independent, self-sufficient, active, satisfied and defy the traditional narratives of decline in old age. This was later expanded by Rowe and Kahn (1998) who proposed the "*new gerontology*" which requires successful agers to fully engage in life, including productive activities and interpersonal relationships. "*Successful aging*" is both an adaptable theory and a testable experience (Katz and Calasanti, 2015). Yet, when tested, McLaughlin *et al.* (2012) found that only between 3% and 33% of the population met the criteria for a "successful ager".

The concept of successful aging does lead to some aged individuals being classified as "*unsuccessful*" agers; therefore, scholars have adapted the model in several ways for optimum inclusion of older people (Phelan *et al.*, 2004; Van Wagenen, Driskell and Bradford, 2014; Katz and Calasanti, 2015). An example of this comes from Young *et al.,* (2009) who felt that the successful aging models focused too heavily on physiological aspects of the person's life. They suggested that the model needs to explain how the adaptation of physical and social aspects could help improve the psychological well-being of the person, resulting in *"a sense of personal fulfilment even in the context of illness and disability"* (Young *et al.,* 2009, pp. 89). Young *et al's* (2009) model of successful aging was shown to be empirically valid by Manierre (2019), who found it accurately predicted future hospitalization, depressive episodes and decreased life satisfaction for up to eight years after the initial assessment was conducted. It is only the multifaceted models of successful aging (ones that include physical, psychological and social factors) that offer a valid measurement of the person's quality of life (Kleineidam *et al.,* 2019).

Havighurst's (1961) successful aging framework is built on the individual adaptation of the older person to their changing lifestyle (Giblin, 2011). The aim of successful aging theory was to defy the traditional "*master narratives*" (Somers, 1994) of people living with dementia as "*the living dead*" (Behuniak, 2011), associated with decline and decay (Cook, 2008). It should be replaced with positive terminology like *"successful*", *"resilient*" and *"fulfilling*" (Harris and Keady, 2008; Cook, 2008), to provide a "*positive outcome*" frame of mind (Giblin, 2011). Some have suggested that the concept of successful aging for people with dementia is an oxymoron, as life with dementia cannot be successful (Baltes and Carstensen, 1996; Harris and Keady, 2008). Successful aging is closely related to high physical and cognitive performance, the latter of which is not applicable to people with dementia (Jonson, 2016). Yet researchers and dementia practitioners are beginning to notice a concept of "*resilience*" within the experiences of people living with dementia that suggests that successful aging whilst living with dementia is still achievable (Harris, 2007; Keady *et al.*, 2007; Harris and Keady, 2008; DiPietro *et al.*, 2012).

Within the concept of successful aging, there are several models with varying explanations on how to achieve this (Katz and Calasanti, 2015). The most applicable gerontology model for this thesis is "*Selective Optimisation with Compensation*"; proposed by Baltes and Baltes (1990). This model suggests that aging individuals faced with loss and limitations will adjust their expectations and life goals (Baltes and Baltes, 1990). Social gerontologists believe that an older person can successfully age whilst living with dementia provided that they stay actively involved in their world (i.e. social connections and meaningful activities) (Giblin, 2011). This is consistent with "*activity theory*" as proposed by Havighurst and Albrecht (1953) and Maddox (1965) whereby people with dementia can successfully age if they maintain activities, acquire new roles, continue psychological involvement in society and maintain social relationships. This has further been supported by the systematic literature review conducted by Martinson and Berridge (2015) which found that the literature strongly supports the association between social activities and the psychological well-being of older people with dementia.

2.5 Differences between the Medical and Social Model

The main differences between the medical model of dementia and the social model of dementia are outlined below in Table 2. This debate is complex; it cannot simply be “*medical model*” or “*social model”.* The medical model explores the disease aspects of dementia and uses this to find treatments and possibly a cure. Whereas the social model tries to improve the inclusivity of people living with dementia into society. Both models have their worth. It is important to recognise dementia as a disease for which scientists need to develop effective treatments (Rahman, 2015). Furthermore, the progressive nature of dementia will inevitably lead to an increase in impairments. These impairments can be alleviated with the adaptation of environmental barriers, increased support and social awareness, thus enabling people living with dementia to live with their impairments (Cahill, 2018). The social model of dementia recognises that a person affected by dementia will experience two changes; physical alterations within the brain that lead to functional decline and changes in their social-psychological environment. Whilst these changes can be identified, discussed and researched separately, the decline experienced by people living with dementia will inevitably be caused by them both (Kitwood, 1997). Furthermore, Henningsen (2015) noted that a medical model can be employed by health professionals who will still recognise the person living with the illness. In the UK today the principles of wellbeing and person-centeredness are however paramount and have been enshrined in legislation.

For this study, the participants’ experiences are kept central to every decision made. This is discussed more in the methodology chapter (pp 81) as the storytelling method of data collection ensures that the participants are able to discuss anything they feel is important and relevant to their experiences of life with dementia. Furthermore, adaptations were made to the research documentation to optimise the inclusion of people with dementia into the study. Participants were also supported to edit their stories, thus giving them full control over the data that has been shared and analysed.

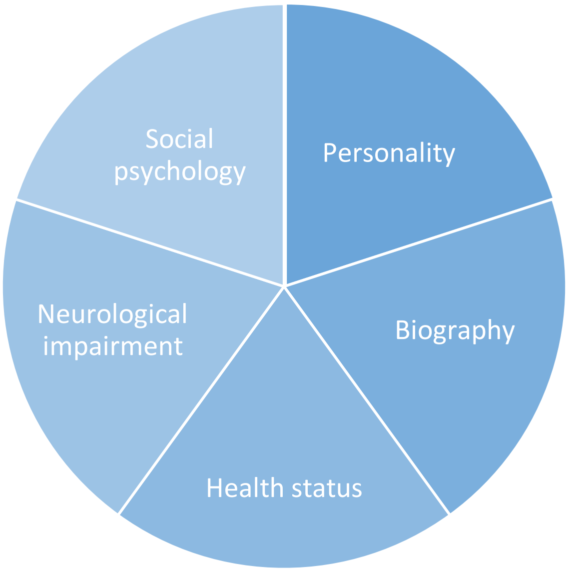
Table 2: Differences between the medical and social models of dementia

Medical Model of Dementia	**Social Model of Dementia**
The problem is a disease within the individual.	The problem arises when there are social and environmental barriers preventing participation from the person with dementia.
Sometimes decisions need to be made on behalf of the person with dementia.	The person with dementia is supported to make their own decisions.
The person with dementia has no control over their lives.	The person with dementia has control, responsibilities and is empowered by other members of society.
People living with dementia are victims of the disease.	The person with dementia has human rights, should be supported to remain active and deserve dignity and respect.
People living with dementia will be dependent on other people.	People living with dementia should be supported to live as independently as possible.
People living with dementia have no power.	The person living with dementia has all the power.
Medical model pushes for funding to go into finding a cure.	Social model pushes funding into improving quality of life.

2.6 Biopsychosocial Model of Dementia

Medical professionals rely on behavioural, social and emotional cues to aid with the diagnosis process (NHS, 2017); in terms of dementia, it is the behavioural changes that generally spark initial concern. During the diagnosis process within the UK, the consultant uses a brain scan, cognitive test score, medical history and behavioural/emotional/social changes to decide on the diagnosis given (NHS, 2017). As recognised within diagnosis processes, an effective model of dementia would need to incorporate both the physical alterations within the brain along with addressing the behavioural, psychological, social and emotional alterations being experienced by the person living with dementia. Despite being primarily acknowledged as one of the "*founders"* of the psychosocial model of dementia, Kitwood (1992) emphasised that dementia is affected by five interlinking factors: personality, biography, physical health status, neurological impairment and social psychology (Figure 1). These five factors are a combination of social, psychological and biological influencers (Bartlett and O'Connor, 2010) which was initially discussed by Engel (1967), and later developed into the biopsychosocial model of dementia by Cohen-Mansfield (2000).

Figure 1: Factors that influence dementia (Kitwood, 1992)



The biopsychosocial model was initially referred to as "*psychosomatic medicine"* by Engel (1967), who believed that illness was the result of several mechanisms all working together: these included cells, tissue, organs, interpersonal and environmental mechanisms. For Engel, a disease could not be fully studied without exploring the environment, the individual and the body (Engel, 1967). Psychosomatic medicine aimed to explore the psychosocial factors affecting individuals, provide holistic patient care and integrate psychological therapies with medical ones (Fava and Sonino, 2010).

Cohen-Mansfield (2000) evolved psychosomatic medicine into the "*biopsychosocial model"* of dementia and assumed that a person's experience of dementia is the result of predisposition (e.g. genetics), lifelong and current biological factors (e.g. vitamin deficiency), psychological (e.g. educational attainment) and environmental factors (e.g. alcohol consumption) (Cohen-Mansfield, 2000; Gagliese *et al.*, 2018). This was later expanded by Spector and Orrell (2010) who categorised the biological, psychological and environmental factors into fixed (things that cannot be changed, e.g. age) or tractable (things that can change, e.g. mood). The interactions between these fixed and tractable factors influence the onset, progression and symptoms of the person's dementia (Spector and Orrell, 2010; Gagliese *et al.*, 2018). This offers a possible explanation as to the differing experiences of people living with the same dementia diagnosis (Fava and Sonino, 2010).

The biopsychosocial model has also played its role in increasing awareness of predisposing risk factors for dementia (Fava and Sonino, 2010); for example, identifying obesity, educational attainment and alcohol consumption as risk factors for the development of dementia (Chen, Lin, Chen, 2009). In this example, dementia is the biological disease that has been influenced by behavioural (alcohol consumption) and psychosocial (education attainment) characteristics. Within the biopsychosocial model of dementia, it has been suggested that increasing awareness of the psychosocial factors that are linked with certain diseases at an earlier age (i.e. in schools) could prevent the students developing them in later life. Furthermore, targeting the younger generations could prove a more successful method of behaviour change than expecting behaviour change in adulthood (Shonkoff, Boyce and McEwen, 2009). There are several initiatives throughout the UK whereby school children are educated about dementia; this includes the "*Dementia 4 Schools Project*" (Dementia Action Alliance, 2015) whereby schoolchildren participate in a variety of activities run by the Alzheimer's Society to learn about living with dementia.

Kitwood (1993) proposed the following equation to explain the variations experienced by people with the same dementia diagnosis:

$$D = P + B + H + NI + SP$$

Where D is the dementia presentation (e.g. Alzheimer’s Disease), P is personality (e.g. strengths/resilience), B is biography (e.g. life history), H is physical health (e.g. vitamin deficiency), NI is neurological impairment (nervous system data-processing capacity) and SP is social psychology (e.g. relationships). Thus demonstrating how a combination of these factors can influence the person’s experience of dementia (Baldwin and Capstick, 2007).

Those in support of the biopsychosocial model of dementia appreciate that a multitude of factors will influence a person’s experiences of living with dementia (Fava and Sonino, 2008). Dementia poses several problems for the person living with dementia and their family members: from physical and mental decline, to depression, social isolation, environmental barriers and a lack of understanding from family and friends. No single model can provide all of the support needed to deal with such a diverse range of problems; therefore, the biopsychosocial model of dementia encourages the use of a multidisciplinary team (medical staff, support workers, occupational therapists, social support groups etc) who can ensure that people affected by dementia receive the exact support and intervention they need, optimising person centred care (Cahill, 2018).

The biopsychosocial model of dementia has implications for dementia care and treatment planning whereby health service staff are trained to ensure all elements of this model of dementia are present within the patient’s care and treatment plans (for example, psychosocial, environmental and pharmacological interventions should be listed: Revolta *et al.*, 2016; Spector *et al.*, 2016). The Mental Health (Wales) Measure (2010), superseded by the Social Services and Well-being (Wales) Act (2014), both state that everyone within mental health services must have a written care and treatment plan. These care and treatment plans consist of eight domains (accommodation, education, finances, physical well-being, relationships, occupation, social cultural and spiritual, medical and other forms of treatment). It is only compulsory for one domain to be completed within a person’s care and treatment plan (Welsh Government, 2010). This could result in a lot of relevant information about the person being left out of their care and treatment plan (Fothergill *et al.*, 2018); for example, if only the finances domain is completed, the reader will know nothing about the patient’s relationships or physical well-being. The person living with dementia's outcome preferences should always be central to their care and treatment plan and ultimately to the interventions being arranged on their behalf; this is evident within the Dementia Action Plan Wales (2018) (pp 2). The biopsychosocial model of dementia can enhance acceptance, awareness and inclusion of people living with dementia regardless of their setting (care home, residential home or within their own home).

The biopsychosocial model of dementia is used by medical professionals to diagnose people with dementia and track the progress of their dementia (Fava and Sonino, 2008). Similarly, the Making a Difference in Dementia: Nursing Vision and Strategy (2016) states that nurses must provide medical assistance to people living with dementia, whilst maintaining person centred care and offering psychological therapies in place of pharmaceutical ones (more on this can be found in Appendix A, pp. 342). Furthermore, a combination of a person's environment, psychology, biology, history and social relationships will affect how they respond to their diagnosis of dementia, and how their dementia progresses (Fava and Sonino, 2008). Despite this, the biopsychosocial model of dementia has been criticised for its over emphasis on the biological, social and psychological factors having equal influence over the dementia progression, when in reality, different factors will have differing levels of influence over someone's life with dementia (Henningsen, 2015). Furthermore, the biopsychosocial model of dementia does not provide any guidance as to which therapeutic intervention would be better suited at which point (Ghaemi, 2009).

2.7 Summary and Reflection

The differing perceptions of dementia have shaped the dementia discourse and are likely to be underpinning people's views and experiences on the topic (Innes and Manthorpe, 2012) and all hold significant value for dementia services. The medical model has its place for initial investigating of the causes and nature of the disease and allows researchers to study the brain and has resulted in the development of pharmaceutical treatments. The social model of dementia highlights how environmental and social manipulations can allow for the maximum inclusion of people living with dementia within society; today's social model of dementia echoes beliefs and practices from the nineteenth century. The biopsychosocial model of dementia incorporates all aspects of dementia to form a multidisciplinary approach towards improvements of the quality of life for people affected by dementia.

"The complex interactions of neurochemistry, genetics, environment, life stories and personality all play a part in how individuals experience dementia. No single approach will explain everything. Indeed, trying to limit our view of dementia to one model … causes people harm and is a dead-end from which there is no way out but back" (Harry Cayton, 2004, pp. 12).

The following chapter contains a literature review on experiences of living with dementia and includes the search strategy used to effectively explore the literature available. The literature is divided into research that focuses on the experiences of people with dementia, family members and joint perspectives.

Reflection on the Chapter

This study is situated primarily within the social model whereby people living with the condition are empowered to share their experiences of life with dementia. This research recognises the personal histories of people living with dementia and uses their stories to understand their current situations. Exploring the other perspectives is particularly important as I have found that people will generally align their beliefs about dementia with one or other of the models. For the most part, people place emphasis on the medical model and look for pharmaceutical therapies to help them live with dementia. There also remains a societal link between dementia and insanity, particularly the trustworthiness of people with dementia. I had many comments when going through the ethical permissions for this study regarding the validity of the participant’s story, and how they could give full informed consent if they have dementia. The historical stigma associated with dementia is still found today and can often deter people from doing research with those living with the condition as their cognitive capacity and capability is questioned. I discuss this more towards the end of this thesis as it helped to shape this study and my own personal resilience towards such adversity (pp 274).

CHAPTER 3   LITERATURE REVIEW

"If you are going to get anywhere in life, you have to read a lot"

(Roald Dahl)

3.1 Introduction

This chapter reviews literature on experiences of life with dementia. "*A literature review is used to provide an informed and comprehensive overview of the best available research from previously published studies related to a specific topic"* (Baker, 2016, pp. 265). This literature review is taking a scoping review approach. As the name suggests, this chapter aims to scope the body of literature of life with dementia. The nature of descriptive phenomenology allows for a more open exploration of a given topic area, in this case, dementia. This fits well with the premise of a scoping review, which is useful for examining the evidence without being too specific (Armstrong *et al.,* 2011). The purpose of scoping reviews are to (1) identify the types of evidence that are available, (2) examine how research is conducted in a given field, (3) identify key factors related to the concept, and (4) identify any knowledge gaps (Arskey and O'Malley, 2005; Munn *et al.,* 2018).

Within this chapter, the guidance from Tricco *et al.,* (2016) is followed regarding the process of conducting a scoping review. The search strategy used to identity the literature is outlined. By following clear search strategies, PRISMA and PICO, the search used to identify relevant literature in this chapter is replicable and allows for the inclusion and exclusion criterion to be clearly identified (Cope, 2014). The studies that meet the criteria and answer the research questions are discussed with links to the previous two chapters regarding perspectives of dementia and legislation being made clear.

3.2 Method for the Review

3.2.1 Research question and aims

This review aimed to answer the following questions:

1. What is the lived experience of older people with dementia?
2. What are the experiences of family members' of an older person with dementia?

This review aimed to identify literature that supported the aims of the research being conducted. Firstly, to explore all the existing work about life with dementia from the perspective of the person with dementia. Secondly, to explore all the existing considerations about life with dementia from the perspective of a family members of an older person with dementia. The articles uncovered were initially used to help inform the methodology for this study by understanding how previous researchers included people with dementia into their research, and what types of methods they used. To avoid any bias occurring in the research student, which may have impacted upon data collection and analysis, the findings sections of the articles were not read until data collection and analysis for this study had been completed. This is central to descriptive phenomenology research, whereby it is recommended that the literature review is the last thing to be conducted, so as to avoid the researcher's prior knowledge of the topic influencing data collection and analysis (Husserl, 2001). However, it was felt that the methodology needed to be informed by prior research, hence the initial exploration of the methods sections of the articles found.

To ensure this literature review was as rigorous and replicable as possible, the guidance from Tricco *et al.,* (2016) regarding the steps necessary for conducting a scoping review (Table 3) are followed. The key steps are predefined research questions, eligibility criteria, search strategy that it is replicable (including individual databases and additional search), synthesis of findings, reporting and discussion of findings (Tricco *et al.,* 2016).

Table 3: Steps/items included for scoping review

Items Included
Rationale
Objectives
Eligibility criteria
Information sources
Search strategy
Study selection
Data collection process
Data items
Synthesis of results
Study characteristics
Results of individual studies
Summary of evidence
Limitations
Conclusions

3.2.2 Search strategy

Initially, a PICO chart was completed (Table 4); a PICO (population, intervention, comparison and outcome) is a tool used by researchers when conducting literature reviews as it uses the research questions to generate key search terms. These key terms can then be used as the basis for a systematic search of the literature (Cooke, Smith and Booth, 2012). As this study was solely explorative and did not use an intervention, the intervention heading of the table has been altered to exploration.

Table 4: PICO Chart

Population	People 65 years of age or older with a dementia diagnosis Family members of people 65 years of age or older with a dementia diagnosis
Intervention (Exploration)	Digital narratives Storytelling Narratives
Comparison	Alternative methods of data collection (i.e interviews, focus groups, questionnaires)
Outcome	Life stories of older persons and family members living with dementia

Ten databases were utilised for the search: MEDLINE, CINAHL, PubMED, ProQUEST, ScienceDirect, Embase, PsycINFO and PsycARTICLES, ASSIA and Cochrane. Unpublished articles were explored through SIGLE (System for Information on Grey Literature in Europe). This was accompanied by a hand search through relevant journals, including "*Dementia", "Journal of Applied Gerontology",* "*Nursing Older People",* "*International Journal of Older People's Nursing*", "*Alzheimer's and Dementia*" and "*Gerontology".* Using the PICO chart, the key search terms used for the literature review were "*older people*" (OR 65 plus OR people with dementia), "*family members*" (OR spouse OR caregiver OR adult children OR family OR dyad OR friend), "*dementia*" (OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontal-temporal OR Lewy Body), "*narratives"* (OR storytelling OR digital storytelling) and "*life story work*" (OR reminiscence OR autobiography OR life history OR memoire OR biography). Limiters included English language only, peer reviewed and the full text being available. As this is a qualitative study, date limiters were not applied to the database searches as influential work in the area may be dated but still useful in informing this study (Coughlan *et al.*, 2007). Historical records sourced from outside of the database searches are discussed in chapter 2, historical context of dementia (pp 20). Published literature reviews and systematic reviews on experiences of life with dementia and life story work were also explored, with references from those being followed up and the relevant studies being included. The literature review search was completed over a period of 3 years, beginning in October 2017 and completed in June 2020.

Each database has varying methods of altering the scope of the search. The table below (Table 5) illustrates the varying refining criteria (limiters) used for each individual database with the number of hits altogether after limiters were applied. Appendix D (pp. 358) illustrates the number of hits from each database for the search terms before and after limiters were applied.

Table 5: Database limiters and total hits

Database	Total hits after limiters applied	Limiters
Medline and CINAHL	70	Full text available Participants: 65+ Language: English only Subject: Humans Subject: Older people** Dementia** Caregivers**
PubMED	77	
ProQUEST**	4889	
PsycINFO	5306	
PsycARTICLES	4655	
ASSIA	176	
ScienceDirect	7707	Research Articles
Embase	213	Publication type: Articles Age: Aged and very aged Study type: Humans

3.3.3 Inclusion and exclusion criteria

The inclusion and exclusion criteria for the literature review is highlighted in Table 6 below.

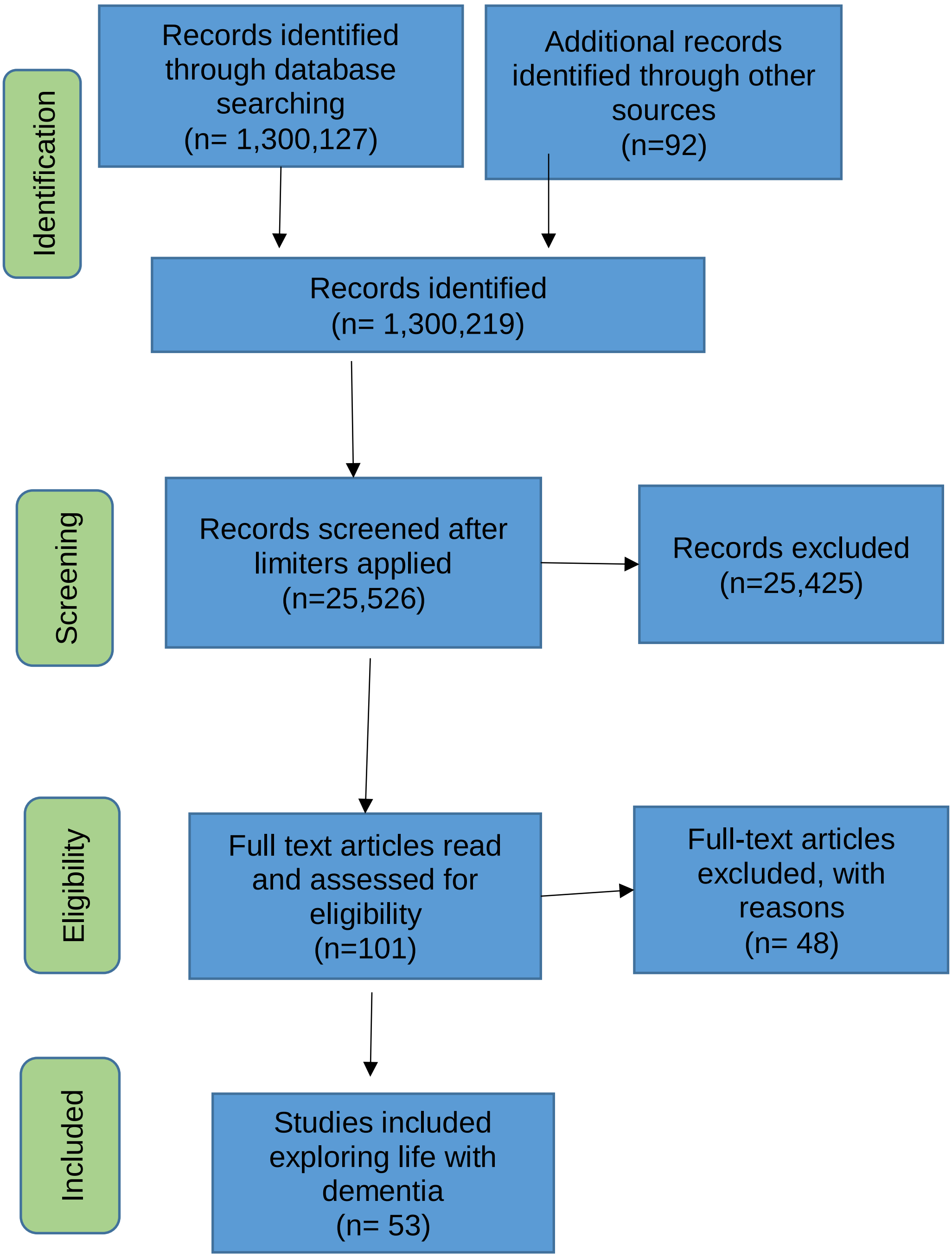
Table 6: Inclusion and exclusion criteria for literature review

Inclusion Criteria
The experiences/views of people with dementia
The experiences/views of family members of people with dementia
The participants with dementia were over 65
The study is available in English
The full text of the article is available
Exclusion Criteria
The study explores early onset dementia
The study used proxy accounts to explore experiences of living with dementia (i.e *"I think she would feel*" as opposed to "*I feel*")
The study did not specify that the participants had dementia
The study measured the effectiveness of different interventions (e.g. drug therapy, music therapy, photographic video therapy, dress therapy)
The study did not have the experience of life with dementia as its focus
The study primarily explored the views of paid care staff

3.3.4 Identification of studies

This literature review was completed by June 2020. A flow diagram (Figure 2) highlights the process used to filter down the number of hits from a general search to the specific papers used in this literature review. When searching for the term "*dementia"* alone, 2,236,607 hits were found. To filter this to make it more specific to this study, key terms were added as discussed under the heading "*search strategy*" (please see 3.2.2, pp. 51).

Figure 2: Flow diagram detailing the identification of studies



3.3.5 Full text articles excluded

Forty-eight articles were excluded from the literature review. The main reasons for article exclusion from the literature review during the eligibility phase was that participants with dementia were under 65 years old, lack of information provided about the age of the participants, no distinction between dementia diagnosis and cognitive impairment or they were not relevant to the literature review aims. All the articles excluded, with reasons, can be found Appendix E (pp. 365).

3.3.6 Data synthesis and synthesis of findings

Data was extracted from all studies included in this literature review (n=53) using a bespoke extraction table (Appendix F, pp 369). This extraction table outlines the study aims, methodology, participants, findings, and critiques of the studies.

The findings from the review of the included papers are divided into three themes; experiences of living with dementia whereby only the person with dementia participated; only the family member participated and research involving both the person with dementia and their family member as a pair. These three themes were further subdivided as shown in Table 7.

Table 7: Summary of themes and subthemes of the synthesis of studies

Themes	Subthemes	Representative Studies
Person with Dementia Perspectives	Sense of self and identity	Nordtug *et al.*, 2018; Heggestad and Slattebo, 2015; Karlsson *et al.*, 2014; Hedman *et al.*, 2012; Barca *et al.*, 2011; Aminzadeh *et al.* 2009; Russell and Timmons, 2009; Ryan *et al.*, 2009; Surr, 2005
	Everyday life	Chen and Lin, 2019; Hellström, Eriksson and Sandberg, 2015; Svanström and Sundler, 2015; Sterin, 2002
Family Member Perspectives	Relinquishing care	Cronfalk, Norberg and Ternestedt, 2018; Hellström *et al.*, 2017; Johansson *et al.*, 2014; Hennings *et al.*, 2013; Palmer, 2013; Hutchings *et al.*, 2011; Mullin *et al.*, 2011
	Family and personal dynamics	Polenick *et al.*, 2020; Oliveira *et al.*, 2020; Lethin *et al.*, 2020; Spigelmyer *et al.*, 2018; Andrews *et al.*, 2017; Elnasseh *et al.*, 2016; Jayalath, Ashaye and Kvavilashvili, 2016; Tuomola *et al.*, 2016; England, 2015; Stokes, Combes and Stoke, 2014; Kjallman-alm, Norberg and Hellzen, 2013; Uei, Sung and Yang, 2013; Shim, Barroso and Davis, 2012; Hayes *et al.*, 2009; Hibberd *et al.*, 2009; Hasselkus and Murray, 2007; Gottlieb and Gignac, 1997
	Segregation	Strommen *et al.*, 2020; Clarke and Bailey, 2016; Zhan, 2004; Hinton and Levkoff, 1999

Joint Perspectives	Experiences of services	Keyes *et al.*, 2016; Koskenniemi, Leino-Kilpi and Suhonen, 2015; Gorska *et al.*, 2013; Karnieli-Miller, 2012
	Life with dementia	Hernandez et al, 2019; Swall *et al.*, 2019; Hellström and Torres, 2013; Black *et al.*, 2012; Robertson, 2010; Daniels, Lamson and Hodgson, 2007; Steeman *et al.*, 2007; Phinney, 2002

3.3.7 Characteristics of papers

The literature search uncovered 53 papers that addressed the research questions and met the aims for this literature review: to explore the pre-existing literature about life with dementia from the perspective of the older person living with dementia and their family members. These papers date back to 1997. Thirteen papers explored life with dementia from the perspective of the person with dementia, 28 explored the family member perspectives and 12 combined both perspectives. Six of these papers were quantitative while the remaining 47 were qualitative. The participant numbers ranged from an individual case study to 508 participants (254 people with dementia and 254 caregivers). The studies took place in 10 different countries (UK, USA, Denmark, Sweden, Israel, Canada, Argentina, Taiwan, Norway and China).

The majority of studies included in this literature review were qualitative and used open ended, semi-structured/unstructured interviews). Whilst qualitative research explored the "*authentic voices*" and "*lived experiences*" of the participants (Grant, 2014), there are some critiques that need to be noted. "*Qualitative research is frequently criticised for lacking scientific rigour with poor justification of the methods adopted, lack of transparency in the analytical procedures and the findings being merely a collection of personal opinions subject to researcher bias"* (Noble and Smith, 2015, pp. 34). Furthermore, in relation to interviews, Lather (2009) noted that some participants may give the impression that their experiences conform to the societal norm instead of sharing their non-conformist experiences. For studies with a small sample size, the generalisability of the study's results could be threatened (Vasileiou *et al.*, 2018).

3.3 Literature Review Findings

3.3.1 Person with dementia perspectives

Two themes emerged from the literature, which explored the experiences of older people with dementia. These were sense of self and identity and everyday life.

Sense of self and identity

Nine studies explored the identity and sense of self of older people living with dementia. Five of these studies recruited participants from within residential care homes and explored how participants maintained their sense of self, how their identities had changed and the impact a residential home has on quality of life. One of these studies is quantitative (Barca *et al.*, 2011) whilst the other four used qualitative interviews to collect their data (Heggestad and Slattebo, 2015; Aminzadeh *et al.* 2009; Russell and Timmons, 2009; Surr, 2005).

For the participants in Aminzadeh *et al*'s (2009) study, moving into a residential care home was an inevitable part of old age in which the person could identify themselves as a "*survivor*". Whilst this study had a relatively small sample of sixteen Canadian participants, which cannot be generalised to wider populations, it highlighted that older people feel that moving into a care home is the end of an era and signalled the inevitable downward trajectory of old age (Aminzadeh *et al.,* 2009). For older people with dementia to maintain their identities when living in residential care homes, care home staff need to get to know the residents by listening to their life stories. This helps the residents feel safe within the chaos of a residential care home as illustrated by Heggestad and Slattebo (2015) who conducted observations within care homes. Unfortunately, whilst observational studies have their worth, sometimes people will act differently when they know that they are being watched, also known as the Hawthorne Effect (Gross, 2010).

Inevitably, some residents within a care home will have similar hobbies and interests; but staff need to ensure that they treat residents as individuals despite their collective similarities (Russell and Timmons, 2009). One way to achieve this is allowing the residents to tell their own life narratives; any stories that are repeated, are likely to be influential over the person's life (Russell and Timmons, 2009). Russell and Timmons (2009) found that listening to the stories of older people with dementia allows the person to gain insight into their understanding of themselves. When older people with dementia were asked about their sense of self, Surr (2005) found that good relationships with family members, other residents and staff within the residential care home was essential to maintaining their sense of self. Both studies (Russell and Timmons, 2009 and Surr, 2005) used unstructured interviews to explore the experiences of people with dementia; this allows the participant to share information that they feel is relevant, not what the researcher has pre-empted.

Barca *et al*'s (2011) quantitative study using self-report scales showed that quality of life was negatively correlated with depression in older people with dementia living in residential care homes. Furthermore, those with a low score on a quality of life scale also completed minimal daily activities and had worse cognitive impairment (Barca *et al.*, 2011). Barca *et al.* (2011) concluded that the resident's quality of life could be improved by treating their depressive symptoms. Observations were used within this study to assess the participant's behaviours (e.g. comfort and discomfort); this has been criticised for being very subjective as the observer did not necessarily know the participant well enough to make this judgement and the person with dementia's behaviour would be open to interpretation (Barca *et al.*, 2011).

Four studies explored how older people with dementia expressed their sense of self and maintained their identities whilst living in their own homes. Using qualitative interviews, Hedman *et al.* (2012) noted how participants felt that their identities had not changed since being diagnosed with Alzheimer's Disease; they did, however, feel apprehension about their social self being scrutinised by family and friends as their condition deteriorated. It is worth noting that all of the participants in Hedman *et al*'s (2012) study were highly educated and able to articulate their answers well; those who are not well educated may have different stories to share (Hedman *et al.*, 2012). Furthermore, most of the participants in Hedman *et al*'s (2012) study had communication difficulties; the two researchers often had to "*fill in the gaps*" and prompt the participants. This researcher input may cause experimenter bias in the findings (Pannucci and Wilkins, 2010). Contrary to this, Ryan *et al.* (2009) found that people with Alzheimer's Disease initially had many worries about the way they would be perceived by friends and family. After writing down their observations, thoughts and feelings, they became very accepting of their new identity and described their dementia using positive terminology (for example, a survivor or an educator to those who do not understand dementia). Similarly, Nordtug *et al.* (2018) also noted how participants in their Norwegian study perceived themselves and their life stories. Looking back at their lives before dementia, including their careers, elicited positive emotions associated with the memories but sometimes resulted in feelings of grief for their former selves (Nordtug *et al.*, 2018). Caution must be made when reading the results from Ryan *et al's* (2009) and Hedman *et al's* (2012) studies as the people with dementia were helped to write down their observations and it is possible that the "*helper*" did not record things accurately.

Karlsson *et al.* (2014) encouraged nine older people with dementia to narrate their life stories, from childhood through to the present day and hopes for the future: much like this study. Karlsson *et al.* (2014) used predefined questions throughout the data collection; this could have limited the participants' ability to talk about important elements of their lives outside of those predefined areas. Nevertheless, throughout the life stories, the participants identified four core dimensions to their lives; contentment, connectedness, self-reliance and personal growth (Karlsson *et al.*, 2014). These core dimensions were present from childhood through to the present day and are all elements of the person's identity (Karlsson *et al.*, 2014). Like Surr (2005), the participants in Karlsson *et al*'s (2014) study wanted to remain connected to their family, friends and local community.

Everyday life

Four studies identified within the literature search explored the everyday lives of older people with dementia. These were all qualitative in nature and ranged from a case study (Sterin, 2002) to 12 participant interviews (Chen and Lin, 2019).

Sterin's (2002) case study explored the difficulties in everyday life faced by an older lady with a diagnosis of Alzheimer's Disease. After a one time data collection session, Sterin (2002) noted how friends and family of the lady in the case study had three reactions to her dementia diagnosis which have been termed "*the process of becoming invisible, the gesture of dismissal and the act of smothering"* (Sterin, 2002, pp 8). Friends stopped talking to her as they used to, family members felt tied to her and professionals wrapped her so tightly in cotton wool that she felt smothered (Sterin, 2002). Whilst Sterin's (2002) case study findings cannot be generalised to other people with dementia, it provides in depth information about her personal experiences which could pave the way for further research.

Whilst the lady described by Sterin (2002) felt that family members were unwillingly tied to her because of her dementia, the participants in Chen and Lin's (2019) study felt that they were burdens on their family and friends. Chen and Lin (2019) also found that the older persons with dementia had a dispassionate view on life and death and were upset about their inability to remember things. Whilst Chen and Lin (2019) and Sterin (2002) were aware that their families were having to do increasingly more things for them, the six participants in the study by Svanström and Sundler (2015) had no family and friends on whom to rely. The six participants lived a "*vague existence*" (Svanström and Sundler, 2015, pp.145); never leaving their homes and having essentials (food and medication) delivered to them by paid care workers (Svanström and Sundler, 2015). Svanström and Sundler (2015) noted that the number of older people with dementia living alone is increasing; if their social needs are not met, along with their care needs, they will become lonely and live a vague existence. These findings were based on unstructured interviews and field notes of the data collection processes. It was noted that the participants often struggled to think of something to discuss and relied heavily on the researcher to suggest the topic of conversation; this may have resulted in the participants being led to discuss certain areas of their life while missing out other important elements (Svanström and Sundler, 2015).

Hellström, Eriksson and Sandberg's (2015) study focused on the experience of seven older women with dementia and how they managed their everyday household chores and the upkeep of their homes. No males with dementia participated in this study and it is therefore unclear how they feel about the changes in household chores. The findings derived from five sessions of unstructured interviews spaced over five years, offering insight into how their lives changed over time and illustrating how the women express their sense of self through their homes and many participants gave the interviewer a tour of their house, pointing out items of importance to them (Hellström *et al.*, 2015). Household tasks were divided between the husband and wife, with the wife doing the in-house tasks like food preparation and the laundry, while their husbands maintained the garden (Hellström *et al.*, 2015). Dividing the household roles in such a way maintains the participants' role within the household and their marriages (Hellström *et al.*, 2015). The women who participated in this study also explained how they had to give up certain household jobs and let their husbands take over; things like driving, baking, finances and shopping were now the sole responsibility of the husbands (Hellström *et al.*, 2015). As the participants begin to lose their ability to perform household tasks properly, their husbands take over the responsibility (Hellström *et al.*, 2015).

3.3.2 Family member perspectives

Three themes emerged from the literature, pertaining to the experiences of family members of older people living with dementia. These were relinquishing care, family and personal dynamics, and segregation (culturally and geographically).

Relinquishing care

Seven of the studies included in this literature review investigated the experiences of family members when it was necessary for their loved one to move into residential care. All these studies were qualitative in nature and employed interviews as the data collection tool.

Three studies aimed to explore how spouses' experiences changed over the course of time their loved one lived in residential care. Hellström *et al.* (2017) noted that the husbands in their study experienced a change in their sense of self the longer their wives were in residential care and their dementia progressed. The husbands went through three stages; "*me and it*" [their wife's dementia] was the initial stage from the study when the wives were still living at home. The second stage occurred when the wives had moved into residential care and the husbands were going through a "*me despite it*" stage. Lastly, after their wives had been living in residential care for a few years, the husbands were described as being in an "*it is me"* stage, whereby they are no longer providing personal care for their spouse and have gained a new independence (Hellström *et al.*, 2017). This study specifically explored the caregiving experiences of the husbands; using such a specific "*lens*" to view their lives could have resulted in several "*real*" factors being missed out (Hellström *et al.*, 2017).

Contrary to the participants in Hellström *et al*'s (2017) study, Hennings *et al.* (2013) noted how the spouses in their study did not feel that they had gained independence after their loved one moved into residential care; they felt torn between spending time in the care home with their spouse and spending time in wider society. Participants in this study also reported feelings of guilt caused by the placement of their spouse in residential care (Hennings *et al.*, 2013). The longitudinal nature of this study allows for better understanding of the complexities of caring for someone else over time yet these feelings of guilt were also noted by Mullin *et al's* (2011) short term study in which participants felt that they were obliged to care for their spouse in accordance with their wedding vows "*until death do us part*" (Mullin *et al,* 2011, pp. 177). When they could no longer manage, and residential care was sought, they felt guilty about the decision and regularly visited the care home to ensure their loved one was being cared for properly (Mullin *et al.*, 2011).

The three studies previously discussed (Hellström *et al.*, 2017; Hennings *et al.*, 2013; Mullin *et al.*, 2011) explored spouses experiences after their loved one had been living in residential care for some time. The following four studies explored family experiences whilst their loved one with dementia was still in the "*moving phase*"; still living at home and about to move into residential care (Cronfalk *et al.*, 2018; Johansson *et al.*, 2014; Palmer, 2013; Hutchings *et al.*, 2011). Participants from all four of these studies explained that they were worried about the relationship with their loved one with dementia changing after they had moved into residential care (Cronfalk *et al.*, 2018; Johansson *et al.*, 2014; Palmer, 2013; Hutchings *et al.*, 2011). Family members also had negative expectations of dementia care within residential care homes which made the decision more difficult (Johansson *et al.*, 2014). Cronfalk *et al.* (2018) and Hutchings *et al.* (2011) found that family members had concerns about the person with dementia being enabled to participate in hobbies, meaningful activities and maintain old habits. Furthermore, Palmer (2013) found that the personhood and wellbeing of the person with dementia was kept central to all decisions made on their behalf. All family members in Palmer's (2013) study were close to the loved one whom they cared for; it is possible that the findings would be very different had they asked family members who were not so involved in their relative's life.

Family and personal dynamics

Seventeen studies explored the personal and family dynamics of the families caring for an older person living with dementia. Three of these studies were quantitative (Lethin *et al.*, 2020; Elnasseh *et al.*, 2016; Uei *et al.*, 2013), while the remaining were qualitative.

Jayalath *et al.* (2016) asked family members to record their relative's symptoms of dementia in a written diary and highlight which ones were causing problems. They were later interviewed about their experiences. The main problems that the family members encountered were incontinence, insomnia, forgetfulness, aggression, hallucinations and anxiety (Jayalath *et al.*, 2016). An additional observation from the study found that the male participants underplayed the severity of the person with dementia's behaviours (Jayalath *et al.*, 2016). The family members in this study reported feelings of depression and anxiety, that did not alter over the 28-day time frame of the study (Jayalath *et al.*, 2016). This study demonstrates that researchers should consider including a written diary as a part of their data collection process as the participants in this study often wrote more details in their dairy about their feelings than they shared with the researcher (Jayalath *et al.*, 2016).

Caregivers have several coping mechanisms when faced with problematic symptoms, as described by Jayalath *et al.* (2016). These coping mechanisms include the family members reminding themselves that the behaviours were caused by the disease and not the person (Gottlieb and Gignac, 1997), and accepting their new caregiving role and taking control of the situation (Tuomola *et al.*, 2016). Uei *et al.* (2013) found positive correlations between levels of caregiver burden and gender, education levels, hours of care, hours of self-care and frequency of challenging behaviours. Women were more likely to feel burdened than men and those with higher education levels were less likely to feel burdened whilst caring for a loved one with dementia (Uei *et al.*, 2013). Furthermore, Lethin *et al.* (2020) found that increased caregiver burden was correlated with low levels of psychological wellbeing. The study by Lethin *et al.* (2020) was conducted in eight different European countries and explored several risk factors (care provisions, depression, well-being, quality of life and cognitive ability) for caregiver burden; this increases the generalisability of the findings. However, correlation research does not show cause and effect (Gross, 2010) and it may be possible that low well-being is causing increased caregiver burden or vice versa.

Elnasseh *et al.* (2016, pp. 2) defined caregiver resilience as *"a psychological phenomenon characterized by effective coping and adaptation in the face of loss, hardship, or adversity. In the context of dementia, resilience is believed to be a protective factor for caregiver stress"* and also claimed that caregiver resilience was directly influenced by wider family dynamics; having few family problems and good communication improved the caregiver’s resilience levels. Additional threats to the caregiver’s resilience were noticing the person with dementia’s deteriorating condition, doubting their caring abilities and worrying about increased caregiver demands in the future (Spigelmyer *et al.*, 2018). When Hasselkus and Murray (2007) investigated the perceived wellbeing of the caregivers in their study through telephone interviews, they found that family members rated their wellbeing in terms of their loved ones conditions; the participants viewed themselves as part of a pair (the caregiver and person with dementia) therefore, assessed well-being as a joint experience. If the person with dementia was having a bad couple of days, the self-reported well-being of the caregiver reflected this (Hasselkus and Murray, 2007). Telephone interviews are limited when used for unstructured interviews as they do not allow the researcher to use visual cues for prompts (Hasselkus and Murray, 2007).

Further studies to explore the well-being of family caregivers of older persons with dementia was conducted by Oliveira *et al.* (2020). Through open ended questionnaires completed by 150 unpaid caregivers, they found that family members believed that financial support, social support and having time to do things that they enjoy outside of caregiving would improve their sense of well-being whilst caring for a loved one with dementia (Oliveira *et al.*, 2020). Whilst the questionnaire was completed by an ample number of participants, they were anonymous and did not allow the research team to follow up any interesting comments. Follow up conversations would have allowed the team to explore key themes further (Oliveira *et al.,* 2020).

England (2017) presents a case study for a husband caring for his wife with dementia. The case study followed Mr Cassidy through his wife’s last year and goes into detail about his struggles while caring for his violent wife. It details his loyalty to her, whereby he insists that she is still the woman he married, and his commitment to a promise made years before that ensured she would be able to die in her own bed (England, 2017). Mr Cassidy insists that his wife is still his wife, and he is still the same man who married her, reaffirming his own identity (England, 2017). Mr Cassidy also battles with his moral reasoning; he is struggling to care for her alone but has made the promise to care for his wife, in their own home, until the day she dies

(England, 2017). This was a case study, but similar studies were not uncovered within this literature review. Mr Cassidy's love and devotion to his wife, along with his insistence to care for her alone, is rare within the dementia caregiver literature (England, 2017); most of the studies found within this literature review explored the family member's burden, anxiety, depression or reduced well-being (Jayalath *et al.*, 2016; Uei *et al.*, 2013; Hasselkus and Murray, 2007).

Similarly, Hibberd *et al.* (2009) noted that there were four key elements of the caregiving relationships; recognising the value of each other, transforming the relationship as the dementia progresses, taking every day as it comes to maintain stability and moving forward whilst encompassing old memories (Hibberd *et al.*, 2009). These four elements are essential to maintaining a positive caregiving relationship between the family members and the person with dementia (Hibberd *et al.*, 2009). Furthermore, Polenick *et al.* (2020) found that caregivers have 6 core methods of managing life with dementia to help enhance the relationship between themselves and the person with dementia. The family members try to slow down the pace of daily life to allow the person with dementia to remain independent whilst modifying the environment in case they forget (for example, leaving instructions) (Polenick *et al.*, 2020). Engaging in fun activities and using humour also helped the family members remain in a positive relationship with their loved one; whilst social support and having time to themselves helps the family members maintain a positive frame of mind (Polenick *et al.*, 2020).

Another study that explored the relationships between family members and the person with dementia was a longitudinal study by Shim *et al.* (2012) who followed the changes in family dynamics over time. This study identified the family dynamic at the beginning of the study as being positive, negative or ambivalent and then compared this to the family dynamic after a year (Shim *et al.*, 2012). Results indicated that the family's classification (positive, negative or ambivalent) had not changed as the dementia had progressed. Those who initially had a positive family dynamic maintained this, those with a negative dynamic remained negative and the ambivalent group were still altering their family dynamic regularly (for example, losing their temper with the person with dementia and then apologising because they feel guilty) (Shim *et al.*, 2012). Whilst a longitudinal study of this nature offers invaluable insight into the family dynamics over a period of time, it is possible that their loved one's dementia did not deteriorate much within the year. Following their dynamic over a longer period of time, as the dementia progresses, may conclude something different (Shim *et al.,* 2012).

Three of the studies that were considered to cover family and personal dynamics within this literature review explored family members' knowledge about dementia (Andrews *et al.*, 2018; Stokes *et al.*, 2014; Kjallman-alm *et al.*, 2013). All these studies noted that the participants were not provided with enough information about dementia and the services that were available to them, nor did they understand the terminal nature of the condition (Andrews *et al.*, 2018; Stokes *et al.*, 2014; Kjallman-alm *et al.*, 2013). Whilst the participants in Stokes *et al*'s (2014) study were spouses of the person with dementia, the other two studies consisted of adult children participants (Andrews *et al.*, 2018; Kjallman-alm *et al.*, 2013). The adult children within the studies explained that they had a fear of dementia being hereditary, and that they might develop it in later life, but due to a lack of knowledge about the condition, they were unsure if this was the case (Andrews *et al.*, 2018; Kjallman-alm *et al.*, 2013). The participants within these two studies were purposely recruited from support groups and are not representative of the family members who do not access such support groups.

Hayes *et al.* (2009) explored how spousal connections altered when they adopted the caregiving role for their loved ones. Results indicated that marital relationships altered with loss of intimacy being the most important factor for the wives who participated in the study (Hayes *et al.*, 2009). The female participants missed the hugging, kissing and saying "*I love you*" with their spouse. The male participants in the study explained that they were still sexually intimate with their wives, despite the dementia, and that their marital relationship was more altered by the increase in household responsibilities (Hayes *et al.*, 2009). Hayes *et al.* (2009) concluded that females felt that the intimate changes in their husbands' behaviours were more influential over their marital roles while the male participants responded to the household changes in their marital roles. This study illustrated a clear gender difference in spousal role changes caused by one spouse having dementia (Hayes *et al.*, 2009). Very few studies within this literature review have made such a clear gender distinction in experiences of living with dementia.

Segregation

Two studies within the literature review explored cultural differences in perceptions of dementia (Zhan, 2004; Hinton and Levkoff, 1999) while the other studies explored the experiences of the families of older people living with dementia in rural communities (Strommen *et al.*, 2020; Clarke and Bailey, 2016). Four of these studies are qualitative and used interviews as their data collection tool.

Hinton and Levkoff (1999) explored the ways that people from four different cultures within Boston viewed dementia; these were African Americans, Chinese Americans, Irish Americans and Latino families. After analysing the interviews, Hinton and Levkoff (1999) noted that the African American and Irish American participants viewed dementia as a disease that deteriorates the person's mind and can threaten the person's identity; similar to the medical model of dementia (pp 28). For the Latino families who participated in the study, they described dementia in terms of loss, loneliness and a family's responsibility to take care of the person with the dementia diagnoses; similar to the social model of dementia (pp 33) (Hinton and Levkoff, 1999). The Chinese American participants did not recognise dementia as a disease and their views that the symptoms of dementia were a natural part of old age analogues to some of the historical perspectives of dementia (pp 24) (Hinton and Levkoff, 1999).

Similarly, Zhan (2004) explored Chinese American's perceptions of dementia and found that there were many misconceptions about dementia within the culture. Some of the more common causes of dementia symptoms, as described by the participants in this study, were fate, bad Feng shui, craziness, a punishment for wrongdoing or a contagious disease (Zhan, 2004). Some participants suggested that re-arranging the furniture within the home would alleviate the symptoms (Zhan, 2004). Within the Chinese American culture, developing dementia comes with negative stigma and feelings of shame as they believe it could be a punishment for bad behaviours (Zhan, 2004). This study highlights a clear need for education around dementia within the Chinese American culture whilst also recognising the cultural differences in perception of, and coping with, dementia (Zhan, 2004). This study has a small sample of four family caregivers. It is difficult to make conclusions about Chinese American caregivers' lived experience based on four peoples' accounts.

To explore the effects of geographical segregation on people living with dementia, Clarke and Bailey (2016) interviewed families from rural areas where everyone knows everyone. The family members within Clarke and Bailey's (2016) study noted how other villagers would treat their loved one differently upon learning of their diagnoses; with most of the villagers completely avoiding the person with dementia (Clarke and Bailey, 2016). Many of the participants in this study had grown up in the villages that they still resided in which benefitted their memories and sense of belonging but as these villages were rural, there was no dementia support available to them locally (Clarke and Bailey, 2016). GP practices helped this research team identify the participants; some could argue that these GPs would purposely select people they know have good experiences of the GP services that are available to them. Despite this, Clarke and Bailey (2016) noted that many of the participants came from rural backgrounds and were not aware of the services that were available to them or what they would be entitled to (e.g. monetary benefits).

Similarly, Strommen *et al.* (2020) explored the challenges in obtaining care for older persons with dementia who live in rural communities. By using pre-existing data sets, Strommen *et al.* (2020) found that families within rural communities struggled to arrange care for their loved ones due to a lack of care services in the vicinity. They did not understand what care was available to them and were not able to afford the care services that they needed. Strommen *et al.* (2020) concluded that families within rural communities should be offered low cost support to manage caring for someone with dementia. Despite this study using data from 306 participants, they were primarily white Americans and their experiences may not be applicable to other cultures.

3.3.3 Joint perspectives

Twelve studies were found within the literature search which explored the lived experience of the person with dementia and family members within one study. Two themes emerged from the literature review, which explored the joint experiences of those affected by dementia. Primarily, these studies explored the experiences of married couples.

Experiences of services

Four studies explored the experiences of people affected by dementia when attending hospital appointments or peer support groups. All these studies were qualitative and used interviews as their data collection method.

The first of these studies to be discussed was conducted in Israel (Karnieli-Miller, 2012) where the memory clinic structure may differ from others around the world. This study explored the expectations of people with dementia and their family member prior to a memory clinic appointment and followed up after the appointment to see if their expectations had been met (Karnieli-Miller, 2012). The participants with a dementia diagnosis were not aware of their dementia, did not know why they were at the clinic and had no expectations from the appointment as they did not understand what it was for (Karnieli-Miller, 2012). During the follow up interviews with those with dementia, they had not understood the information that had been given to them at the clinic and still did not know why they had to attend the appointment (Karnieli-Miller, 2012). This may be attributed to the delay between attending the appointment and taking part in this study whereby the two-week gap may have resulted in the person with dementia forgetting what their appointment was for. The family members who participated in the study wanted the appointment to confirm the diagnosis and provide them with additional information and support which would allow them to move forward; however, all of the participants explained that they were not satisfied with the post-diagnostic support they received (Karnieli-Miller, 2012).

Similarly, Gorska *et al.* (2013) examined the post-diagnosis needs of families affected by dementia and found that the participants had three basic requests; better post-diagnosis support (the same finding as Karnieli-Miller, 2012), continuity of care (having the same care workers) and the implementation of non-pharmaceutical interventions aimed at maintaining the identity of the person with dementia (for example, reminiscence therapy) (Gorska *et al.*, 2013). The participants within Gorska et al's (2013) study were all in their 80s; it is likely that they all had additional health conditions which the research team did not record. It is possible that the participants were mixing their health complaints together when explaining the care and support they felt they needed (Gorska *et al.*, 2013).

Koskenniemi *et al.* (2015) studied the relationship between the nurse and the person with dementia to advise on methods of ensuring the person with dementia is comfortable and helped during their hospital appointments. Based on interviews with people with dementia, family members and nurses, Koskenniemi *et al.* (2015) noted that the person with dementia is more likely to co-operate, ask questions and share information with the nurse if they demonstrate a level of understanding and respect that would be associated with holistic care. If the nurse is solely focused on the tasks that need completing, the person with dementia will co-operate (e.g move when asked) but will not offer additional information and will not feel comfortable to ask questions (Koskenniemi *et al.*, 2015). If there is a negative relationship between the nurse and the person with dementia, then they will not co-operate at all and this can be deemed as displaying "*challenging behaviours"* (Koskenniemi *et al.*, 2015, pp. 294). This study demonstrated how important a holistic approach to dementia care is to empower the person with dementia to ask questions and provide information but the findings were not returned to the participants for validating; doing this would have added to the credibility of the results (Koskenniemi *et al.*, 2015).

Keyes *et al.* (2016) investigated the importance of peer support groups for families affected by dementia. This study ensured that they had a representative sample by recruiting participants from rural and city communities and ethnic minorities. Recruitment sites included charity organisations, NHS organisations and local councils (Keyes *et al.*, 2016). Findings from the interviews highlighted that the peer support groups benefitted both the person with dementia and their family members (Keyes *et al.*, 2016). Family members explained that support groups allowed them to meet other family members who have common experiences which grew into a support network to help deal with the emotional and social issues they were facing whilst caring for their loved one (Keyes *et al.*, 2016). The participants with dementia explained that the support groups allowed them to come to terms with their diagnosis and feel comfortable around others with similar diagnoses who would understand their situation (Keyes *et al.*, 2016). Within these support groups, the person with dementia was able to be themselves and not have to worry about saying the wrong thing or forgetting what they were saying, as everyone around them understood what they were going through; this then reaffirmed their identities (Keyes *et al.*, 2016).

Whilst these four studies differed in the research questions they asked, they all shed light on aspects of dementia services. Some need improving (Gorka *et al.*, 2013; Karnieli-Miller, 2012) while others are working well to maintain the personhood of those affected by dementia (Keyes *et al.*, 2016; Koskenniemi *et al.*, 2015).

Life with dementia

This is the second theme within the joint perspective studies. Eight studies within this literature review aimed to understand the everyday experiences of people affected by dementia. One of these studies was quantitative (Black *et al.*, 2012) while the remaining used semi-structured interviews to collect their data.

Swall *et al.* (2019) explored the togetherness of older spouses when one has dementia. Through video recorded conversations with the married couples, Swall *et al.* (2019) found that married couples felt that their relationship was strengthened by the one having dementia. Their sense of "*us*" was challenged by the person's dementia but ultimately, it enriched their sense of being a unit, or "*us*" (Swall *et al.*, 2019). Swall *et al.* (2019) noted that the video recordings offered unique insight into the stories being narrated by the participants and whilst they acknowledge that they may have behaved differently if they knew they were being watched, the research team do not believe that this occurred within their study; they think that the participants acclimatised quickly to the video (Swall *et al.,* 2019). A sense of "*couple-hood"* was also explored by Hernandez *et al.* (2019) who explored the experiences of 19 married couples when one has a dementia diagnosis. Findings from the study suggests that maintaining a sense of couple-hood was a primary goal for couples facing a life with dementia; the couples try to maintain joint and independent activities (Hernandez *et al.*, 2019). Furthermore, the couples use their personal histories to highlight events in their past that have strengthened their relationship and demonstrate that they can cope as a couple. It is possible that only couples with good relationships participated in these studies, resulting in participant bias (Swall *et al.,* 2019; Hernandez *et al.,* 2019).

Black *et al.* (2012) looked at the quality of life for people with dementia and tried to distinguish if the person with dementia's perception of their own quality of life differed from their family member's rating of the person with dementia's quality of life. After correlating the scores for various scales, Black *et al.* (2012) found that there were some similarities in the perceived quality of life but also several differences. The participants with dementia's quality of life correlated with race, unmet needs and depression (Black *et al.*, 2012). The family members rated their loved one's quality of life based on caregiver burden and function ability, but also unmet needs and depression (the same as the participants with dementia) (Black *et al.*, 2012). This study demonstrated that it is important, where possible, to ask the person with dementia about their experiences, instead of relying solely on the family members' accounts. Whilst there may be similarities in what they say, there could also be differences such as the family members indicating the cognitive functioning and care needs would affect their loved one's quality of life, but the person with dementia not reporting this (Black *et al.*, 2012).

There are benefits to exploring both sides of the same story. Phinney (2002) wanted to explore the different symptoms experienced by people with dementia by asking firstly, the person with dementia alone, then their family member alone, and lastly, the person with dementia and their family member as a pair. Dementia symptoms were categorised into three groups; salient (always there and can be discussed), forgotten (rare symptoms that do not come to mind when talking about symptoms) or non-existent (the person has never experienced them and cannot talk about it) (Phinney, 2002). When the participants were interviewed together, Phinney (2002) found that a lot of the forgotten symptoms were remembered and therefore discussed. When participating together, they were able to "*fill in the gaps*" in the other person's memory and Phinney (2002) was able to obtain more in-depth data about the symptoms experienced by the person with dementia.

Similarly, another study exploring the daily threats to a person with dementia's quality of life was conducted by Steeman *et al.* (2007) who interviewed 20 people with dementia and their family members. Steeman *et al.* (2007) admit that their personal bias interfered with the questions they asked during data collection and this may have influenced the results. Nevertheless, findings from this study indicated that the person with dementia has a daily battle with their loss of cognition and identity, and often feels worthless (Steeman *et al.*, 2007). Despite their narratives being primarily positive, with the participants stressing their contentment with life and maintained abilities, they did express a daily desire to feel valued (Steeman *et al.*, 2007). Regular interactions with family and friends helped the participants with dementia feel a sense of value and allowed them to reaffirm their identities; this was termed "*counterbalancing devaluation"* (Steeman *et al.*, 2007, pp 119).

Participants trying to maintain that their lives are positive experiences was also noted by Daniels *et al.* (2007) who completed a case study of a married couple where the wife had a diagnosis of dementia. The couple tried to maintain that their life was full of positive experiences and used phrases like "*good life together"* and *"meant for each other"* to explain their story (Daniels *et al.*, 2007, pp. 169). Occasionally, Daniels *et al.* (2007) noted a slip in the positive phrasing when the husband would begin to talk about feeling lonely and unable to discuss good memories with his wife as she could no longer remember them. The couple described life with dementia as a learning experience that had changed their relationship roles, but Daniels *et al.* (2007) noticed that the husband would often interrupt his wife, or talk over her, if she was saying something that he did not agree with. Whilst this was a case study of one married couple and may not be typical of other married couples living with dementia, it demonstrates that things cannot be taken at face value. Looking beyond the general theme of an interview, allows a researcher to understand what it really going on within the relationship. It was only when playing the interview back, that Daniels *et al.* (2007) noted the husband's behaviour towards his wife.

Another study that noticed married couple's reluctance to paint a whole picture during their interview was a study by Hellström and Torres (2013). They conducted 40 interviews to explore married couples' preferences on what they would share about their lives with dementia and what they wanted to know. This study found that the married couples would only disclose information if the person with dementia chose to (Hellström and Torres, 2013). The family members were enabling the person with dementia to take the lead during the interviews although this was not requested by the research team (Hellström and Torres, 2013). Additionally, the couples were more likely to share information if it was directly related to a question that they wanted answered (Hellström and Torres, 2013). Furthermore, the family members explained that they would seek out information about dementia but only share limited information with the person with dementia (Hellström and Torres, 2013).

Robertson (2010) interviewed six older people with dementia and 10 family members to understand the impact the diagnosis has open their lives. The participants with dementia were able to maintain their ordinary day to day lives by participating in meaningful activities that supported their pre-existing roles and relationships; for example, still doing housework to maintain their role as a homeowner, or having regular conversations with family members to maintain the family dynamics (Robertson, 2010). These participants emphasised the importance of maintaining a sense of normality whilst managing the challenges associated with their cognitive impairments (Robertson, 2010). To assess the wellbeing of the people with dementia, the family members would often compare the person's current position to their previous ones; for example, if they were once able to do a crossword but cannot any longer (Robertson, 2010). Additionally, the family members would compare their loved one to societal expectations of a person with dementia; if their loved one was seen to be "*better*" than societal expectations, they were doing well (Robertson, 2010). This study highlights the importance of maintaining, where possible, a person's previous roles and relationships for as long as possible.

3.4 Limitations of Scoping Review

There are several limitations of this scoping literature review that need to be addressed. As scoping reviews aim to map the evidence available, instead of concluding with a critically appraised, synthesised answer to a specific question, there is a risk of bias towards the articles included (Munn *et al.,* 2018). Some of the articles uncovered within this review were deemed to be more useful elsewhere in this thesis. For example, articles regarding the inclusion of people with dementia in research. These were better suited in the methodology section and therefore excluded from the literature review.

As the flow diagram illustrated (Figure 2), there is an enormous wealth of dementia research being conducted, in various fields. As this is very much a social science thesis, articles concerning the biological, or organic, structures of dementia were not included. Pharmaceutical papers were excluded too. Whilst the general database searches were not field specific, when it came to the individual journals being searched (for example, Dementia journal, Nursing Older People or Journal of Applied Gerontology), some fields may have inadvertently been excluded (for example, the Humanities) which is likely to impact upon the articles included and may have resulted in poignant papers being missed.

3.5 Summary and Reflection

The literature discussed in this chapter was used to initially develop the methodology for this study. It is evident that qualitative research methods, namely phenomenology, are the preferred means of exploring life with dementia. Descriptive phenomenology and interpretive phenomenology appeared to be the preferences. This helped inform the methodology for this thesis. After much research into the two methods, descriptive phenomenology was deemed the most appropriate. This is discussed more in the next chapter. Some of the articles included in this review also offered unique insight into the difficulties they faced with ethical permissions and recruiting people with dementia. This enlightened the research student into possible difficulties that she may face and allowed her to prepare in advance.

The research questions for this literature search matched the research objectives for the thesis. Ultimately, both aimed to understand the lived experience of those affected by dementia, without preconceptions or bias influencing the data. After data collection and analysis was completed for the empirical study, the articles were explored fully. Several themes are present within both.

For those living with a dementia diagnosis, the bulk of the literature focuses on how they try to maintain their identity, self-worth and a sense of normality with everyday life. A few articles explore how relocating from their own home to a residential care home has its own challenges, both for the person with dementia and their families, that primarily impact upon how they feel their identity has been altered by the move.

The family members of people with dementia often feel a variety of emotions. There are many barriers to accessing support and information, some of which can be overcome with a simple modification of the environment. A change in the marital relationship was noted by some with their marital commitments often preventing them from seeking additional help as they vowed to care for each other in sickness and in health. A general overview of the family member literature highlights the emphasis on negative elements of life with dementia. Seldom within the literature is there an article that concentrated on the positive components of life with dementia. This may be representing the true nature of life with dementia, or may be due to the researchers' own bias, particularly concerning their specific research questions. This was a contributing factor in the decision to keep this study's research question open, not to limit the responses from the participants or hinder the process of understanding the entire experience of living with dementia. Therefore, the research question for the empirical research is "what is it like to live with dementia?" This allows the participants to share anything they feel in important, instead of supressing their responses to solely answer a narrow, specific research question.

This review helped highlight the benefits of having the person with dementia and their family member participating in the same interview. It can help the person with dementia as the other person can fill in the gaps in their memory. Yet, those affected by dementia can be reluctant to share information about their experiences; particularly if the person with dementia does not want other people knowing. This chapter has highlighted that the literature on life with dementia is insufficient for understanding the complexities experienced by those affected by the condition. This thesis will enhance this understanding by using a narrative approach to explore life with dementia.

The next chapter of this thesis describes the methodology for this study. It begins by discussing phenomenology as a philosophy and a research method and then goes on to explore the use of life story work and digital storytelling as the data collection tool. The process of gaining ethics permissions is addressed along with the sampling strategy used to recruit participants. The data collection process is outlined followed by the ethical issues encountered throughout this process and lastly, the data analysis possibilities are explored.

Reflection on the Chapter

I found that a large amount of the literature uncovered within this review was not relevant as it focused on life with early onset dementia. I assume that this is due to the societal expectation of dementia occurring at an older age. When a younger person gets diagnosed, it challenges that norm and attracts researchers.

There also appeared to be a lack of distinction between mild cognitive impairment and dementia. Many studies were excluded as they did not specify that participants had dementia, most had mild cognitive impairment. I wonder if this is related to the ethical challenges experienced when a researcher submits permissions for “dementia research” (which I discuss in the next chapter) as opposed to mild cognitive impairment research. This may also offer explanation for family member research outweighing research with people who have dementia.

Whilst writing this chapter, I noted that relatively few studies highlighted the positive elements of life with dementia. For the most part, the studies are primarily negative, focusing on the struggles, loss and stress induced by life with dementia. I therefore endeavoured to try and capture both the positive and negative components of living with the condition in my own themes, which are discussed in length later in this thesis.

CHAPTER 4 METHODOLOGY

"Within descriptive phenomenology, there is an acknowledgement that there is a "given" that needs to be described precisely as it appears and nothing is to be added to it nor subtracted from it.
(Giorgi, 2012, pg. 4)

4.1 Introduction

This chapter encompasses the entire methodological process of this study. This descriptive phenomenological study aimed to answer the research question "*what is it like to live with dementia?"* The objectives of this study are firstly, to explore and understand the lived experiences of older people with dementia and secondly, to explore and understand the lived experience of family members of a person with dementia. Some of the studies within the literature review helped inform elements of the methodology, namely those who had also used a life story approach to their data collection method (Karlsson *et al.,*2014; Nordtug *et al.,* 2018). While others outlined their ethics approvals process which helped when completing the applications for this study.

This chapter begins by discussing phenomenology as a philosophical approach and a research method and then goes on to explore the use of life story work and digital storytelling as the data collection tool. The process of gaining ethics permissions is addressed for USW and NHS ethics. The sampling strategy used to recruit participants is outlined followed by the data collection process. The ethical issues encountered throughout this process are highlighted and lastly, the data analysis options are explored along with a discussion of alternative methods of presenting the findings. Reference is made within this chapter to the Mental Capacity Act (2005), as outlined in Chapter 1 (pp 8).

4.2 Research Method

4.2.1 Qualitative research methods

Within the social sciences, there are two branches of research, qualitative and quantitative (Bryman, 2016). *"The qualitative researcher is said to look through a wide lens, searching for patterns of inter-relationships between a previously unspecified set of concepts, while the quantitative researcher looks through a narrow lens at a specified set of variables"* (Brennan, 2017, pp. 11). There is a distinct difference between the two branches of social research; both have their strengths and weaknesses (Rugg and Petre, 2006).

Firstly, quantitative research is *"a method of research that relies on measuring variables using a numerical system, analysing these measurements using any of a variety of statistical models and reporting relationships and associations among the studied variables…Quantitative research techniques include experiments and surveys"* (Lucas-Alfieri, 2015, pp. 20). Quantitative research generally starts with a hypothesis that the researcher will test by manipulating variables (Brennen, 2017).

Quantitative data can be analysed using computer based statistical programmes which run complex calculations on the numbers inputted, to tell the researcher if their findings are significant; this means that there is a relationship between the variables being measured (Hanna and Dempster, 2012). In quantitative research, the participants are not treated as individual people, they are treated as *"passive and mechanical information-processing devices, whose behaviour can be split up into variables"* (Gross, 2010, pp. 40). Furthermore, quantitative research does not typically include the important contextual details that lead to individual differences between participants (Orgrajenšek, 2016).

The other branch of research, and the branch used for this study, is qualitative which is "*research that focuses on non-numerical data, such as verbal reports and that uses such techniques and analysis as thematic analysis…grounded theory, interviews… and phenomenology"* (Colman, 2009, pp. 629). Verbal reports can be interviews and case studies (Bryman, 2016). Unlike quantitative studies, qualitative studies try to define general concepts, which may change their definitions as the research progresses (Brennan, 2017).

Qualitative research tends to delve deep into the personal experiences of the participants; *“in other words, qualitative work does not survey the terrain, it mines it”* (McCracken, 1988, pp. 17). This tends to occur through interviews or case studies (Bryman, 2016). Interviews rely on the participant to self-report their experiences and this can lead to some issues. Firstly, the interviewer may lead the participant to give certain answers, which is called interviewer bias (Glassman, 2000). Secondly, the participant may not give an accurate representation of their experience; this may be accidental where they have forgotten the details of their experiences or intentional, when they do not want the interviewer to know the truth (Glassman, 2000).

Qualitative methods were used for this study as the aim was to explore peoples’ experiences of living with dementia by getting to know their values, thoughts, cognitions, emotions, beliefs and personal histories; all of which are central to qualitative research and cannot be measured quantitatively (Orgrajenšek, 2016). Phenomenological research methods were used for this study as they offer a more humanistic approach to research (Holmes, 1996).

4.2.2. Philosophy of phenomenology as a research method

Phenomenology is *“a philosophical method of enquiry introduced in 1901 by the German philosopher, Edmund Husserl (1859-1938) that concentrates on the detailed description of conscious experience while suspending or bracketing all preconceptions, interpretations and explanations. More generally, a qualitative research method in psychology that concentrates on the analysis of mental experience rather than behaviour”* (Colman, 2009, pp. 571).

Husserl offered the first alternative approach to positivist data collection methods (Fewtrell and O’Connor, 1995). Positivist data collection methods refer to research that is based on real facts, not abstract deductions like thoughts and feelings (Harvey, 2009). Husserl (1913) believed phenomenology was a way to explore a person’s conscious experiences of a phenomenon. Phenomenology suggests that a person’s behaviour will be determined by their perceptions of their experiences, not objective and physical realities (Cohen *et al*., 2007). Husserl (1913) stated that phenomenology should be purely descriptive, offering thorough insight into the experiences being explored. This idea has been adapted over the century by various supporters of Husserl's work, including Heidegger (1927) who believed that human experiences needed to be interpreted, not just described. "*Elucidating the condition whereby understanding takes place"* (Holroyd, 2007, pp. 1447) was emphasised by Gadamer (1989) who believed that the situational context in which the phenomenon is experienced should also be interpreted. Other phenomenologists include Sartre, Giorgi, van Manen and Merleau-Ponty (Sloan and Bowe, 2014; Langdridge, 2007; Smith *et al*., 2009).

All phenomenologists advocate the study of individual experiences (Sloan and Bowe, 2014). When a researcher adopts the key elements of phenomenology philosophy, namely researching the conscious experience whilst suspending interpretations, into their research design, phenomenology then becomes a research methodology (Kvale and Brinkmann, 2008; Langdridge, 2007). Phenomenology offers a frame of mind which allows the researcher to build their scientific practice upon the understanding that the person is the expert in their own experiences (Giorgi, 2000). Descriptive phenomenology was initially adopted by psychologists, such as Giorgi, Witwicki and Bandrowski, as a research method in the late 20th century to explore human experience (Langdridge, 2007).

Phenomenological research is the study of an individual's life as they have experienced it with the researcher aiming to fully understand these experiences (Van Manen, 1984). Within phenomenological research, Todres and Holloway (2004) suggest that the researcher should view themselves as the mediator between the participants and the broader community. Todres and Holloway (2004) offer four factors that need to be implemented for phenomenology to be used successfully in research as illustrated below:

1. The researcher needs to make their initial interest in the topic area and their research agenda explicit.

2. The researcher should use their preconceptions about the topic to formulate the research questions whilst removing this preconception from the data collection process.
3. Phenomenological research should uncover similarities and differences within the participant’s experiences; these generalisable similarities will form the transferable insights about the phenomenon.
4. Phenomenological research should be written up in a manner that addresses both the scientific and communicative concerns of the study. This last step includes presenting the experiences of the phenomenon in an articulated and insightful manner whilst making it understandable to the required audience.

All research methods have a philosophical underpinning (Ashworth, 1997). It is essential for a researcher to understand the philosophical underpinning for their chosen research method, as this will influence the application of the method to their study (Clark, 1998). Within phenomenology, this is difficult as the philosophy has significantly changed over the century and had been split into several different branches (Corben, 1999). There now exists seven different branches of phenomenology as outlined in “*The Encyclopaedia of Phenomenology”* (Embree, 1997). These are descriptive, naturalistic constitutive, existential, generative historicist, genetic, hermeneutic and realist (Embree, 1997). More information on the seven branches can be found in Table 8. Despite there being seven branches of phenomenology, leading to a myriad of phenomenological research methods, the underpinning phenomenological stance for this study is that which was originally proposed by Husserl (1913); now termed descriptive, or transcendental, phenomenology.

Table 8: Seven branches of phenomenology

Type of Phenomenology	Founder	Description
Descriptive ***also referred to as transcendental or eidetic**	Husserl (1900)	Explores the pure conscious experience of the phenomenon, setting aside any relationship to the world in which the person lives.
Naturalistic constitutive	Farber (1943)	Assumes that consciousness is a part of nature, and therefore explores the person's conscious experiences in relation to their natural environment.
Existential	Sartre (1948)	Explores how the person reacts in particular situations, concerning itself with abstract concepts such as free will.
Generative historicist	Husserl (1930)	Explores how collective human experiences, over a period of time, will influence how something is experienced today.
Genetic	Husserl (1917)	Explores the genesis of meaning within the individual.
Hermeneutic ***also referred to as interpretive**	Heidegger (1927)	Interprets the structure of human experiences through the interpretation of their narratives around their experiences.
Realist	Daubert, Pfänder, Reinach and Scheler (1902)	Explores consciousness and intentionality, assuming that they are externally influenced and not an internal process.

Adapted from Wojnar and Swanson (2007) and Embree (2013)

4.2.3 Descriptive phenomenological research method

This is a descriptive phenomenology study as it aims to understand individual's experiences of living with dementia through life story work. Descriptive phenomenology was deemed the most appropriate methodology to conduct this study as its exploratory and descriptive nature allows the researcher to gain insight into the participant's interpretation of their lives and the world they live in, without preconceptions and intellectual bias having an impact on the findings (Wirihana *et al*, 2018; Munhall, 1994). Phenomenology is commonly used in health care research (Edward and Welch, 2011) as it allows the researcher to explore previously overlooked experiences (Polit and Beck, 2014). The philosophical underpinnings of phenomenology is that a *“world is knowable only through the subjectivity of being in the world”* (Munhall, 1994, pp. 15). In regard to this study, every person who has lived through dementia will have a different “*knowledge*” of life with dementia. Furthermore, Dilthey (1976) believes that a researcher can only understand a person’s experiences of a phenomenon by understanding their personal history as their experiences will depend on this.

Husserl (2001) proposed the concept of *“bracketing”* within descriptive phenomenology research whereby the researcher should abandon their own reality and be able to describe a phenomenon in its universal sense (Husserl, 2001). To achieve this, a researcher should make notes of their personal bias and previous knowledge of the research topic to ensure that it does not impact upon the data collection process or analysis (Husserl, 2001). “*The adoption of this attitude is unique to the phenomenological approach”* (Chan *et al.,* 2013, pp. 2). However, others have argued that personal experience and bias cannot ever be dismissed (Swanson-Kauffman, 1986; Finlay, 2009). To appease this, Jackson, Vaughan and Brown (2018) propose that the researcher should not dismiss their prior knowledge but be fully aware of it and give priority to the spoken words of the participant. When bracketing is carried out successfully, a researcher will be able to converse with the participant with a sense of openness and without trying to validate their own beliefs (Munhall, 1994).

When a researcher is investigating personal experiences, the description provided by participants will be a combination of “*real*” and “*irreal*” factors (Jackson, Vaughan and Brown, 2018). Real factors are concerned with time, space and causality, while irreal factors are experiential, like thoughts and feelings (Husserl, 2001). To fully appreciate an experience, the real factors need to be acknowledged but particular emphasis needs to be placed on exploring the irreal factors as these will be unique to each individual. Descriptive phenomenology allows the researcher to explore these irreal experiences as these provide a more in-depth, holistic view of the phenomena (Todres and Wheeler, 2001). Interview questions should focus on asking participants to describe their experience not explain it; describing will provide the irreal details whereas explaining is likely to focus on the real factors (Jackson, Vaughan and Brown, 2018). The irreal factors are equally as important as the factual data (Holloway and Freshwater, 2007).

The participant's account should not be judged in terms of value to the study (Todres and Holloway, 2010) and the researcher should be open to varying experiences of the same phenomenon as every participant will have a differing background and situational contexts that will influence their experience (Munhall, 1994). Furthermore, phenomenological research should not be concerned with the "*truth*", instead it should focus on what the participant believes to be true (Munhall, 1994). *"Phenomenological knowledge should be seen as contingent, proportional, emergent, and subject to alternative interpretations"* (Finlay, 2009, pp. 17). It is important to note that experiences are not exact and can alter when investigated at a different time (Giorgi, 2009), they are culturally and temporally bound (Munhall, 1994). For example, today's lived experience of older persons would differ from sixty years ago. Descriptive phenomenology is concerned with clarifying individual experiences, not verifying a theory-driven hypothesis (Jackson, Vaughan and Brown, 2018).

4.2.4 Digital storytelling as a method of data collection

Whilst this study is grounded within descriptive phenomenology principles, digital storytelling was the chosen data collection method for this study. Digital storytelling refers to a story collected using digital media (de Jager *et al*., 2017). The use of visual methods within qualitative research has been recommended by many (Litchman, 2014; de Jager *et al*., 2017; Benbow and Kingston, 2016; Mannay, 2016) as it combines the written word with visual imagery to send powerful messages to the audience (Litchman, 2014). Digital imagery has become central to our society; therefore, qualitative research needs to adapt to incorporate this (Crawford, 2012). Litchman (2014) states that the combination of words and imagery is vital for effective communication amongst humans. The link between digital storytelling and descriptive phenomenology is strengthened by using a "*flat hierarchy*" within digital storytelling (de Jager *et al*., 2017) whereby the same principles as "*bracketing"* within phenomenology are applied (Gearing, 2004). The researcher will identify any pre-existing assumptions about a given topic and will attempt to eliminate these assumptions from the data collection process. Within both descriptive phenomenology and digital storytelling, the researcher needs to be aware of these pre-existing assumptions as they could influence data collection and the analysis process (de Jager *et al*., 2017; Gearing, 2004); for example, keeping a diary of these assumptions and how they develop is helpful to maintain a flat hierarchy.

The participants with dementia who participated in this study were asked to narrate their life stories whilst being video recorded; this has been termed "*digital life story work*". Life story work is commonly used therapeutically for people living with terminal conditions, such as cancer (Ando *et al.,* 2011) and dementia. For people with dementia, it helps them remain connected to their past and allows them to have meaningful communication with other people in the present (Doran *et al.,* 2019; Novy, 2018; McKinney, 2017; Tamura-Lis, 2017; McKeown *et al.,* 2015). Life story work has been adapted for use in research by many fields; for example, Solomon *et al.* (2011) used it to understand family business dynamics, Jensen (2013) used it to learn about intergenerational housing and Chongo *et al.* (2018) used it to explore the experiences of men with HIV. Yet its' use for those living with dementia is rare. Life story work is an innovative method of data collection for those with dementia which can help researchers understand the experiences of living with the condition in a more creative and personalised manner (Benbow and Kingston, 2016). A narrative life story needs to have a specific time span, illustrate personal experiences, contain a plot, characters and a linkage from the past, present and future (Sarbin 1986; Elliot, 2005; Holloway and Freshwater, 2007). Rejnö *et al.* (2013) further emphasise that a narrative structure must have a beginning, middle and end. For this study, the beginning was childhood, their adult life represented the middle and their current lives with dementia signified the end of the story, with some projection into their hopes for the future. Asking people with dementia to narrate their life stories is particularly poignant as *"we need to tell someone else a story that describes our experience because the process of creating a story also creates the memory structure that will contain the gist of the story for the rest of our lives. Talking is remembering."* (Shank, 1995, pp 115).

Some have argued that there is a subtle difference between a narrative and a story (Frank, 1995; Connolly and Clandinin, 1990), as no one would say *"let me tell you a* *narrative".* Whilst Frank (2000) claims that a narrative creates the structure that underpins a story, Connolly and Clandinin (1990) suggest that it is the other way around; a story is an essential element within a narrative. All agree that they are not dissimilar (Frank, 2000; Connolly and Clandinin, 1990) and therefore, for this thesis, the terms "narrative" and "story" have been used interchangeably.

Connolly and Clandinin (1990) further suggest that narratives are lengthy in nature and reflect the narrator's experiences through a series of stories about life. More recently, there has been an increase in the use of narratives within phenomenology research. This has been termed "*the narrative turn"* (Holloway and Freshwater, 2007). Health narratives have been of particular importance both within research and practice as they illustrate patient experiences of living with various health problems. Regarding research, using stories and narratives allow for a deeper understanding of the person's life, and can offer insight into experiences that may have been missed with other research methodologies (Rejnö *et al.,* 2013).

A life narrative differs from an episode of illness as the latter refers to short term illness episodes, for example, those with bipolar disorder will have stable, manic and depressive episodes (Basu and Manning, 2010). A life narrative understands the personhood of the participant and explores their life experiences, beliefs, relationships, interests, preferences and values to appreciate their current life situation (Hammami *et al.,* 2019). Finding similarities in different peoples' life narratives can be difficult, but conclusions can be drawn from their experiences of life with dementia, which is informed by their life narrative.

In qualitative research, audio recording is generally the norm (Austin and Sutton, 2015) as this can be easily anonymised, are straight forward to set up and keeps an accurate record of the spoken words within an interview (Al-Yateem, 2012). As these are the norm, this thesis offered an alternative method of recording the interviews, video recordings. Video recordings allow for a more creative and personal means of illustrating a person's life story (Benbow and Kingston, 2016). Videos are a successful communication tool for educating people about lived experiences and can engage the imagination of the viewer more effectively (Mitchell, 2006). They proved particularly impactful when shown at conferences and during examinations related to this thesis; this is discussed further in the last chapter of this thesis (pp 274). Video recordings are commonly used to highlight patient stories within health and social care settings, but seldom for research (Jewitt, 2012). Videos for research offers "*a tool to re-orientate the power of the researcher gaze and to give voice to the research participants"* (Jewitt, 2012, pp 3). Videos help the audience, in this case the examiners, connect to the participant and give them a sense of "*being there"* with the researcher at the time of interview (Goldman, 2009). There are some specific ethical considerations that need to be addressed when using video recordings, these are discussed later in this chapter (pp 103). Similarly, there are some limitations associated with the use of videos. These include the Hawthorne Effect whereby participants will behave differently if they know that they are being recorded, and sensory overload for the researcher who is analysing the data. Further limitations on the use of video recordings are discussed in the conclusion chapter (pp 266).

There are two major limitations of using digital life story work. Firstly, people can often act differently if they know that they are being video recorded which also applies to observational research and must be considered whilst analysing the interview data. Secondly, descriptive phenomenology is built around the person's conscious thoughts about a phenomenon; it is specific to the time and place where the question is asked. Therefore, the retrospective information provided within life story work may alter depending on the time and place the questions are asked, and how the person with dementia remembers it. The nature of phenomenology does not allow for right or wrong information which allows a person with dementia the space to explain their live events, as they remember them, not necessarily as they occurred. These limitations are discussed more later in this thesis (pp 262).

Digital storytelling and life story work is a new concept within dementia research, which adds to the originality of this study but came with many challenges when going through ethics approvals as the reviewers were not familiar with it as a data collection tool. The process of gaining the correct approvals is outlined next.

4.3 The Process of Gaining Ethical Approval

4.3.1 Selecting and accessing recruitment sites

The National Institute for Health Research states that all primary research must have a study steering committee (NIHR, 2019). In compliance with this, this study was advised by a steering committee which consisted of the research student, director of studies, two academic supervisors, two managers from a private care company and a senior nurse from each of the participating health boards: one dementia lead and one senior nurse for older adults' mental health services (see Appendix G, pp 391). The steering committee was set up to advise on the direction of the study and oversee the progress made. This group facilitated access to the services, discussed recruitment, analysis choices, findings and dissemination.

4.3.2 Obtaining university ethical approval

Ethical applications are divided into high and low risk at USW (University of South Wales, 2019). This study was deemed high risk as (1) it involves adults with a dementia diagnosis and (2) some participants are living in residential care homes. Obtaining ethical approval for this study was a lengthy process, with an initial application being submitted to the faculty committee in December 2017 (to recruit through care homes) and final permission being granted in October 2019 (to recruit through memory clinics). A full timeline outlining the ethical approval process can be found in Appendix H (pp 392).

Recruitment through residential care homes needed ethical approval from University of South Wales only; this high-risk application was approved by the University of South Wales' Faculty of Life Sciences and Education Ethics Committee on 13th February 2018 (ref. 2018AWAF1201). The relevant information for this ethical application can be found in Appendices I through to N (pp 394).

To recruit participants through the health board memory clinics, NHS ethical approval had to be sought from IRAS. Prior to submitting an application to the NHS ethics committee, ethical approval first had to be granted by the University of South Wales as they were the sponsors for the study and provided the indemnity insurance. The second high-risk ethical application to the University of South Wales' Faculty of Life Sciences and Education Ethics Committee, for the permission needed to submit an application to NHS ethics, was approved on 15th July 2019 (ref. 19AW0201HR). The approval certificate can be found in the Appendix J (pp 415).

4.3.3 Obtaining NHS ethical approval

When a researcher submits an application to NHS ethics, they have to use an online system called IRAS (Integrated Research Application System). The initial step of IRAS is to complete a series of filter questions which decides if the application is high or low risk, and which committee would be suitable to review the application, as each committee has a different set of expertise and some applications require full review, while others only need partial review (IRAS, 2019).

This study required full review by Wales Research Ethics Committee 1: Cardiff. The research student and Director of Studies (Dr Fothergill) attended the committee meeting to defend the application on 3rd September 2019. The main committee feedback from the meeting was that they would not permit the use of the videos for conferences and therefore, they offered to approve the application if the use of the videos was limited to solely being shown to the PhD thesis examiners. After making some amendments in accordance with this feedback from the ethics committee, a favourable opinion was granted on 17th October 2019 (ref. 19/WA/0292). The IRAS application form can be found in the Appendix K (pp 416), followed by the favourable opinion certificate, Appendix M (pp 449).

4.4 Sampling Strategy

4.4.1 Inclusion and exclusion criteria

Gubrium *et al.* (2014) suggests that it can often be difficult to find participants at the right stage of their dementia for research engagement. For this study, it was essential to have participants with dementia who were able to give informed consent and who were aware of their dementia diagnosis and able to discuss it. These criteria meant that only those with early stage dementia would be the targeted participant population. However, the study required participant to have some experience of living with dementia and their confirmed diagnosis which ruled out those newly diagnosed with dementia. Additionally, those with a new dementia diagnosis may have been dealing with the diagnosis label and not ready to discuss it at length for research purposes. Therefore, it was decided that potential participants would need to have had their diagnosis for a minimum of six months, needed to be aware of their diagnosis, able to discuss their diagnosis and able to give full informed consent. The inclusion and exclusion criteria are in Table 9.

The participants in this study were purposively selected as they met the inclusion/exclusion criteria and could provide in depth information about life with dementia.

Table 9: Inclusion and Exclusion Criteria

For People with Dementia		**For Family Members**	
Inclusion	*Exclusion*	*Inclusion*	*Exclusion*
Aged 65 or above	Are under 65 years old	Relative of a person with dementia who is also taking part in this study	Have a diagnosis of dementia
Have a formal diagnosis of dementia	Are in late stages of dementia		
Aware of their dementia diagnosis	Have no awareness of their diagnosis	Able to give full informed consent	Are not able to give full informed consent
Access care from the participating residential care home or the memory services from the two participating health boards	Does not access care from the participating residential care home or the memory services from the two participating health boards	Will consent to being video recorded	Will not consent to being video recorded
Able to give full informed consent	Are not able to give full informed consent		
Have had a formal diagnosis for over 6 months	Have had a formal diagnosis of dementia for less than 6 months		
Will consent to be video recorded	Will not consent to being video recorded		

4.4.2 Participant identification

The steering committee members of this study facilitated access to the health and care services where participants might be identified; this was three residential care homes and seven memory clinics across South Wales. Initially, the three care home managers and seven lead nurses from the memory clinics were approached by the research student who explained the study and what criterion the participants needed to meet. The managers and lead nurses were then asked to identify people accessing their services who met the criteria (as identified above, in the inclusion and exclusion table). The managers and lead nurses were provided with information packs to give to those they felt met the criteria. The information packs contained an invitation to participate in the study, an information sheet, a copy of the interview prompts and a copy of the consent form; the information packs can be found in the Appendix O and P (pp 455 and pp. 466).

Those who received information packs were required to sign a "*permission to be contacted*" form so that the managers, lead nurses and research student would have permission to telephone them regarding their participation in the study. A minimum of two days later, the manager or lead nurse contacted the possible participant to obtain verbal consent. The contact details for those who gave verbal consent to participate were passed on to the research student. This guaranteed that the research student did not know the participant's details until they had given verbal consent ensuring that confidentiality was maintained in respect of potential participants.

Once the research student had been given the participant's contact details, a telephone call followed during which the research student answered any questions, confirmed verbal consent to participate and arranged a data collection time/date and location.

4.5 Data Collection

4.5.1 Obtaining consent

Written consent was obtained when the research student met with the participant in person. Verbal process consent was used throughout.

Some of the participants with dementia, from within the residential care homes, who initially gave verbal consent to participate were not able to participate in the study. Their health deteriorated quickly, and they were no longer able to give fully informed consent, were aware of their diagnosis or in good enough health to take part in the study. Their family members were still invited to take part in the study as they had shown interest.

Twenty-two people participated in this study, 10 older people with a dementia diagnosis and 12 family members. Participants details can be found in the next chapter of this thesis (pp 117), which outlines the participant’s life stories.

4.5.2 Setting for data collection

Participants were given the opportunity to decide where data collection took place. For those with dementia, this ensured that they did not become disorientated or anxious. Participants chose locations where they felt comfortable. These locations included the participant’s bedroom within the residential care home, a meeting room within the residential care home, a consultation room within the memory clinic or their own homes. Conducting data collection in familiar surroundings aided the research student with prompting, as photographs or objects in the room could be used to encourage conversation (for example, a wedding photograph prompted questions about their spouse).

Some participants requested that their family member remain in the room whilst data collection was being conducted. Five of the participants with dementia had their family member in the room with them whilst participating. For some, the family member served as “*silent support”,* while others actively incorporated their family member in the conversation to provide additional information that they had forgotten (for example, “*can you remember how that came about?*”).

4.5.3 Recording narratives and data collection process

The research student conducted all the data collection alone, including managing the recording equipment. The video recordings were done using a video camcorder placed on a tripod in front of the participant and a lapel microphone attached to the collar of the participant’s top (jumper or shirt). Full details of the recording equipment can be found in Appendix Q (pp 477). Prior to data collection, the consent forms were filled in and demographic information collected. Once the participant was comfortable, data collection began.

To ease the participants into their narratives, and to get them accustomed with the recording equipment, they were once again asked the questions on the demographic information sheet followed by *“can you tell me about your childhood?”.*

The research student then worked her way through the interview prompts (Appendix O.4, pp 460 and P.3, pp 470), asking additional questions when she thought something was of interest or wanted the participant to provide more information. All interviews covered the participant’s life prior to having dementia, life with dementia and hopes for the future. The final question to the participants was *“is there anything else you want to tell me that you think I have missed?”.* This allowed the participant to add additional information to their story that they thought was relevant but that was not covered within the questions asked by the research student.

Some of the participants took regular breaks whilst narrating their stories (n=4) but all completed the data collection stage within the same day. The shortest video was 13 minutes and the longest was 105 minutes. In total, there were 1170 minutes of video recording, equating to 148,558 words of transcription.

4.5.4 Transcribing and editing

The interviews were transcribed verbatim by the research student within a week of data collection. The research student then returned the transcript and video recording to the participant for editing. The editing process involved the participant watching their video, whilst the research student read along with the transcript. If the participant decided that they wanted something removed from their story, the research student made a note of this on the transcript. If the research student thought there was information within the participant’s story that could upset someone else, she discussed it with the participant and suggested that they remove it. Whilst completing this stage of the study, some of the participants (n=3) became upset as they were being confronted with their own thoughts and feelings about their condition. None wanted any additions to their stories but some asked for information to be removed; for example, one of the participants had spoken about Christmas cake for a chunk of her interview and did not want that included in her final story. Participants were also given the opportunity to choose their own pseudonym. All participants confirmed that they were happy for the edited version of their story to be included in this study.

Once the research student had returned to the office, the changes were made to the video recording and the transcript. It was at this point that pseudonyms were applied to the transcript data. To further ensure that the stories within the transcript were anonymised, locations and the names of services were also removed.

4.6 Ethical Issues

4.6.1 Researcher training

The Research Governance process is a broad range of regulations and standards of good practice that researchers need to follow to ensure research quality in the UK (NHS, 2020). In accordance with these regulations, the research student completed Good Clinical Practice training (November 2017), Taking Valid Informed Consent training (January 2018) and Taking Informed Consent from Adults Lacking Capacity (December 2017); all of which were delivered by Public Health Wales. Good Clinical Practice and Taking Valid Informed Consent are strongly recommended by Public Health Wales for all health and social care researchers; additionally, the research student felt it was necessary to attend the Taking Informed Consent from Adults Lacking Capacity due to the participants having dementia. Although nobody in the sample lacked capacity, it was felt that this training was essential to be prepared. The certificates for these training courses can be found in the Appendix S (pp 483).

4.6.2 Research documentation

The inclusion of people with dementia within this study was an important consideration for the research student. To optimise their inclusion as participants, the research student ensured that the research documentation was easily understandable for people with dementia who may have visual impairments, low concentration levels or cannot understand the academic language used. The research documents were written following the Dementia Engagement and Empowerment Project (DEEP) (2013) guidelines for writing dementia-friendly information. This guidance states that a larger font should be used, academic "*jargon*" should be removed, important information should be made to stand out (underlined, bold, different colour or within a box), not too many words on a page, use of an easy read font like Arial and be concise (DEEP, 2013). To further validate the documents as "*dementia-friendly*", the research student advertised for people with dementia and family members to comment on the documents and suggest further alterations. This is in line with the National Institute for Health Research encouraging researchers to involve members of the public in research designs (INVOLVE, 2015). Suggestions from people with dementia included a more simplistic title and some terminology was altered; for example, the family member consent form states *"I confirm that I have had chance to ask questions and have had them answered to my satisfaction"* whereas the participants with dementia consent form states *"I have had chance to ask questions and understood what they told me in reply"*. On the research documents for people with dementia the title was altered to *"A Study of Stories of Older People with Dementia".* All the research documents can be found in the Appendix O and P (pp 455-466).

4.6.3 Safeguarding

The steering committee advised that the research student approach local authority safeguarding leads to establish any safeguarding issues that would need to be addressed when incorporating people with dementia in research. The safeguarding leads replied that people with dementia and family members must not be asked questions which they cannot answer or have limited capacity to answer. Furthermore, the research student must not force answers from participants. Consent must be obtained for filming. This advice from the local authority safeguarding leads was adhered to.

4.6.4 Capacity to consent

All the participants in this study were required to give fully informed consent for themselves. Initially, verbal consent to participate was obtained; this was followed by written consent and process consent followed whereby each participant was required to provide verbal consent to continue participating at every interaction with the research student. The staff tasked with identifying the potential participants with dementia were asked to ensure they were identifying people who they believed had the capacity to consent. However, fluctuating capacity is common with dementia (Trachsel, Hermann and Biller-Andorno, 2014) and this was taken into account.

To ensure the participant had capacity at every interaction with the research student, the Mental Capacity Act (2005) was adhered to. This allowed the research student to assess capacity on that day, prior to data collection beginning. The Mental Capacity Act (2005) states that everyone has assumed capacity until it can be proven otherwise (Department of Health, 2005). Furthermore, to assess capacity on a regular basis, the research student would check that the participant understood what was required from them, could repeat the information back accurately, was able to assess the information and could clearly communicate their decision (Mental Capacity Act, 2005). If the participant's capacity was temporarily lost (for example, due to illness or tiredness), the research student arranged an alternative day to visit the participant. It was agreed during ethics that if the lost capacity was permanent, and the participant was unable to provide clear consent to continue participating, the research student (1) removed the participant from the study if they were still within the data collection/editing stages or (2) kept the participant's story within the study if the video had already been edited to the participant's satisfaction. Whilst this was pre-empted and included in the ethics processes, this did not happen. A flow diagram outlining this process can be found in the Appendix S (pp 483). Dementia is a progressive condition; having a digital copy of the participant's life story will illustrate the "*person behind the dementia*" when the person may not be able to remember for themselves (McKeown *et al*., 2015).

4.6.5 Confidentiality

Confidentiality in research is *"the agreement to limit access to a participant's information…in research, we commonly pledge to limit the dissemination of information about the participant"* (Cooper and McNair, 2015, pp. 100). To ensure no participant could be linked to the study or the services they access, all data files (video recordings, transcripts, names and demographic information) were stored on a password protected computer to which only the research student had access.

Biographical information about the participants can be found within the results chapters of this thesis (pp 117), but the research student has ensured that these details will not compromise any participants' identity. Pseudonyms have been used throughout and when a participant has spoken about a specific person in relation to a service they received, this has been made vague (for example, instead of saying Joe Bloggs from the memory clinic, the research student has altered it to "*dementia co-ordinator*"). The identity of the residential care homes, the care organisation and the health boards has been concealed and no reference is made to specific locations or identifiable attributes.

For the VIVA examination, the research student only has ethical permission and permission from each participant to show the examiners clips from the video recordings in defence of this thesis, and to support the use of digital storytelling as a data collection tool for older people living with dementia. The videos must not be shown in a public domain (dissemination).

Participants are not solely sources of data (Smythe and Murray, 2010), and this was echoed within the premise of this thesis; to empower people with dementia to share their stories, recognise them as individuals with unique experiences and feel proud of their stories. The narrator should always be credited as the storyteller (Gubrium *et al*, 2014) and if these stories were collected and used by a health board or charity (for example), there would be no concerns over confidentiality. For research, however, ensuring confidentiality of the participant is essential. The ethical permissions for this study were dependent on the participants being made anonymous. Yet, it has been suggested that the use of pseudonyms can damage the relationship between the researcher and the participants and hinder the data collection process as the participants only feel like sources of data (Josselson, 2007). It is, therefore, difficult to strike a balance between ethical regulations regarding confidentiality and crediting the narrator for their story. To overcome this, the stories were anonymised for any work related to this study, but ownership of the videos has been granted to the person in the video (the participant) and only they can permit the use of the video for other purposes. The participants are now in complete control over who sees their story.

4.6.6 Disclosing sensitive information

It has been noted that people with dementia will often lose the ability to maintain a self-controlled silence about their personal histories (Capstick and Clegg, 2013). This could result in the disclosure of sensitive information that may have once been kept private. "*Sensitive information*" includes, but is not limited to, physical abuse, sexual abuse, financial abuse, psychological abuse or criminal activity, including drug use (Murdoch *et al*., 2014). Similarly, a participant could disclose information that would be upsetting to another, for example, family affairs. During the consent process, the research student explained to the participants that the disclosure of sensitive or hurtful information would be removed from the stories straight away. If the participant disclosed illegal activity, the research student would be legally obliged to pass the information on to the relevant persons. This was incorporated in the information sheets and consent form. All participants agreed to this. No participants disclosed any sensitive information as detailed.

4.6.7 Ethical considerations of digital storytelling

The use of digital storytelling in research has some unique ethical considerations that needed to be acknowledged. The increasing use of multimedia data collection tools has called for new approaches towards ethics to be implemented (Gubrium *et al.*, 2014). The Research Ethics Applications Database (TREAD) contains a collection of best-practice ethics applications for innovative methodologies. This archive was used to identify and address the ethical considerations for digital storytelling as a data collection tool within this study. The primary considerations are, upset while reminiscing and ensuring any names or photographs of people within the participants' stories are anonymised.

It is possible for participants to become upset when participating in any form of life story work (Desalvo, 2000) as the reminiscence aspect of it can elicit emotional memories or the participant may still be "*living the traumatic experience*" and could be put at risk when asked to discuss it at length (Desalvo, 2000); this is also applicable to life story work being used within research. Participants were provided with the interview prompts prior to signing the consent form; this would allow the participants to see what sort of topics the narrative would cover and prepare answers if necessary. In addition to this, participants were made aware that they could pause or terminate data collection at any point. Participants were directed back to their memory clinic, their GP or residential home manager for additional support where necessary.

"*Lives are not lived in isolation*" (Mannay, 2016, pp 121). This statement refers to the characters within a participant's life who have shaped the course of their life stories. These characters are essential to the story and are likely to be referred to by name, yet they have not provided consent to be within the data (Richardson, 2015). The research student altered the non-consenting person's name from the stories to use for the PhD and dissemination; however, the name remained in the participant's copy of the story as that person is likely to be a significant part of the participant's life and cannot simply be deleted (Rose, 2010).

4.7 Data Analysis

4.7.1 Choosing the right approach

Research that uses storytelling has to be careful when choosing the analysis method. There is a risk that, once transcribed, the researcher becomes removed from the stories and *"specialists without spirits"* (Frank, 2000, pp. 355). Therefore the analysis chosen needs to keep the stories central. As mentioned at the beginning of this chapter, there are several different methods for analysing qualitative data (Colman, 2009). The literature review demonstrated a range of methods for analysing qualitative data including content analysis, thematic analysis, grounded theory, interview data analysis and descriptive phenomenology analysis. Choosing the right analysis for phenomenological research is difficult as the phenomenological view of experience is complicated (Smith *et al*., 2009). The five possible methods of analysis will now be discussed in turn, with an explanation for why they were or were not used to analyse the data collected within this study. A summary of these analyses and a justification for not including them as the analysis method in offered in Table 10 (pp 110).

Content analysis is a process used to explore the content of communicative data sources (Krippendorff, 2018). Content analysis is adaptable to many different sources of data, including qualitative and quantitative, and can be used inductively or deductively. Inductively meaning instances where there is little previous knowledge on the subject and deductively when testing a theory (Elo and Kyngäs, 2008). Content analysis is a systematic and replicable technique for analysing data (Erlingsson and Brysiewicz, 2017) which uses explicit coding rules that allow for themes to be identified quickly and efficiently within the data sources (Stemler, 2000). Qualitative content analysis explored the language characteristics used by participants and tries to find meanings within the text (Hsieh and Shannon, 2005). Content analysis intensively examines the language and tries to present categories of similar meaning (Weber, 1990). While some researchers thrive within the flexibility of content analysis, the lack of definitions and structured procedures can put researchers off using this analysis method (Hsieh and Shannon, 2005). This was certainly the case for the research student, who felt that she needed a more structured way of analysing the participants' experiences of living with dementia; a method which would allow for a descriptive approach to analysing the data, not an interpretive one.

Thematic analysis is a method used by researchers to identify, report and analyse themes within qualitative data (Braun and Clarke, 2006). Researchers poorly report the stages undertaken when conducting thematic analysis, and there is no unified way of conducting it (Attride-Stirling, 2001). Braun and Clarke (2006) outlined a six-step process for conducting thematic analysis as they concluded that other researchers tend to be vague about the process they followed. Braun and Clarke's (2006) six steps were (1) familiarise yourself with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) define and name themes, (6) produce the final report. The steps outlined here are central to the steps used within other qualitative analysis methods such as grounded theory, narrative analysis and interpretive phenomenology (Ryan and Bernard, 2000; Boyatzis, 1998). As thematic analysis is central to most other qualitative analyses, some have questioned if it should qualify as an analysis method in its own right (Holloway and Todres, 2003). Thematic analysis has been criticised for being shallow due to its simplicity (Brooks *et al*., 2015). For this PhD, it was felt that thematic analysis was too vague to fully explore the extent of participant experiences of living with dementia; however, the steps outlined above are central to the preliminary analysis method used to analyse the twenty two life narratives collected for this study, but more steps needed to be incorporated.

Grounded theory (Glaser and Strauss, 1967) proposes that a researcher should analyse the data simultaneously to data collection to allow for adaptation of further interview questions as themes begin to occur; this should inform the direction of the study. The method of simultaneously data collecting and analysing can identify areas to conduct further research. This may lead to interviewer bias as the interviewer may ask specific questions until the participant's statement fits with the occurring theme (Willig, 2013). Many descriptive phenomenology studies employ Glaser and Strauss (1967) grounded theory analysis methods as it shares many similarities with phenomenology (Willig, 2013). Grounded theory can provide a rich, complex and dense description of a phenomenon. Although Glaser and Strauss (1967) provide a process for undertaking grounded theory, the process may take different forms and be presented in multiple ways. Glaser and Strauss (1967) believe that research published as a theoretical discussion comes with the automatic assumption that the theory is still developing, the theory will forever be developing. However, it might be argued that if the theory is never completed, how can the researcher come to conclusions about their research topic? Glaser and Strauss (1967) state that researchers who come to a conclusion about their theory are "*freezing*" the theory instead of encouraging further research on the topic. Glaser and Strauss (1967) suggest that the theory formed needs to be a combination of pre-existing literature, personal experience of the researcher and the analysis of the data. For this PhD thesis, the research student had prior experience of caring for people with dementia (four years as a care assistant) and did not want her personal experiences impacting on the conclusions made about life with dementia, from the perspective of the person with dementia and their family members, as the research student's perspective would be completely different.

Burnard's (1991) framework for analysing interview transcripts incorporates some of the principles of grounded theory and combines it with content analysis as described by Babbie (1979). Burnard (1991) provides a fourteen-stage framework for a thorough analysis of the data. Burnard's (1991) framework assumes that the data being analysed has been transcribed in full and came from semi-structured, open ended interview questions. Additionally, the researcher is advised not to follow the steps in a strategic order, but to be flexible (Burnard, 1991). Burnard's (1991) framework tries to keep the interview data as close to the original transcript as possible but still allow for categories to be generated. Burnard's (1991) analysis framework has certain similarities to phenomenology, these similarities may have stemmed from the combination of Glaser and Strauss' (1967) grounded theory and Babbie's (1979) content analysis to create Burnard's (1991) framework. Burnard (1991) suggests that all the data collected should be included in the analysis, however, Elo and Kyngäs (2008) argue that not all of the data will be relevant to answer the research question. Burnard (1991) recommends several analysts code the data, this has been criticised by (Stokes and Urquhart, 2013) as they believe different individuals will interpret the data set differently. An adapted version of Burnard's (1991) analysis has been used for this study and is discussed more below.

Colaizzi's (1978) descriptive phenomenology method of data analysis is very similar to Burnard's (1991). Burnard (1991) describes the process of analysis in fourteen stages, whereas Colaizzi (1978) uses eight; a comparison of both analysis frameworks can be found in the Figure 3. Colaizzi's (1978) analysis, similar to Burnard's (1991), requires the researcher to read over the transcripts several times to get a feel for the data. Then the researcher needs to extract significant statements, formulate meanings from these statements and create theme clusters (Colaizzi, 1978). These theme clusters are to be used to identify themes which are to be validated within the original transcripts (Colaizzi, 1978). After this step, the themes are to be used to describe the phenomenon being researched, with misused descriptions being removed to refine the definition of the phenomenon (Colaizzi, 1978). The final step of Colaizzi's (1978) analysis requires the description of the phenomenon be returned to participants for validating. Colaizzi was described as a phenomenologically orientated psychologist who provided systematic steps for analysing experiential data and arriving at a "*structure*" of the experience (Munhall, 1994). The accurate application of Colaizzi's (1978) descriptive phenomenology framework should provide a detailed description of the participant’s experiences of living with dementia (Shosha, 2012). An adapted version of Colaizzi’s (1978) analysis framework was used for this study and is discussed in more depth below.

Figure 3: Comparison of Burnard's (1991) and Colaizzi's (1978) Analysis Frameworks

Burnard's (1991) framework

Step 1: The researcher makes notes after each interview regarding any thoughts about possible themes, that may occur in the data.

Step 2: Read through transcripts and make notes on general thoughts about the data.

Step 3: Read through transcripts and openly code the data attributing headings.

Step 4: Group together the open coded headings to collapse them into general categories.

Step 5: Merge any similar or repetitious categories.

Step 6: Have the data coded by other researchers and discuss any similarities/discrepancies within the categories produced.

Step 7: The researcher checks that the categories are present within all transcripts.

Step 8: Sections of the transcripts are attributed to the different categories.

Step 9: The transcripts are cut into categories and all the data related to each category is grouped together.

Step 10: Assemble all the cut-out parts onto one sheet. One sheet per category.

Step 11: Ask participants to check the appropriateness of the categories.

Step 12: File all the sections together for ease of reference.

Step 13: Begin write up. Provide commentary between quotes.

Step 14: Link the data commentary to pre-existing literature.

Colaizzi's (1978) framework

Step 1: Read the transcripts several times.

Step 2: Extract significant statements from within the transcripts.

Step 3: Formulate meanings from the extracted statements.

Step 4: Group together similar formulated meanings to create theme clusters.

Step 5: Merge similar theme clusters together to create themes and check that these are present within the original transcripts.

Step 6: Generate a theoretical model of the experience of the participants

Step 7: Remove any redundant or misused themes.

Step 8: Return the themes to the participants to check that it is an accurate representation of their experiences.

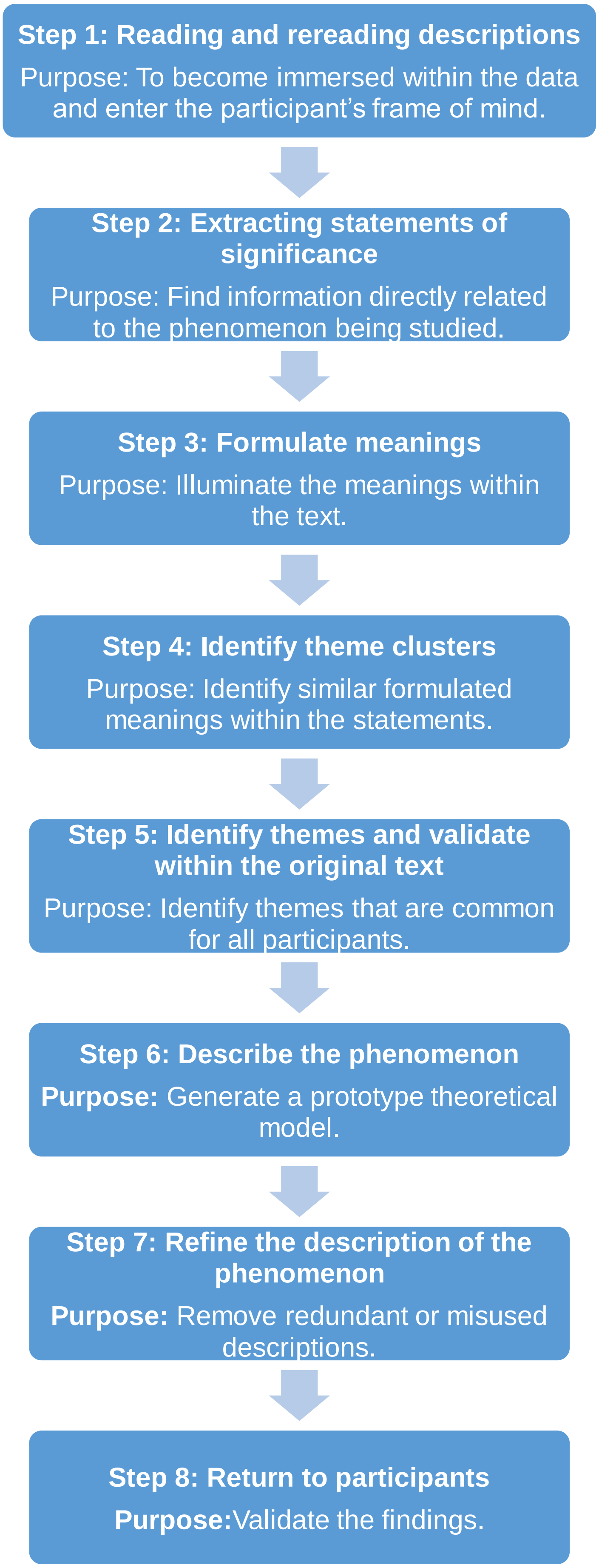
Table 10: Summary of possible analysis methods

Analysis	**Reason for exclusion/inclusion**
Content analysis	Excluded because it lacks definition and structure
Thematic analysis (Braun and Clarke, 2006)	Excluded because it is too simplistic to explore the complex experiences of the participants.
Grounded theory (Glaser and Strauss, 1967)	Excluded because it encouraged the researcher to merge their knowledge with the participants', not to bracket their assumptions and place the participant as the expert in their condition
Burnard's (1991) framework for analysing interview transcripts	Included because of clear steps and focus on original transcript
Colaizzi's (1978) descriptive phenomenology analysis framework	Included because of pre-defined stages and emphasis on the participant's story

4.7.2 The chosen analysis

The analysis used for this study is a combination of both Colaizzi's (1978) descriptive phenomenology method of data analysis and Burnard's (1991) framework for analysing interview data. These frameworks were adopted here as they provide clear step by step guidance on the analysis methods and ensure the participants' experiences remain the focus of the analysis (Wirihana *et al*, 2018). The eight steps undertaken by the research student to follow Colaizzi's (1978) and Burnard's (1991) analyses are outlined in the flow diagram below (Figure 4). The purpose of each step has also been explained.

Figure 4: Flow diagram of analysis used



Ideally, all the data within a transcript should be used for the analysis (Burnard, 1991). However, there may be some sections within the transcript that have no meaning and cannot be analysed; for example, a participant saying, *“I don’t know, maybe, you know”.* Whilst this would make sense within the context of the interview conversation, it cannot be analysed. Phrases such as this are referred to as “*dross”* by Field and Morse (1985).

For ease, Colaizzi (1978) proposed the use of a table to undertake the earlier stages of the analysis. This table allows the researcher to input the significant statements, who said them, the formulated meaning of the statement, the theme clusters and the overarching theme. An example of the table headings is below (Table 11), with a sample of the text.

Table 11: Analysis table used

Theme	Theme Cluster	Formulated Meaning	Statement	Person
Isolation	Burden	Does not like relying on her family for help. She does not want to be a burden.	I’m independent, I like to do my own things and I haven’t been able to, I’m relying on my daughters and that’s an awful feeling where you, I don’t want them to be burdened by me.	Lynne

4.7.3 Generating themes

To generate themes from the stories provided by research participants, the research student firstly read over the transcripts and watched the video recordings multiple times to become familiar with them. The research student then read through one transcript at a time and extracted any significant statements. These significant statements were put into the analysis table as outlined above with the location of the statement and the meaning that the research student attributed to the statement.

After significant statements were extracted from all the transcripts, and all had meanings attributed to them, the research student organised the attributed meanings into theme clusters. To do this, the research student printed out the extracted statements and attributed meanings, cut them into strips and arranged them manually into theme clusters. A photograph of this process can be found in Appendix U (pp. 487). The same process was then used to formulate the themes, whereby the research student arranged the theme clusters by hand into overarching themes. The table outlined above was then formulated and can be found in Appendix V (pp. 488). The completed table was peer reviewed by the supervision team and returned to some of the participants to validate the themes. Not all the participants wanted to take the time to validate the themes but ten did.

Whilst there was coding software available, such as NVivo, to complete the analysis, it was felt that they offered no advantages over manually arranging the statements and the use of such software could decontextualize some of the quotations (Holloway and Jefferson, 2000). The use of a coding software would have quickened the process of analysis (Bassit, 2003), but regardless of this, all qualitative analyses must be warranted ample time to be completed properly (Delamont, 1992). Zamawe (2015) stated that a researcher must master a given software to be able to conduct an analysis properly, this can take a long time to do. The function of such packages is not to do the analysis, but to aid the process; the researcher is always in control of the outcomes (Zamawe, 2015). Whilst the software is helpful when working with large data sets, it is not essential that it is used. Manual coding can be equally as effective for smaller data sets (Wicks, 2015). *"I dislike seeing manual coding compared with computer coding because it suggests that the computer does the coding, instead of the researcher"* (Wicks, 2015, pp. 170). Zimawe (2015) argues that coding software allows third parties to see exactly what steps were taken. To overcome this, the steps taken when analysing the data for this study are made explicitly clear within this methodology section.

4.7.4 Quality, validity and trustworthiness of themes

To produce high value qualitative data, a researcher must demonstrate the appropriateness of the participants and the adequacy of the data (Morse and Field, 1996). Appropriateness of participants emphasises that only people with an in-depth understanding of the phenomenon under investigation should be included as research participants (Morse and Field, 1996). Adequacy of data, more commonly termed data saturation, is ensuring that enough detailed information is collected from the participants to fully answer the research question (Morse and Field, 1996). This study fulfilled both of these requirements by only recruiting people who had first-hand experience of living with dementia, for more than six months, and conducting interviews until data saturation was achieved. In narrative studies, it is unlikely for participant's narrative journeys to be the same; therefore, the research student deemed that data saturation was achieved when the details within the narratives were similar (Walker, 2012). Furthermore, phenomenological researchers suggest that the correct number of participants for a descriptive phenomenological study should be between five and twenty five (Creswell, 1998) or at least six (Morse, 1994); this study's recruitment figures (twenty two participants) are in line with this.

Qualitative research has to demonstrate rigor and trustworthiness (Speziale and Carpenter, 2007). Trustworthiness can be demonstrated through credibility (Shosha, 2012). Credibility ensures that the data used in the analysis was a true representation of the information that the participants provided (Wirihana *et al*., 2018). To ensure the themes were credible, and subsequently trustworthy, they were returned to the participants to ensure they were an accurate representation of the participant's life with dementia. Qualitative rigor is a way to establish trust or confidence in the findings of a research study (Thomas and Magilvy, 2011). To add qualitative rigor to the present study, the results were validated by the supervision team and steering committee. This rigor was further strengthened by the participants (n=10) checking the themes[4].

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[4] Not all participants were able to/wanted to validate the themes.

4.7.5 Presenting the findings

Both Wengraf (2001) and Holloway and Freshwater (2007) have highlighted the importance of understanding who the participants are within narrative studies. Qualitative research presents fragmented quotations from participants' whole stories but does not highlight the true picture of who that participant is. Therefore, the research student felt strongly that this study should offer the reader the opportunity to "*meet the participants*" as a central part of this thesis, not just in the appendices (Genders, 2016). The following chapter of this thesis will do just that, introduce the reader to the twenty-two participants as they were all crucial to understanding what it is like to live with dementia. Snippets of their biographical histories are presented in short case study format, as suggested by Holloway and Jefferson (2008), Holloway and Freshwater (2007) and Wengraf (2001).

A decision then had to be decided as to how to present the results of the descriptive phenomenological analysis. Whilst there were some nuances between the two groups of participants, their experiences were ultimately very different. Therefore, it was decided that their results would be presented separately. There is one chapter on the participants with dementia (pp 148) and one chapter on the family members (pp 186).

4.8 Summary and Reflection

This chapter has explained the research methodology used in this study. The rationale behind using descriptive phenomenology and digital storytelling has been described. The processes of obtaining ethical approvals, sampling participants and data collection has been detailed. The ethical issues encountered during data collection were illuminated, followed by an outline of the approach taken for data analysis and presentation. The importance of recognising the person behind the narrative is central to life story research and the next chapter builds on this premise. Chapter 5 is the first of three to present the results of the study. This chapter will introduce the reader to the twenty-two participants who took part in the study, exploring their personal histories and the interview dynamic.

Reflection on the Chapter

The methodology for this study came with many challenges. Initially, phenomenology was a challenge to understand. Followed by a significant amount of time trying to obtain ethical permissions (Appendix H). I have since come to understand that obtaining permissions for a study relating to dementia is challenging for all those who attempt it. Yet I found that the committees were more concerned with the use of video recordings. As the videos did not follow the usual convention of audio recording, there was considerable concern over their use, who would see them, what they offered the study and who ultimately owned them. After a conversation with the Chair of the University of South Wales' ethics committee, it was decided that we could use the videos in defence of this thesis and, if we asked the participant for their permission every time, we could use video clips for conferences. When this application went through NHS ethics, this decision was overturned. The videos can solely be used in defence of this thesis at VIVA. After that, the participants are the sole owners of the videos and they decide when and if the videos are shared. Whilst it would have been nice to share the videos at conferences, I am content with the participants being recognised as the storytellers and the owners of the stories.

Data collection was by far my favourite part of this study. As descriptive phenomenology states, bracketing should be used. I made written notes of what I thought I knew about life with dementia throughout the three years of this study and have noticed that these notes have become more refined as I got closer to the end of the PhD. During the initial interviews, I found it difficult to completely put aside any prior knowledge of life with dementia, particularly when participants spoke about having home care, as this was an area I had worked in previously. The more interviews I conducted, the easier it became to put aside my own knowledge of life with dementia, and I came to realise that I knew very little. The participants really are the experts.

Despite all interviews following a life story structure, beginning at childhood and working through to the current day, I found that no stories were the same. Every participant thrived on the opportunity to share the stories that they felt were most influential over their lives.

CHAPTER 5 RESULTS: PARTICIPANT BIOGRAPHIES

"Who am I? And how I wonder, will this story end? My Life? It isn't easy to explain"

(Nicholas Sparks, The Notebook, pp.1)

5.1 Introduction

This chapter represents the importance of knowing the person behind the narrative within qualitative research to truly understand their experiences. The aim of this chapter is, therefore, to introduce the reader to the people behind their dementia by highlighting a small fraction of their personal life stories (Benbow and Kingston, 2016). It gives insight into the personal histories of the participants, their childhood, employment history, relationships with family members and their lives with dementia. You cannot truly gain the perspective of someone else's situation until you understand their lived experiences (Karlsson *et al*., 2014).

Narrative research must link the past, present and future to fully explore the personal experience of participants within research (Elliot, 2005). The use of detailed portrayals of the participants within qualitative research has been recommended for many years (Geertz, 1973); this is particularly important for narrative research as the participant's life stories are central to the findings (Holloway and Freshwater, 2007). Furthermore, Holloway and Freshwater (2007) suggest that a researcher should ensure that the relationship between the researchers and participants be discussed, along with notes from data collection, as this adds to the reader's understanding of the participant's experiences.

Thus, this chapter begins by outlining the demographic information for the ten older people with dementia and twelve family members who participated in this study. Their sociodemographic data can be found in Table 12. Whilst all the participants with dementia had a confirmed dementia diagnosis, their diagnoses varied.

The chapter then further describes the participant's personal histories, combined with field notes from the data collection process. This is consistent with guidelines from various narrative researchers (Wengraf, 2001; Holloway and Freshwater, 2007; Holloway and Jefferson, 2008; Todres and Holloway, 2010) regarding the presentation of narrative research. Where possible, the life stories for those who participated in pairs (mother and daughter/husband and wife) are presented together. For ease of reference for the reader, the people with dementia will have a blue background on their life stories and their family members will have green.

Table 12: Participant demographics

Pseudonym	**Age**	**Diagnosis**	**Recruited from:**
May	87	Vascular dementia	Care home
June	82	Alzheimer’s disease	Care home
Nancy	68	Vascular dementia	Health board
Lynne	78	Alzheimer’s disease and mixed dementia	Health board
Louise	66	Alzheimer’s disease	Health board
David	71	Mild dementia/Alzheimer’s disease	Health board
Rob	69	Frontotemporal lobe dementia	Health board
Beverley	69	Alzheimer’s Disease and posterior cortical atrophy	Health board
Pat	85	Alzheimer’s Disease	Health board
Rose	71	Alzheimer’s Disease and primary progressive aphasia	Health board
Pseudonym	**Age**	**Relationship to the person with dementia**	**Recruited from:**
Laura	61	Daughter of May	Care home
Pippa	52	Participated alone	Care home
Gail	87	Participated alone	Care home
Geraint	59	Son of June	Care home
Sara	61	Participated alone	Care home
Bethany	45	Daughter of Lynne	Health board
Trystan	71	Husband of Nancy	Health board
Darren	62	Husband of Louise	Health board
Dianne	70	Wife of David	Health board
Kim	49	Wife of Rob	Health board
Tony	71	Husband of Beverley	Health board
Hannah	51	Daughter of Pat	Health board

5.2 Participant Life Stories

5.2.1 June and Geraint

June

June was born in Scotland and has 3 siblings. She left school when she was 15 and went to work as a sales assistant in a clothing shop in Glasgow. June moved to Wales due to her husband's employment, but they later divorced. She raised their 4 children alone. Once her children were grown, June worked in a rugby club. Upon retiring, she loved to volunteer within the community and won an award for her volunteering efforts. Two of June's sons have passed away, but she does not remember this.

June had always been forgetful, but it had become worse in recent years. She does not forget faces, but she does not know some people's names. June has a diagnosis of Alzheimer's Disease and now lives in a residential care home. It took June a long time to get used to being in a residential care home; she felt her family no longer wanted her. June is very independent and does not like to ask for help. She participates in all activities within the care home and interacts with staff and other residents almost all day, but she forgets that she does this.

Geraint

Geraint is June's son. Since his parent's divorce, Geraint has become close to his mother. Yet in retrospect, Geraint feels that he could have spent more time with his mother but his own family commitments made this difficult. Due to his own ill health, Geraint's sister was primarily involved in his mother's care while she was living at home. It was Geraint's sister who accompanied June to the memory clinic when she received her Alzheimer's Disease diagnosis 4 years ago.

Geraint finds it difficult to repeatedly reassure his mother that a residential home is the best option for her, but June feels that she is not wanted anymore. Every time Geraint visits June, she tries to go home with him, and he finds it hard to keep explaining that she lives there now.

Geraint believes that June's dementia was triggered by the deaths of his brothers. They died within a year of one another which did not give June the time to grieve for the one before the other passed away. June did not cry over their deaths either. After the second funeral, Geraint noticed that his mother stopped leaving the house, and developed depression. Geraint thinks that this suppression of grief may have triggered the onset of her dementia.

June and Geraint are mother and son and their narratives were collected in June's bedroom within the care home where she lives. June requested that Geraint be with her while she spoke; therefore, Geraint sat in during the data collection process and only spoke a few times during June's interview, to help prompt his mother when she became a little muddled.

It was difficult for Geraint to answer a lot of the questions that were asked around the diagnosis process and choosing a care home as Geraint's sister had taken over the responsibility for these things. Geraint had been unwell roughly the same time as his mother and was unable to help his sister with the responsibility of choosing a care home for his Mam.

June always participates in social activities within her care home, yet, when June narrated her experiences of living in a care home, she claimed to never leave her bedroom because she hated living there. June could not remember the social activities that she participated in daily. Geraint was quick to correct her and explain that she loved joining in, she just could not remember doing it.

Similarly, June got muddled about her life story. At one stage, she was explaining about her divorce and then began describing her second marriage. Geraint was stunned at this as June had never married again. When corrected, June said

> *"Have I not? Well maybe I didn't. That was a bit silly of me, why didn't I marry again? …no I can't remember another man's name so I can't have been [married twice]"*

June's memory was a real problem for her and often results in painful reminders about things she has previously forgotten. As Geraint explained, his mother struggled to come to terms with the death of two of her sons. Prior to data collection with June, she explained that only her one son visits; the other two live too far away to come regularly. She had forgotten about their deaths; this clearly highlights the detrimental effects that dementia can have over a person's memory and how upsetting it might be for other family members.

5.2.2 May and Laura

May

May was born in South Wales and has 2 younger sisters. As a child, May enjoyed playing in the fields around her house and going on holidays to Barry Island and Porthcawl. May left school when she was 14 and worked in a shop, renting out relays. After two years, she went to work in a biscuit factory. May has 2 children, a daughter, and a son who she does not see. She returned to education after her children had grown and sat her A level exams at the same time as her daughter. May has one grandchild.

May was married for 54 years before her husband passed away. They regularly went dancing, the waltz being their favourite dance. She has fond memories of family holidays and years of long friendships.

May forgets dates and her memory is not as good as it used to be. She has a diagnosis of vascular dementia and now lives in a care home where she is very happy as there are a lot of activities, the food is good and there is company. She knows that she is safe and well looked after but wishes she could see more of her family and friends.

Laura

Laura is May’s only daughter. Laura has an older brother but due to a family rift, they do not speak, nor does he visit May. After the death of her Dad, Laura became very supportive of her mother. May depended on her husband so after his death, she became very vulnerable which is why Laura became involved. Every day she would visit May.

Laura finds it difficult to visit her Mum because she does not want to interrupt the activities at the home. She feels a bit redundant as she used to be her Mum’s full-time carer but the staff have now taken on this role, leaving Laura with minimal care tasks. Laura receives a lot of support from her husband and daughter but highly recommends that people attend the carer support groups run by the Alzheimer’s Society, as these helped her greatly with her mother’s dementia journey.

May and Laura are mother and daughter and their narratives were recorded within May's bedroom in the care home where she lives. Laura stayed with May while she told her life stories, as Laura was concerned May would not be able to hear the questions properly due to her deafness; Laura was there to repeat anything her mother did not understand.

Both May and Laura were talkative, providing a lot of detail about their lives with dementia. Prior to data collection, Laura explained that May does not like to say the word "dementia". May would happily discuss her memory problems, but did not like to say, "*the D word"*. Laura believed that this is because of the stigma associated with the word. She was still trying to convince her mother that "*dementia*" is just a word used to describe memory loss; it does not mean that someone is incapable of doing things for themselves. May was still trying to accept this so Laura's suggestion was adhered to during data collection.

May was very happy living in a care home, unlike June, who hated being there. May said "*when I look at other people, I think I have got nothing to grumble about. I am lucky. And it's company. We do daft things... You know, you can't fault them. But this is the best place for me because Laura and Martin have got lives of their own. And I have been very, very lucky".*

This might be due to May choosing to move to a home whereas June's daughter made the decision on her behalf. Similarly, May could remember the activities that she participated in daily, whereas June could not remember them; this may have added to their differing levels of acceptance of living in a care home.

May had also forgotten serious life events because of her dementia. For example, she had forgotten about the argument that occurred with her son on the night that her husband passed away, resulting in her son not speaking to the family anymore.

Laura became upset during her narrative when she was discussing her mother's future. The data collection process had to be paused but resumed shortly afterwards. Laura hoped that her mother stays happy and content for the remainder of her life, while May wished for her family to be happy and healthy.

5.2.3 Nancy and Trystan

Nancy

Nancy was born in South Wales and has 7 siblings. Nancy was bullied a lot in school as she was different; the children would often say "*here comes fatty*". Nancy left school when she was 15 and has had several sewing jobs throughout her working life. Nancy met her husband, Trystan, 54 years ago and they have 2 sons. After having her sons, she did not return to work.

Nancy has had several strokes and when she noticed that she was forgetting things, she thought that she was going insane. Shortly after Nancy received her diagnosis of vascular dementia 9 years ago, her father was diagnosed with vascular dementia. Seeing how her father died with dementia scared Nancy as she thought that would also happen to her.

Nancy's children no longer visit her, and she believes it is because of her dementia also, her sister has accused her of being a hypochondriac. She is very self-conscious and feels like people always watch her. Nancy and Trystan have a caravan in Pembrokeshire, and they go every weekend. When the caravan is closed for the winter months, they arrange other holidays as they try to remain independent and active.

Trystan

Trystan has been married to Nancy for 50 years. He worked long shifts in Chepstow and when he got home from work, his meal would always be waiting for him. Trystan had paid employment while Nancy was a housewife.

Nine years ago, Nancy had a stroke which resulted in her being wheelchair bound. Around the same time, she began to develop dementia. Trystan had to give up work due to poor health and took over all of Nancy's care. Trystan now has to help Nancy with most daily tasks including cooking and personal care. Nancy regularly mistakes Trystan for her father which proves problematic when Trystan is trying to help her shower and dress; she will often refuse the assistance, saying "Dad, I can't dress in front of you".

Since Nancy has had dementia, Trystan's life has completely changed. Previously, Nancy would do all the housework, now Trystan has to do it. He thinks that his relationship with Nancy has grown much closer since she has had dementia.

Nancy and Trystan are husband and wife and their data collection took place in their living room, within the supported living complex where they live. They were both present for each of the interviews and regularly corrected one another or interjected with additional information. Trystan spoke first and when it was Nancy's turn, he thought of additional things that he wanted to say which resulted in him interrupting Nancy's stories; for this indiscretion, he was told to *"shut up"* by Nancy. Nancy liked to talk; one question would lead to three pages of transcription for Nancy's answer.

Trystan feels that his relationship with Nancy has been strengthened since she became so dependent on him. *"I think we've become closer to be honest with you. She might not think that, but it is closer because you take things for granted when we were both fit and well, but you know she can't do things. Sometimes I moan about doing things, but you've just got to get on with it, but we are a lot closer now than what we used to be".*

Nancy disagrees, she feels that she is now the blank within their relationship and Trystan is a double six [dominos]. She does not like having to rely on him to do everything. Trystan had taken over all his wife's care; this is also true for several of the husbands who participated in this study. He feels that it is his responsibility as Nancy's husband to care for her in sickness and in health. While Trystan is now accepting of his role as Nancy's carer, he does admit that he was initially embarrassed, particularly when he had to push Nancy around in the wheelchair.

Nancy and Trystan do not let Nancy's dementia stop them from having fun. They go to their caravan in West Wales every weekend. When the caravan is closed for the winter, they go on alternative holidays. They ensure that the holiday venues are wheelchair friendly and have plenty of activities to keep them occupied throughout the day. As Nancy kept reiterating, "*use it or lose it*", so she tries to use it as much as possible with holidays, bingo and games on her iPad.

5.2.4 Lynne and Bethany

Lynne

Lynne was born in South Wales and has 3 siblings. Lynne left school when she was 15 and went to work in a clothing factory for 18 months before training to become a nurse.

Lynne worked in three different hospitals throughout her career. She worked as a nurse until she retired at 60. When Lynne's husband passed away, she felt lonely and began volunteering with a caring company.

Approximately 2 years ago, Lynne noticed that she was struggling to write, forgetting people's names and babbling over her words. This made her feel dreadful as these are things that she has had to do throughout her nursing career and now they have become a struggle. Lynne no longer feels like herself and regularly says "*my head is in the shed".*

Lynne received a diagnosis of Alzheimer's Disease and Mixed Dementia, which she is not happy about and is very reluctant to share with other people. When Lynne was nursing, she had to take care of advanced dementia patients; this has increased her fear of developing dementia as she thinks she will be like them. As a nurse, she would often say *"please God, don't let me get that"* and now she feels devastated that she has dementia.

Lynne now feels miserable most days, she feels very poorly and not the same happy person that she once was. Lynne does not like to be in social situations because people might notice that there is something "*wrong with her".* She also finds it frustrating when people keep correcting her or pointing out her mistakes.

Bethany

Bethany is Lynne's daughter. Bethany worked in the community and her sister is a nurse so they spotted the signs that their mother may have dementia early. Bethany found the memory clinic appointments very upsetting. During the initial assessments, Lynne revealed a lot of things that she had experienced which the two daughters knew nothing about; for example, hallucinating there were other people in the room and the television being distorted. Bethany says that the diagnosis process was very difficult as *"we weren't just coming out with a diagnosis; we were coming out with how vast it [her mother's dementia] was".*

Bethany's life has completely changed since her Mam has developed dementia, she has taken on the role of Lynne's carer and does not have time to do anything else anymore.

Lynne and Bethany are mother and daughter and they participated in data collection from the living room of Lynne’s “*pensioner’s bungalow*”. Whilst the one was sharing their stories, the other waited in the kitchen. Lynne has an anxious personality and asked to pause her data collection halfway through because she had “*had enough*”. After having a cup of tea, over which Bethany went through the remainder of the interview prompts with her, she finished the other half of her narratives.

Despite doing the data collection phase of the study separately, they chose to sit together to watch their videos for editing. Bethany became upset at some of the feelings her Mam had shared within her narratives; saying that she did not know that her mother felt like that as Lynne tends to hide her feeling from her family. Similarly, Bethany did not know about the severity of Lynne’s dementia symptoms until they attended the memory clinic appointment and Lynne explained them to the consultant. This could be Lynne’s way of trying to remain independent and not worry her family.

Bethany and her sister care for their mother full time. Juggling home life with caring for her mother and her own health is a real struggle for Bethany; one that Bethany cannot picture a solution for. Lynne’s past experiences of nursing elderly patients has influenced her reaction to her dementia diagnosis. Throughout her career, Lynne always prayed to God that she would not develop dementia, as that was the one diagnosis she did not want to get. Both Lynne and Bethany have first-hand experience of working with people who have dementia; this allowed them to identity the signs sooner. Unfortunately, this experience has also made them aware of how difficult life with dementia can become. When asked about hopes for the future, Lynne said “*I just want to be normal and this isn’t normality”.*

5.2.5 Louise and Darren

Louise

Louise was born in South Wales and left school when she was 15 to work in a shop for a few years after which, she trained as a hairdresser. Whilst hairdressing, Louise met her first husband. Louise was born with a heart problem and was advised not to have any children; she ignored this advice and had a daughter. Her first husband earned a good wage, so Louise was able to stop working to raise her daughter and did not return to work until her daughter was 15. Louise's marriage to her husband became rocky and they divorced. Shortly afterwards, she met Darren and got a job as a home carer with the council. Louise and Darren have been married for 20 years.

Louise became forgetful and was later diagnosed with Alzheimer's Disease. She was very angry at herself for developing dementia and gets upset when thinking about all the things that she can no longer do; having to stop baking cakes was one of the hardest things for Louise as she loved this. Louise and Darren planned to move to Spain after retirement, but they feel that this is no longer an option because of Louise's dementia. Louise gets very emotional thinking about this and feels guilty that she is preventing Darren from following his dream. Louise says that the most important things in her life now are her husband Darren and her two dogs.

Darren

Darren has been married to Louise for 20 years. Since being together, Darren and Louise have had a fantastic life, regardless of her Alzheimer's Disease. Prior to Louise's health deteriorating, they travelled the world. Now they travel Britain as Louise cannot fly due to her heart condition and she does not want to leave her dogs behind.

Darren is very proud of the way that Louise has accepted her diagnosis and moved on with her life. Darren still works full time. Currently, Louise is ok to stay in the house alone while Darren goes to work, but there will come a day when he will have to give up work to become her full-time carer. Darren and Louise are very independent and do not like to ask for help.

Darren tries to encourage Louise to be as independent as possible, but he feels trepidation at what is to come. He promises never to turn his back on Louise and has prepared himself for the future; including the possibility of needing to provide personal care.

For Louise and Darren, wife and husband, data collection was conducted in their living room and they stayed together for both interviews. They are a friendly and open couple, although Darren tends to dominate the conversation. Darren and Louise were the youngest couple to participate in the study. He was still in full time employment but understood that he would have to give that up one day to care for Louise. Due to their age, Darren felt that all the information they had received was aimed at elderly couples, who had retired and the person with dementia could no longer do things for themselves; but this was not applicable to Darren and Louise. Darren would like an information pack that is for him, not a “one size fits all” pack.

During Louise’s interview, it was noted that she would often divert the question onto Darren and get him to answer on her behalf. Once Darren had answered, Louise would add any additional information that she felt was important. Similarly, if Darren felt that Louise was not answering the question, he would reword the question for Louise to give her answer. For example:

> *Louise: You can answer this one.*
>
> *Darren: I can’t answer it, the question is when you noticed it.*

To further support Louise, Darren held her hand throughout the interview to reassure her. Louise became upset when thinking about their future plans; Darren stroked the back of her hand with his thumb to reassure her that it was ok.

Louise had worked with people who have dementia and, like Lynne, Nancy and Pat, knows how difficult things can become. Thinking of herself as a dementia patient was difficult for Louise as she had always cared for the patient and was not accustomed to being one.

When Darren and Louise had finished sharing their stories, they remarked that the process of talking about their experiences was therapeutic and enlightening. As Darren says, “it’s been therapeutic to talk about it” .

5.2.6 David and Dianne

David

David was born in South Wales and is the oldest of 8 siblings. David learnt to ride a bike when he had his first job at 13 years of age, delivering meat for the local butcher. David hated school, he preferred to be earning money. David met his wife, Dianne, when they were still in school and they have been married for over 50 years. They have 3 children. He had his own building company and he ran the local rugby club. David retired from building work when he was 60 and now runs a small taxi service with his daughter as he is still able to drive.

David has a diagnosis of Mild Dementia and Alzheimer's Disease and thinks that a mental health problem does not mean that someone is unwell, to David, someone is unwell if they have a physical problem (e.g. a broken foot). He attends a local dementia support group weekly, where they have a "*men's group"* with an indoor curling team. Occasionally, they play at tournaments. David has a little garden by the side of his house where he grows fruit and vegetables; he says this is his little hideaway, from his wife, where he can relax.

David wants to remain as he is for as long as possible; he does not want to get to the stage where he needs to be fed and washed. Participating in this study was the first time David had said out loud that he has a diagnosis of dementia.

Dianne

Dianne has been married to David for over 50 years. Three years ago, Dianne noticed that David was getting forgetful and encouraged him to go to the doctors where he was diagnosed with Mild Dementia and Alzheimer's Disease. Dianne finds it more difficult to deal with David's mood swings than his forgetfulness and describes her husband as Dr Jekyll and Mr Hyde as he can be the biggest joker in the world one minute, and a "*nasty little person"* the next. Dianne says it is like living with a "*ticking time bomb".*

Dianne has always been the sort of person to speak her mind, but since her husband's temperament has changed, she often finds herself having to *"bite her tongue".* Whilst David is in "*men's club",* Dianne attends the female equivalent, "*crafty knitters",* which she describes as her freedom. Diane feels that most of her support comes from her children, who telephone daily to make sure everything is ok. Dianne has also received a lot of support from local charities who have helped Dianne complete forms for financial help. Dianne says that she is not proud, she will take help from whoever is offering it.

David and Dianne are husband and wife and their data collection was conducted in the living room of their home. They chose to share their stories alone. Both were talkative and open about their experience, but David was a joker throughout his narratives and had a humorous response to most questions. The only question which David answered seriously was *“how did you feel about receiving a diagnosis of dementia?”* to which he explained *“this is the first time that I have said it out loud”*.

David participated first. When it was Dianne’s turn, she wanted confirmation that David had *“been tidy*”. Being tidy meant that he had been polite and answered questions properly.

> *“He was tidy enough with you? Laughing, joking, being his wonderful self? And that’s how he is, if we’re on our own, it’s a different story.”*
> DIANNE

Dianne struggled to live with David’s changing temperament; he would become verbally aggressive within seconds. She said that it is like living with a ticking time bomb. Dianne became upset while explaining how life with dementia makes her feel.

> *“Inadequate. Sometimes I feel that I’ve let him down in some way. I know I haven’t, but it does make you feel like that, makes you feel useless”*
> DIANNE

David and Dianne have been together since they were in school. They had separate elements to their lives but now David has dementia, they do everything together. Dianne worried about leaving David alone for extended periods of time; attending the local dementia support group provides a break for both. Dianne joined the knitting group, while David played curling with the men; this little bit of independence, away from one another was “*heaven*” for Dianne. David also likes to *“hide*” from his wife in the garden.

David used to be a social person, he played in a band, owned a rugby club, played sports and enjoyed a drink with his mates. Since developing dementia, David does not leave the house unless it is with his daughter to complete his taxi round or to attend the dementia support groups.

5.2.7 Rob and Kim

Rob

Rob was adopted as a baby and grew up in Bath. He left school when he was 13 as he had a job in a local supermarket. Rob has been married 3 times and has 7 children. His current wife is Kim, who he married 18 years ago. They have one child together; this is the only one of his children that Rob sees. Rob moved around a lot and had several different jobs as a lorry driver, a builder, working in a call centre and having his own driving school. Rob was one of the builders who worked on the Second Severn Crossing. Rob now has a small area of land where he keeps chickens, ducks, geese and goats that he tends to daily.

Rob finished working in 2008 after having several health problems, including arthritis, five damaged vertebrae in his back, two strokes and high blood pressure. Rob has a diagnosis of Frontotemporal Dementia and was happy to receive this diagnosis as it reassured him that there was something wrong, he was not making it up.

Rob knows that his condition is going to get worse, possibly to the point where he can no longer do things for himself and worries about the impact this will have on his family. Rob attends a local dementia support group where he is captain of the curling team and takes it very seriously.

Kim

Kim has been married to Rob for 18 years and is 20 years younger than her husband. Kim has a daughter and son from a previous marriage and one son with Rob. Kim stopped working in 2008 to look after her husband and youngest son who is autistic and needs additional support.

Kim misses the natural spontaneous affection that she used to have from Rob and no longer receives due to his Frontotemporal Dementia. She finds that Rob can be quite rude when talking to people as he no longer has a filter on what he is saying, and this sometimes embarrasses her; luckily, he does not say anything sexually inappropriate.

Kim attended a dementia carers course at the local memory clinic and was shocked to find that a lot of the helpful “tips and tricks” were the same as those she had previously learnt when attending a similar course on caring for autistic children. With both Rob and their son, Kim must break instructions down into clear steps for them to follow. Juggling the care for her husband and son is exhausting and Kim worries about how she will manage in the future, when Rob’s dementia deteriorates.

Rob and Kim are husband and wife and participated in data collection alone, in a consultation room within their local memory clinic. Rob felt that Kim hates him for developing dementia, while Kim explained that there is no love between them anymore.

> *"She thinks that I'm not the man that I used to be…Whether she hates me for it, I don't know"* ROB

> "*The person that I loved and married is gone"* KIM

Kim explained that Rob is no longer able to feel empathy or pick up on emotional cues during conversations, yet Rob became upset when thinking about the future. He feels that he is already a burden on his family, and he does not want them to feel any more burdened by him and his increasing care needs. Rob was the only male in this study to become upset while explaining his experiences of life with dementia.

As Kim explained, the training for caring for someone with dementia was like caring for someone with autism. When Kim wants them to do something, she must break the task down into smaller instructions. The same was true when the research student was asking Rob questions, she regularly had to break the question down into smaller parts for his answers to be smaller; when asked a long question, Rob would forget what had previously been said and become muddled.

Rob and Kim have no extended family to offer support. Both of Kim's sons have additional needs related to their autism and her daughter lives away. This results in Kim having to care for both sons and her husband alone. She makes it clear that her sons are her priority and if Rob's care needs become too demanding, she will have to seek out residential care for him. Rob was unaware that Kim had given thought to this as she did not want to upset him.

5.2.8 Beverley and Tony

Beverley

Beverley was born in Cardiff but moved around a lot as a child due to her Dad's employment. She has 3 sisters and a brother. Beverley comes from an intelligent family and has a twin sister. Beverley and her sister were severely bullied in school for being different. Beverley has periods of depression and still gets upset when discussing her childhood and having to think back to the torture she endured. Despite Beverley's intelligence, she did not do well in school because of the bullying. Beverley left school as soon as she could, aged 15, and began working for the electricity board.

Beverley met her husband, Tony, 48 years ago at a local dance and they have 2 sons whom Beverley stayed at home to raise. Beverley and Tony have 4 grandchildren, the youngest of whom is 3 years old and has been battling with a rare form of cancer since her birth. In retrospect, Tony believes that Beverley's dementia began around the same time as this.

It took a long time for Beverley to receive a diagnosis of Alzheimer's Disease as the clinician was focusing on her history of depression and attributing the behavioural changes to that. After paying for a private consultation, Beverley was diagnosed with Alzheimer's Disease and Posterior Cortical Atrophy (PCA).

Tony

Tony has been married to Beverley since 1975. Tony admits that he was a chauvinist pig as he travelled a lot for work and left his wife to care for their children. Since Beverley has had dementia and PCA, she has become Tony's number one priority; he devotes all his time to her. Beverley's best interests are always at the heart of every decision Tony makes. Tony has taken over all the housework and barely spends time in the garden anymore. They do everything together. More recently, he has also began helping with Beverley's personal care, choosing the outfit for the day, combing her hair and doing her make up.

Tony thinks that his relationship with his wife is much closer now that she has dementia. Previously, they had separate elements to their lives which have now merged as Beverley needs additional support. Tony believes that his experience of living with dementia has turned him into a better person; he is now a less selfish, self-centred person. *"It's a people thing now, more of a people thing".*

Beverley and Tony are wife and husband and participated in the study from the sitting room in their home. They stayed together as Beverley often became anxious when she could not formulate her answers and Tony would prompt her. Beverley stayed with Tony whilst he participated in the study as the two have no secrets, but occasionally, Tony would say, *"Yeah a difficult one to answer, that, candidly", w*hich indicated that the information he was providing was not as detailed as it may have been if Beverley was not in the room. Tony was trying to protect Beverley's feelings whilst still answering the question.

Like Louise and Darren, Beverley would divert any questions that she could not answer to Tony. During Beverley's interview, Tony seemed to dominate the conversation, but he later explained; "*To be honest, if any questions are asked and I am with Beverley, I tend to answer the questions because you sometimes get stuck, you know what you want to say but it doesn't always come out".*

Tony thought that Beverley was struggling to answer questions because she felt intimidated. Beverley insisted this was incorrect. Despite this, it was noted that Beverley was much more comfortable explaining her experiences when it was Tony's turn to be interviewed. While the focus was on Tony, Beverley's anxiety levels dropped, and she was able to formulate her thoughts and share them. Several times, Beverley corrected Tony or shut down what he was saying by claiming that it was not relevant.

> *Tony: Right. My wife comes from a family that's very intelligent, far more intelligent than me. She had issues at school which…*
>
> *Beverley: Which I don't care about.*

Similarly,

> *Tony: I do not leave Beverley for more than a quarter of an hour.*
>
> *Beverley: That's too much information*

5.2.9 Pat and Hannah

Pat

Pat was born in South Wales and has one sister who is 12 years older than her. The family lived in a three-story house with Pat's auntie living in the basement. Pat has fond memories of her childhood town. When Pat was 16, she decided that she wanted to be a nurse. She helped in the local hospital until she was 18 and when she was old enough, she began her nursing training in Newport. After 4 years, she qualified and then decided to train as a midwife for an additional year. Pat compares her district midwife career to "Call the Midwife" where she had to ride a bike from patient to patient, carrying all her equipment. She has one daughter, Hannah.

Roughly 9 years ago, Pat noticed that she was beginning to forget things and was taking wrong turnings when driving in the car. Given her family history of dementia and her medical background, Pat knew that she had to be tested as soon as possible. Pat received a diagnosis of Alzheimer's Disease and was prescribed medicated patches to slow down the progression of her dementia. Pat feels that these patches are wonderful as she has not deteriorated much within the last 9 years.

Pat nursed her grandmother towards the end of her life and then nursed her mother and husband at the end of theirs; all had dementia and became very aggressive. Pat has made Hannah promise to move her to a residential care home if she becomes aggressive because she does not want her daughter having to live with that.

Hannah

Hannah is Pat's only daughter. As an only child, Pat was always very protective of her. Once Hannah grew up, she and Pat were friends more than mother and daughter. Since Pat can no longer drive, Hannah has to take her everywhere which she finds difficult. Hannah lives approximately 40 minutes away from her mother and driving back and fore everyday has taken its toll on Hannah's career. Hannah was a peripatetic music tutor but had to leave her job to take care of her parents, as her Dad was ill too. Hannah is currently having some renovation work done on her house; once this is completed, she hopes that her mother will come to live with her to ease the travelling pressures and to give herself more time to do the things that she enjoys. Hannah feels she is more responsible now; previously, Pat would check up on Hannah but now that is reversed, and Hannah finds herself checking up on her Mam.

Pat and Hannah are mother and daughter and their data collection was conducted in Pat's living room. They stayed together whilst narrating their stories. Pat remained quiet throughout Hannah's narratives while Hannah offered her mother occasional assistance. Pat spoke at length about her experiences, but Hannah was not so open with her narratives. Many of Hannah's answers were short and to the point, despite probing for more information, Hannah was reluctant to give it.

Pat had been living with her dementia diagnosis for 9 years prior to her participation in the study. She had patches for her dementia, instead of taking oral medication, and was convinced that the patches have prevented her dementia from deteriorating. Pat had noticed that she was no longer able to do certain things around the home but that has more to do with her other health conditions than her dementia. For example, she can no longer hoover the house because of a fracture at the base of her spine.

Pat was aware that Hannah had sacrificed a lot to take care of her; Hannah had stopped working as a music tutor, stopped training guide dogs, no longer went to yoga classes and did not spend time with her friends anymore. To try and alleviate the pressure on Hannah, Pat had agreed to move in with her after some renovations are done to Hannah's house.

Unlike Geraint, May and Bethany, who had husbands or siblings to support them while caring for their parents, Hannah had no one. She was not married and had no children or siblings to help her take care of her mother. There was no one to share the responsibility with; but Hannah felt that she was lucky that her mother's condition has not deteriorated much over the last 9 years.

Several people within Pat and Hannah's extended family have had dementia and all became aggressive towards the end. This had led to Pat being worried that she may also become aggressive towards the end of her dementia journey; as a result, she had made Hannah promise to find her a care home if she does become aggressive as she did not want Hannah having to care for her then. Pat said *"I've told Hannah if I do get any worse, then push me in a home out of the way. I don't want her to go through what I went through with my mother and what we went through with my grandmother, you know, it was hard, very hard going".*

5.2.10 Rose

Rose

Rose was born in Bradford. Shortly after her birth, her mother died from the complications she experienced during labour. Rose’s biological father could not raise a child without his wife and so his brother, Rose’s uncle, adopted her and raised her as his own. It is only in recent years, since Rose’s adoptive father has had dementia, that she found out about this.

Rose left school when she was 14 and began working as a printer’s assistant. It was here that she met her first husband, and they had 3 children together. After raising her children, Rose returned to work as a cleaner. Rose and her first husband divorced, and Rose remarried. Her second husband was not a nice person and Rose had to relocate to Wales to escape him and took early retirement.

Rose had a car accident a few years ago and had severe whiplash. While at a physio session, she asked the physio if the accident could have also caused her speech to change and her memory to begin failing her. The physio did not think the two were related but referred Rose elsewhere to have this investigated. After vigorous testing in several different hospitals, Rose received a diagnosis of Alzheimer’s Disease and Primary Progressive Aphasia (PPA).

Due to the aphasia, Rose struggles to talk for long periods of time. She has not let this stop her though; she attends a few support groups for people with dementia and has also made several of her own life story scrap books which have been shown to dementia groups all over Wales as examples. She has recently started painting too. Rose makes her own greetings cards which she sells at the dementia groups with all proceeds going to the Alzheimer’s Society.

Rose has stopped going out with friends as she feels that they do not understand her condition and she quickly becomes overwhelmed in noisy areas. Rose does not drive and relies on public transport; if she knows the bus will be busy, she will turn around and go home as she cannot cope with the crowds of people.

Rose was the first of 4 participants who did not participate with a relative. Rose's family did not want to take part in the study, but Rose was interested; therefore, she participated alone. Rose's data collection took place within the living room of her flat. Due to Rose's PPA, regular breaks had to be taken throughout data collection as Rose finds it exhausting to talk for extended periods of time. Generally, after 5 questions, Rose would take a break. During the break, Rose would mentally prepare her answers to the following 5 questions.

Within the data collection setting, Rose was able to prepare what she wanted to say prior to being recorded; "real life" does not allow her the time to do this. Rose had a funny, friendly personality which was often masked by her Alzheimer's and PPA. She would often avoid social situations as she did not feel that she could cope with the demands of having to respond quickly within conversations. Similarly, Rose felt more comfortable going shopping if she knew that the shop is "*dementia friendly*".

> *"I'm trying to think of the shop up the street, they have got a big sign… they've got Alzheimer's friendly. I had to go in and get a kettle and because I saw that sign, I thought [sigh of relief], you know, you feel that you are going to get somebody who is going to be patient and things like that. So, it does make a lot of difference to have these big signs in the shops."*

Rose was the only participant who had completed her own "this is your life" scrap book. Rose had completed 3 when data collection was conducted and was working on her 4th. The scrap books are full of photographs, newspapers clippings and handwritten notes; Rose hoped that these books would help her remember who she was when her memory gets worse. Rose was a very creative person, in addition to the scrap books, Rose also painted and made her own greetings cards. The proceeds that Rose made when selling these products went to the Alzheimer's Society.

5.2.11 Gail

Gail

Gail is 81 years old and her husband has dementia. They have been married for 61 years and met whilst they were in their teens. Both were academics; Gail was a headteacher and her husband was a successful teacher and later lecturer. They have 2 daughters, both of whom live in England where they grew up. After retirement, Gail and her husband bought a house in South Wales; one with plenty of bedrooms and bathrooms for when the family visit. Gail and her husband got on well, did a lot of activities together and are both very kind and stubborn. She did all the housework and shopping while her husband dealt with all the family finances and house maintenance.

In 2011, Gail's husband was diagnosed with Parkinson's Disease and in 2014, he was diagnosed with vascular dementia. Gail's husband's mobility is poor due to the Parkinson's and his cognition is poor due to the dementia. Gail cared for her husband in their own home for as long as she could but eventually requested home care from social services. Her husband's poor health has had a devastating effect on the whole family as he was always the centre of the family.

Gail's husband now lives in a nursing care home which makes Gail feel like a single person again. Despite having 2 daughters, Gail feels like she needs to portray a successful, self-sufficient image to her family as she does not want them worrying about her. She finds support in her local religious group and runs a book club; members of this club also offer her a source of support.

Gail was originally going to participate with her husband, but his health deteriorated quickly, and he was unable to take part. Gail took a long while to decide if she wanted to participate in the study without her husband because she felt that she would embarrass herself by becoming upset. After some reassurance, Gail decided to give it a try and made herself a list of topics that she wanted to cover within her narrative. Gail did not use the prompts as the natural process of narrating her experience covered everything. Despite Gail's initial concerns about becoming upset, this did not happen during her interview.

Gail's daughters are teachers in England, and she knows that they are worried about her, but she does not want them to know how much she is struggling. She tries to portray an image of coping when talking to her daughters. Gail's main support was a religious group that she has joined since her husband became ill and a book club that she ran a few miles down the road. During the time of data collection, Gail had not been able to get to book club for many months due to road restructuring between her home and the location for book club; thus, isolating her from some of her friends.

For Gail, data collection was conducted within her husband's care home, in the staff training room. Gail and her husband had a close relationship; but like Kim, Gail also feels like her husband is no longer the man she married. Gail feels that her husband is gone, and she has been left with a shell that looks like him; *"there's this shell and him in there has gone, he is not there anymore, he is just not there, he has gone".* She now must rely on herself to manage the household, family and finances.

Like Darren and Louise, Gail remarked that she had found narrating her experiences of dementia to be therapeutic. It was nice for Gail to talk to someone about her true feelings and not try to maintain an image of coping.

Gail was initially optimistic about her husband's future life with dementia, hoping that he could go on as normal for as long as possible but that was not the case. Gail's husband deteriorated quickly, and she began to realise that the outcome of the dementia was not good, *"he could not survive it".* Her husband's care home was marvellous, but there were people with dementia at all stages of their journey. Gail felt that this shows the families what is to come for their loved one, and that scared her.

5.2.12 Sara

Sara

Sara’s mother has dementia. She is an only child and has always been close to her mother. They lived near one another and Sara would visit her mother most days. Her mother was in paid employment until she was 70 years old and has always been a very independent woman. Sara’s mother was a very smart woman, always dressed tidy and kept the house clean. Sara noticed that her Mam was wearing the same clothes for a few days, whereas before, she would have changed her clothes daily. She also noticed that her Mam had stopped preparing herself meals, stopped maintaining a clean house and her personal hygiene deteriorated. To try and help her Mam, Sara implemented a cleaner and arranged meals on wheels, but her Mam’s cleanliness continued to deteriorate.

Sara’s concerns for her Mam rapidly grew when she received a letter from the bank containing details of a loan that had taken out; her Mam had received a loan for £5000 and could not remember anything about it, nor could she remember where she had put the cash. Sara found the cash hidden in her Mam’s house and returned it to the bank explaining that she thought her Mam had dementia but the bank explained that they cannot refuse to give her another loan should she ask for it as she seems “of sound mind”. This is when Sara knew a diagnosis was essential.

Sara accompanied her Mam to the memory clinic and received a diagnosis of dementia. Sara also sought out power of attorney. Her Mam had several falls in her home, and it was decided that she needed more care. Sara found it horrible discussing the idea of a care home with the medical staff as she really wanted her Mam to go back home.

Sara was going to participate with her mother, but her mother was unwell at the time of data collection and, after recovering, was no longer aware of her diagnosis. Sara's data collection took place in her mother's bedroom within the care home. She talked at length about the relationship she had with her parents and how that had changed since her mother developed dementia and her father passed away. Being an only child, Sara had a lot of responsibility on her hands to care for her mother. She felt that she was always closest to her mother, and misses being able to confide in her, she does not have anyone else she can speak in confidence to.

Sara's mother had breast cancer several years ago which resulted in a mastectomy. Her mother has never let this bother her, but Sara felt that some of the carers may be disrespectful of this. Sara had to have serious discussions with the care home manager after she found out that a young male carer was bathing her mother. The managers assured her that male carers bathing female residents was completely normal, but Sara was not comfortable with it, especially with her mother's dementia and having one breast.

> *"I had a meltdown one week…I don't want a boy to bath my mother. I got really upset about that, I had to go in the office… I still don't think it is right, and especially with dementia… I know if she'd have been of sound mind, she would have been completely horrified…and the fact that she's only got one breast as well… what if he went out with the boys and he, and I'm not saying he would, but what if he went out with the boys and they were having a laugh "oh I washed this old woman the other day and she only had one breast"*

Sara had many examples of times when she felt the health and social care system had let her down. Sara tried to keep her mother in her own home for as long as possible and had implemented several methods to try and achieve this. Unfortunately, Sara's struggle to care for her mother became too great and her Mam had to relocate to a care home. Sara has since bought her parent's house and when taking her mother home to visit for the day, she did not recognise the house as once being her own. Sara became upset several times throughout her narratives as she struggled to accept that her mother has dementia and lives in a care home.

5.2.13 Pippa

Pippa

Pippa's Dad has dementia. She would describe herself as a "real daddy's girl" as she would do everything with her Dad, to the point where she would get ready for school, walk to the top of the street, meet her Dad and go to work with him for the day, selling cigarettes all over Wales instead of going to school. At the end of the day, he would drop her off at the top of the street and they would go home as if nothing had happened.

Pippa is an only child and worked full time therefore struggled to take care of her parents when they were both unwell. Her mother had bowel cancer, followed by breast cancer and was an alcoholic while her Dad was struggling with his memory and recovering from heart surgery. Pippa had difficulty getting her Dad to the memory clinic appointments as he was adamant that he did not have a problem.

Pippa's mother has since passed away and her relationship with her father has drastically changed; before he was the parent and she was the child, now it is like she is the parent, with all the responsibility that entails and he is the child. Pippa's Dad was beginning to get very agitated and very unsettled at home without his wife; therefore, Pippa was advised to find a secure dementia unit for her Dad to live in. Shortly after moving into the residential care home, her Dad was sectioned. Pippa has found that her Dad's friends have distanced themselves from him and no longer ask how he is doing. Pippa has no children and her husband does not understand why she insists on visiting her Dad when he cannot remember her being there. There have been times when Pippa has felt like she does not know what is going on with her father but the staff in the residential care home have been very helpful.

Pippa's dad was unable to participate in the study. The care home manager felt that he had the awareness of his dementia required to talk about it for research purposes, but Pippa felt that he did not. Her narratives were recorded in the staff training room of her Dad's care home. Pippa had participated in several advertisement campaigns within her Dad's care home and was used to explaining her experiences in front of a camera. She spoke openly and honestly about her knowledge, providing excellent stories to accompany her understandings.

Like Laura and Sara, Pippa tried to keep her parents in their own home for as long as possible. She stopped working to become their full-time carer but when her mother died, her Dad became very ill and she could no longer cope with the demands of caring for him alone. Shortly after finding a care home for her father, he was sectioned. In retrospect, Pippa agreed that it was probably a good thing because they managed to get his medication under control, but at the time, Pippa found the experience very traumatising for both herself and her Dad.

As Pippa was a *"Daddy's girl"*, she found it strange to swap roles; before he was the responsible adult and she was the child, now he needs more care and she had become the responsible adult. Like Laura, Hannah and Sara, Pippa is an only child, had no children of her own and her husband's lack of understanding of her need to visit her dad regularly meant that Pippa had to cope with living with dementia alone. She was very aware of friends who had cut off contact with her and her father because of his dementia; they did not know what to say and therefore would say nothing at all; *"his friends distanced themselves, and even now, nobody visits him…his friends will walk past me in the street and not even say hello".*

Pippa did not have a bad word to say about the care home where her Dad lives. In the absence of support from family and friends, the staff in the care home had become her support network. They provided answers to her questions and made her feel as much at home within the care home as her Dad.

5.3 Summary and Reflection

“It’s a people thing now, more of a people thing” *TONY*

All participants in this study are currently residing in South Wales and are white British. All are working class with most leaving education at fifteen years of age. Gail, Lynne, Pat and Hannah are the only participants with university level qualifications. The participants with dementia explained that they were part of a loving, supportive family with only Rob and Rose feeling a lack of support from their loved ones. Kim was the only family member who seemed to have a negative relationship with her loved one; all other family members gave the impression that meeting their loved one’s needs was at the forefront of their daily routines.

The aim of this chapter was to introduce the reader to the participants who were essential to this study. By providing detailed portrayals of the participants’ life histories, the reader should feel a sense of “knowing” the participants (Holloway and Freshwater, 2007). This link between the past, present and hopes for the future is essential for narrative research (Elliot, 2005), yet it is difficult to draw themes from the participant’s personal life histories as they are unique to the person.

The information provided in this chapter is drawn upon throughout the remainder of this thesis. The following chapter contains the findings for the people with dementia who participated in this study. Key themes have been drawn together from the narratives provided by the participants using a combination of Burnard’s (1991) and Colaizzi’s (1978) analysis frameworks.

Reflection on the Chapter

I personally felt that this chapter was essential to capturing the essence of this thesis. The participants are central to this entire study. They are recognised as unique individuals with valuable information to share. I needed to ensure that the readers of this thesis also understand this. As this chapter does not follow the norm for a PhD thesis, I had to justify its place. I now believe that anyone who takes the time to read this, understands why it is an essential element.

Writing this chapter was tough as I wanted to give accurate, yet anonymised, details about each participant that offered explanation for their experiences of life with dementia. I wanted it to be purely descriptive and give credit to the life lived by each participant. Limiting myself to one page per participant was hard, as I have so much information about them that I want to share with the reader.

I have offered some insight into the individual interview settings as I think this can sometimes explain why certain information was, or was not, shared. For example, Tony was holding back a lot of information to prevent Beverley any upset. Similarly, Darren dominated Louise's interview. A more experienced interviewer may have felt confident enough to ask them to step outside the room, or let their spouse speak instead, but I am not an experienced researcher and did not feel comfortable requesting this. Similarly, the person with dementia had requested that their loved one stay with them for support, and who am I to tell them otherwise in their own home? They may have decided not to take part at all if I were to make the situation uncomfortable by not respecting their wishes. Whilst this dual interview may have hindered the data collection, in some cases, it did help when the spouse was able to prompt the person with dementia. It was also interesting to note the dynamic within the relationship; the vulnerabilities of the person with dementia that were being protected by their spouse dominating the conversation.

Furthermore, throughout these findings' chapters, I echo the terminology used by the participants. For example, using "Mam" instead of mother. Given the personal nature of life story work, it worked well to humanise the participants' data.

CHAPTER 6 RESULTS: PEOPLE WITH DEMENTIA

"Pray, do not mock me…I fear I am not in my perfect mind. Methinks I should know you and know this man; yet I am doubtful for I am mainly ignorant. What place this is and all the skill I have. Remember not these garments nor I know not where I did lodge last night. Do not laugh at me."
(William Shakespeare's King Lear; Act 4, Scene 7)

6.1 Introduction

This is the second of three findings chapters for this thesis, and it presents the results for the participants with dementia in this study. The themes which arose from the analysis conducted on the interview data are presented individually and are supported with extracts from the participant's narratives and their personal histories as outlined in the previous chapter. The four themes identified within the analysis for people with dementia are identity, resilience, acceptance and isolation. Within each theme are several subthemes, as highlighted in Table 13, these will be discussed in turn.

Table 13: Themes and subthemes for people with dementia

Identity	**Resilience**	**Acceptance**	**Isolation**
Former self. Threats to accepting new self. New sense of self.	Maintaining normality. Remaining positive. Participating in meaningful activities. Being optimistic.	Disclosing their diagnosis. Good support systems. Being with people in a similar situation.	Negative reaction from family and friends. Being avoided. Problems communicating. Burden. Struggling to cope.

6.2 Identity

Identity is a person's sense of self defined by a set of psychological, physical and interpersonal characteristics (American Psychological Association, 2020). There were three subthemes identified within the identity theme; they are former self, threats to adapting to new self and new self. Identity is a topic covered regularly within dementia research, as indicated within the literature review. The participants in this study were not welcoming of their new sense of self, as their new identities were forced upon them by the symptoms of dementia. The participants were aware of the changes that they were experiencing, and this caused them a lot of negative emotions about themselves and their situation. They struggled to adapt to their new identities as feelings of frustration and not understanding their diagnosis clouded the acceptance process.

6.2.1 Former self

Several of the participants with dementia felt that having dementia would not impact upon their sense of self. These participants did not understand why their identity could alter as a result of the dementia.

> *"I thought well if I'm Nancy now, I'm going to be Nancy then… you're still the person that you used to be just you're not as clever as, or you can't remember things like you used to".*
>
> *NANCY*

While Nancy feels that she is still the same person that she used to be, Lynne struggles to accept that she is still the same person as she has lost so much of herself. Her confidence and independence have gone in recent years and she desperately wants them back.

> *"My good friend has said don't be silly…you're still the same Lynne. And I can understand that, but it takes a bit of accepting because part of you is gone and you're losing that part that you want desperately to have"*
>
> *LYNNE*

For people with dementia, feeling that they have lost their former sense of self can be a difficult sentiment to comprehend. Whilst Nancy feels that she is still herself, despite her forgetfulness, Lynne feels that she has lost a part of her identity because of her dementia. This could be related to by most participants, particularly when reflecting on how they used to be compared to how they are now.

6.2.2 Threats to accepting new self

Within the life stories, the participants' past careers were identified. Some of the participants had worked directly with people who had dementia throughout their careers and understood the nature of the condition. For these participants, their reaction to receiving a dementia diagnosis was informed by their past experiences.

> *"I think because I had nursed so many people with dementia and I was expecting to be like them, we used to have some pretty bad dementia patients and I think that had a lot to do with it and older people would say she's gone a bit funny you know, and I was holding back from it, I didn't want to talk about myself.. I think because we had so many dementia patients that I felt well why is this happening to me now but it's happening to loads of people you know…I just felt that it wasn't happening to me, but I knew it was… I felt devastated"*
>
> *LYNNE*

Similarly, Louise struggled to come to terms with once being a carer for clients with dementia and now she is the client needing a carer for herself. This change of role elicited a negative reaction to her dementia diagnosis.

> *"Like shit…because I look after the clients and I don't want to be told that I'm one of those"*
>
> *LOUISE*

Several of the participants in this study explained that they did not know what their diagnosis meant. Many did not understand the difference between the various forms of dementia and often referred to "normal dementia" and Alzheimer's disease or “normal dementia” and vascular dementia. If a person does not understand the diagnosis that they have been given, then they cannot fully accept that as a part of their new identity.

> *“She [consultant] said “oh you’ve only got the vascular dementia”, which I thought was a lot easier, a lot better the way she said it to me, but I think it’s just as bad as ordinary dementia. And I still don’t know what the difference is between ordinary, vascular dementia and just plain dementia”*
>
> *NANCY*

Similarly, some of the participants claim that they have never encountered dementia prior to receiving a diagnosis themselves. Historically, there has been little coverage within the media about living with dementia as it was rarely discussed and typically associated with old age. Despite dementia being portrayed within media more in recent years, a few participants did not understand what dementia was until it became a part of their world. David explains that he had not heard much about dementia prior to receiving a diagnosis himself.

> *“What is dementia? That’s what I try to work out? It is just loss of memory or is it other things you know? And like I say, you don’t see a lot of it, you never hear a lot about it to tell the truth. I hear a lot about it now because I’m involved in it”*
>
> *DAVID*

A person cannot adapt to their new diagnosis label if they do not understand what that label means. This is irrespective of the diagnosis a person receives, whether it be dementia or schizophrenia. Central to accepting their changing identity, as a person with dementia, is understanding it. Lynne’s previous work as a nurse allows her to understand how dementia progresses and pre-empt what is to come for her and her family; this leads to Lynne trying to reject her diagnosis and convince herself that this is not happening to her. Whereas Nancy and David do not understand their dementia diagnosis. Nancy was led to believe that vascular dementia is not as bad as ordinary dementia and David struggles to figure out if dementia is just memory loss.

6.2.3 New self

All participants in this study explained how they were often reflective, comparing their past self to their new self. This reflective process was typically accompanied with negative emotions and the participants wishing that things would go back to the way they were. June was a very social person when living at home, she won an award for her volunteering efforts within the community; now June feels lonely and stays in her bedroom in the care home most of the time.

> *"I did love to volunteer for anything that was going on… I am more or less in here [bedroom] all of the time you know… Lonely, but I am getting used to it. I don't go downstairs very often, no, I don't go down at all really unless I've got to but I don't know what goes on downstairs you know, I don't know if people get together or not"*
>
> *JUNE*

Like June, many other participants had noticed that their lives were changing and felt unhappy about it. The participants rejected their new selves and felt very unhappy about the way things are changing.

> *"I'm miserable for starters, I'm not happy like I was and I feel poorly every day which I don't know whether it's due to the dementia or the tablets I'm taking…I've slowed down, my whole body has slowed down…It's not a nice feeling"*
>
> *LYNNE*

Some of the participants explained that the changes that had occurred as a result of their dementia often impacted on their families. They felt that their family had come to dislike the person they had become. Relationships that were once strong were now being tested by the person's dementia and reflecting on the loss of "great relationships" led the person with dementia to feel hated by their loved ones. The people with dementia also noted that their families act differently towards them. As previously mentioned within Rob’s life story, he feels that Kim hates him because of his dementia. She has changed the way she acts around him and knowing that he cannot do anything about it makes Rob feel awful.

> *“She [Kim] thinks that I’m not the man that I used to be, which I’m not, I know but I can’t do anything about it. If I could change it, I would. I would love to go back to the way I was and that sort of thing but I don’t know, I just can’t do it, it’s not going to happen and I don’t know what to do about it. There’s nothing I can do about it. Kim has changed a lot towards me because of this I think, I don’t know why... Whether she hates me for it, I don’t know, because I’ve got it [dementia] and she hates me, I really don’t know but she has changed a lot. And that, I regret, we had a great relationship previously but now I always say the wrong things”*
>
> *ROB*

Despite not fully understanding their diagnosis, the diagnosis label of “dementia” impacted upon the way the participants viewed themselves, having a detrimental impact upon the person’s self-esteem. For Nancy, the label a “patient with dementia” has become her main identifier, or her “master narrative” (pp 38); she feels that nothing else about her is worth knowing.

> *“I don’t feel that I’ve got any worth at all and I don’t feel anything about myself is worth knowing. As far as I’m concerned, I’m just Nancy, another patient with dementia”*
>
> *NANCY*

Some of the people with dementia who participated in this study explained that they often compared themselves to others they know with dementia. Whilst undertaking this comparison, they would often conclude that they have no similarities with the other person. This sometimes led them to question their diagnosis or forget that they have a diagnosis of dementia too. May lives in a care home with many other people who have dementia; during her narrative, she compared her ability to those around her. May's dementia is still in the early stages; therefore, she often forgets that she has the same diagnosis.

> *"There's other people, they're not so [points to head] as me. Some of them are really bad. It's a pity with some of them. And I forget sometimes that I have got a bit more up here [points to head] than them you know. But it is sad to see some of them...The ladies I'm with, they're all a little bit [points to head], got something wrong with them. And sometimes I forget I have too"*
>
> *MAY*

The participants expressed a lot of negative emotions regarding their lives with dementia. For Nancy, her struggle to think of things has caused her to feel that she is an empty shell.

> *"You just think of yourself as an empty shell because I can't think of anything else to say about it, I'm just an empty shell because my body feels completely empty and especially up there [point to head] and when I'm trying to think of something and I can't think of it"*
>
> NANCY

Similarly, Lynne struggles to think of things and feels that her "*head is in the shed*". Lynne wishes that someone would flick a switch and make everything better; accepting that will never happen is hard to live with.

> *"Dreadful and it makes me feel dreadful now that I can't, I don't feel myself, I don't. I do say that my head is in the shed because it is. You can't think the same and as much as you try, it's hard to think because this isn't me. I just wish a light would click on and say you're better, but I know that that isn't going to happen, and I know I've got to understand that but it's pretty hard to live with"*
>
> LYNNE

Combined with feeling negatively about themselves, frustration was common amongst the participants. Frustration with themselves for initially developing dementia and then for their forgetfulness. Louise was angry with herself for developing dementia. Her first husband had told her some cruel things about herself and when she received her dementia diagnosis, she felt that all the cruel things her first husband had said were true.

> *"Tearful. Angry. Why me? And then all of the things that my ex-husband said I was, horrible things, I felt like that. I just felt that this has happened because of what I've done. But I had a marriage like that, it was like everything was my fault, so this was just another thing that was my fault"*
>
> *LOUISE*

Similarly, Rose also felt frustrated and angry at herself because of her memory and Primary Progressive Aphasia struggles. Always being a doing person, Rose struggles to maintain this.

> *"Frustrated. It [dementia] makes you, it gets you angry with yourself and frustrated and you want to basically bang your head against a wall sometimes or bang your feet because you can't really do anything, it's just part of where you're at. I've always been a doing person and to want to keep doing things, it's hard but I keep trying my best"*
>
> *ROSE*

Alongside the negative feelings experienced by the participants with dementia, they had also noted how their temperament had altered since developing dementia. In particular, almost all participants explained that they had become less patient.

> *"Patience, that's what is starting to lack"*
>
> *DAVID*

The aggression associated with a lack of patience was discussed by Nancy, who felt that her attitude towards her husband has ruined their marriage. Nancy can sometimes say nasty things to her husband in moments of anger.

> *"I know it has ruined our house and ruined our marriage because I'm so nasty with him now"*
>
> *NANCY*

A further change in the marriage dynamic was noted by many within this study, as Rob has previously explained. Within the marriage dynamic are marital roles. Marital roles are central to a person's identity and when these must be altered because of the dementia, it can leave the person with dementia feeling worthless and upset.

> *"Not very happy about it, not very happy one bit. Because I see it this way, when I married Trystan, we were a wife and a husband, and we had children. Now I don't feel that way anymore, I just feel that Trystan is a man and I'm a woman because what I should be doing, now he does it and what he does, he does himself as well, he does his own life for himself and then he has to do my life for me because I can't do it myself. So, I don't like it one bit… He's a good cook…But that's my job, when I married him, that was my job, to look after him and the house and to have a family if you were lucky enough to and keep on going but I'm not going to keep on going am I, I'm just going to be like this all the time. Like a blank, it's like playing dominos, he's a double six and I'm a blank, nothing at all, no number or nothing on me and that's very upsetting."*
>
> *NANCY*

June feels that the quicker the person accepts their diagnosis, the better. Feeling nervous or upset will continue if they do not accept their diagnosis and move on.

> *"If it has happened [receiving a dementia diagnosis], and you're nervous about it, it means that those nerves will go on the rest of your life, and you know, you have got to try and avoid that kind of thing. So, I wouldn't want to be nervous about it, I just accepted it and, and I don't worry that much about it"*
>
> *JUNE*

People with dementia have to adapt to their new identities, as a person with dementia. But not only that, they also have to come to terms with the behavioural alterations and changes in role that go hand in hand with dementia. It can be difficult for a person with dementia to allow marital roles and responsibilities to change; as Nancy said, she used to share marital roles with Trystan but now Trystan does everything. This upsets Nancy and makes her feel like she is nothing. All the people with dementia in this study explained that they disliked the person that they had become, the person that their dementia has turned them into.

6.3 Resilience

Resilience is the ability to adapt well when faced with adversity (APA, 2020). For people with dementia, being able to adapt to their new identity can be challenging. The participants in this study explained several ways in which they have adapted to live with dementia. The subthemes within this theme identify the different ways in which the participants have demonstrated elements of resilience in their lives by maintaining normality, remaining positive, participating in meaningful activities and being optimistic.

6.3.1 Maintaining normality

Some participants explained that they were trying to maintain normality by continuing to pursue hobbies that they have enjoyed throughout their lives. Jigsaw puzzles, word searches, baking and reading are amongst some of the hobbies that they are trying to maintain. All explained that it is a struggle to maintain old hobbies with dementia as they cannot concentrate as well as they used to.

> *“I tried to read a book the other day. I was a great book reader and I started… I can’t seem to get it to concentrate. I keep on reading the same line all the time”*
>
> *Louise*

Similarly, Rob has a small holding with some animals who he still tends to daily. He used to go there twice a day but now only once as he is afraid of being there in the dark due to his illnesses. He knows that as his dementia progresses, he may have to get rid of his plot of land and animals.

> *"Chickens, ducks, geese and goats. I've got them on a bit of land. Five minutes down the road. I've got two fields… I take my time. I used to go twice a day but I only go once now. Night-time is tricky for me with the falling over and that. I haven't fallen over for a long time but yesterday I fell over for the first time in about three weeks which isn't bad so. Yeah, it's not a problem at the moment because I just go out there, throw out some corn. I feed the goats first because they are out all day and all night, they've got a shed to go in out of the rain. And then I go and feed the chickens and ducks and the goose, I've got one goose, and collect the eggs... So I've got thirty four chickens, twelve ducks…The farming of them is easy enough but like I say, I will have to give it up some time. It's sad because it's my hobby. I'll have to think of something else to do"*
>
> *ROB*

Both Rob and Louise explain that they now struggle to maintain old hobbies. This was also true for May, Pat, David and Beverley. Unlike the other people with dementia, Pat struggles to maintain old hobbies because of her physical health more than her dementia.

> *"I do crosswords and I watch the game shows on the television…I have always enjoyed doing crosswords. I used to enjoy doing jigsaws, but I find that sitting by the table doing the jigsaw, my back gets painful…But it isn't only my brain, it's my physical condition that doesn't help me…It isn't only the Alzheimer's, it's a little bit of everything [all of her health problems causing her troubles]. But its old age isn't it, that's what I'm putting it down to. I mean I'm eighty-five"*
>
> *PAT*

A determination to maintain any element of normality prior to their dementia diagnosis demonstrates resilience. They are all aware that they cannot perform these hobbies the same as they did previously due to their ill health, not necessarily their dementia, but still they try. There may come a time when they cannot participate in their hobbies at all because of their health and, whilst this saddens them, they are realistic about the possibility of it happening.

6.3.2 Remaining positive

Despite participants with dementia explaining that they struggled to come to terms with their new identities while maintaining old hobbies, most manage to remain positive. Several explained their emotional response to receiving a diagnosis of dementia. Mostly, the participants explained that they were happy to have received a diagnosis as it was central to receiving support and after it had a label [dementia], they could deal with it.

> *"I was glad to go really [to see the doctor about her memory] because I knew that there was something wrong and I knew that they were finding treatments, so I thought let's knock the nail on the head and go and see him. And I was glad that I went. I was disappointed with the results, naturally, but at least I thought, well at least they can do something about it now"*
>
> *PAT*

When June received her dementia diagnosis, she did not think her memory was bad enough to have dementia, but then felt that she was one of many people who have a dementia diagnosis. June also accepted her diagnosis as she felt that she cannot do anything about it, and she would never be able to stop it.

> *"I just took it as well lots of people have so you know if I have got it, it doesn't really matter, but I didn't think I was as bad as that. That is probably the way I looked at it because you know you can't do anything about it, you can't stop it, so I just had to accept it"*
>
> *JUNE*

Not all the participants were as accepting of their dementia diagnosis (Lynne, Louise and Pat). For those who had worked in health care settings, receiving a diagnosis of dementia was devastating.

> *"Devastated [with her diagnosis]. I couldn't believe it. It was always something we would say please God, I don't want that"*
>
> *LYNNE*

Remaining positive about receiving a diagnosis of dementia demonstrates resilience within the participants. Accepting that a lot of people are in the same situation offered comfort for June while Pat acknowledged that a diagnosis was essential for "*doing something about it*".

For May and June, the only two participants who live in a residential care home, they must accept that their lives are now lived within their new homes. For May, who made the decision to move and chose her own residential care home, accepting that this is now home was easier for her.

> *"I mean it's not like your own home. But I can't be on my own, so this is the best thing… on the whole, it is very good. Food is good. The staff are wonderful. Very caring… I am spoilt. Yep, when I look at other people, I think I have got nothing to grumble about. I am lucky. And it's company"*
>
> *MAY*

May is positive and accepting of her life within the residential care home. The same cannot be said for June. June does not like living in a residential care home and desperately wants to go home.

> *"I have sort of accepted it now but still want to go from here back home. But I don't see that happening. It's got to happen"*
>
> *JUNE*

Geraint explained that June has tried to leave her care home a few times and has become aggressive when the care staff tried to stop her. Sometimes June forgets that she lives in a residential care home and tries to go home with Geraint when he visits. June's daughter and social worker decided that June had to move into a residential care home and her daughter chose which home. This may be an influencing factor in the differing acceptance levels between May and June regarding life within a residential care home. Remaining positive and making the most of their time there demonstrated elements of resilience.

6.3.3 Participating in meaningful activities

All the people with dementia who participated in this study regularly participate in meaningful activities to keep their brains active. "*Use it or lose it"* was a phrase used by several of the participants when explaining their hobbies. Nancy tries to use her brain as much as possible. She plays bingo five times a week and enjoys doing a wordsearch.

> *"The more you use it, I was always told, use it or lose it, so I said I try as much as I can to use it. Even if it's only for bingo because then I know I am doing something to keep my brain occupied"*
>
> *NANCY*

Maintaining old hobbies was sometimes a struggle for the participants but several explained that they still try to crochet, knit or cross stitch. If they keep it simple, they can still do it.

> *"I do a little bit of reading. Sometimes I do a bit of sewing and I have done a bit of knitting. But it's hard, the time just goes"*
>
> *MAY*

Participating in old hobbies was easier for the participants than learning new ones. Several of the participants had tried to learn a new instrument since being diagnosed with dementia, and they all found it difficult.

> *“[Learning to play the piano] thought it would be a challenge that I could learn something by but then when we try to put it into practice, it became more and more frustrating…it really upset me”*
>
> *LOUISE*

Whilst Louise is trying to learn piano from scratch, Rob used to play guitar in a band when he was younger but stopped when his second marriage broke down. For Rob, not being able to remember how to play can cause him to become upset because he used to be pretty good.

> *“I’m having guitar lessons… two a week, Kim pays for them, it’s a treat and it’s good for me… The only problem with that is that I forget. I get it written down all of the time, which is brilliant, but I need the paper in front of me so I can read it because I can’t remember the chords which is terrible”*
>
> *ROB*

Other hobbies for the participants included gardening. David originally joined the dementia support group for gardening, but the weather was poor for several weeks resulting in David joining the curling team. The gardening group was cancelled because all the gardeners had joined curling. The only place David can do gardening is his own garden. This provides enjoyment for David but also an escape from his wife.

> *“The garden, I like the garden, that’s one thing I would like, a bigger garden, nothing too big because we’ve got that thing round by the side and I think there’s three trees there, they are only miniature trees I think but we have had apples off them, we’ve had grapes, but we haven’t had any nectarines yet but tomatoes, potatoes, beans…And it’s a hideaway right because she moans…it’s just somewhere to get away from the wife that’s all”*
>
> *DAVID*

Whilst the participants acknowledge that they try to keep their brains active with different hobbies, some of the participants also discussed how they try to save some of the brain energy for more important tasks. Tasks that are not essential are often put to the side to save the brain from getting tired. Cooking is one of these tasks. Over time, some of the participants have forgotten how to cook different meals and now have convenience meals; this saves the brain energy for other tasks.

> *"I feel I am ok with other things at the moment, so I don't do a lot of cooking... It is not so much lazy... It's a bit like brain saving instead of brain draining"*
>
> *ROSE*

The participants tried to keep their brains active, despite their dementia sometimes making it tricky. Use it or lose it was a phrase used by all participants when explaining why they push themselves to participate in meaningful activities. Rose prioritises jobs so that she saves her brain energy instead of draining it, while Nancy tries to use her brain as much as possible. Both Louise and Rob tried to expand their skill set and learn new instruments but the forgetfulness that comes with their dementia has made it very difficult and, at times, upsetting. Nevertheless, they keep trying.

6.3.4 Optimism

Optimism or hope for the future was common amongst the participants. All the participants said that they would like to remain happy and surrounded by people they love for the remainder of their lives.

> *"I would just like to be happy and all my friends, I've got around me, I'm not on my own"*
>
> *BEVERLEY*

Remaining happy was central to all participant's wishes for the future. Similarly, they all spoke about their dementia deteriorating but hope that keeping their brain active would help delay the deterioration. Rose acknowledges that everyone's dementia journey is different but hopes that by remaining active, she can slow down her own deterioration.

> *“I am hoping that I don’t get too much worse. Everybody goes at a different speed on the journey and I am hoping, because I keep myself busy, that it will help to keep the grey matter going longer. And the longer that I keep going, the older I get, it will be better because then I will be as best as I can at an older age… People that have lost it, they don’t understand things, I’m just hoping that I don’t get there too quick”*
>
> *ROSE*

Similarly, Pat hopes to remain as she is for as long as possible. She is hoping to live as long as her mother providing that her dementia stays stable. For Pat, getting aggressive like her husband, mother and grandmother, would be worse case scenario and she has made Hannah promise to find her a residential care home if she does get like that. To try and ease the pressures on Hannah, Pat has agreed to live with her.

> *“I don’t get any worse, that’s my hopes. I mean, my mother lived until she was ninety-five, so I’ve got another ten years to go. As long as I don’t get any worse, I don’t mind, but I’ve told Hannah if I do get any worse, push me in a home out of the way. I don’t want her to go through what I went through with my mother and what we went through with my grandmother, you know, it was hard, very hard going. And that’s what I feel, she wants me to go up there and I think well if I do go up there, at least she won’t be back and fore”*
>
> *PAT*

Like Pat and Rose, David hopes that he does not get any worse. David’s main concern is losing his independence; he does not want to get to a stage where he cannot do things for himself.

> *"If it stays like this, I will be brilliant I will. That's one thing I don't want to happen is when I can't do something for myself, I don't want that"*
>
> *DAVID*

Not all the participants with dementia had an optimistic outlook on the future. Some were aware that their family were already struggling with their dementia and as the dementia progresses, things would only get harder for them. The people with dementia were aware of this and it scared them. They do not want their dementia to get worse and put more strain on their family relationships.

> *"The scary thing is, I don't like the way it's going and how it's going to go…I don't really want Kim seeing me like this, I don't want her to see me like this, I don't want her to see me get worse, you know, because I know how much I've changed now and she's finding it hard and when I change more, I can't bare how she's going to be and I don't know what to do, there's nothing I can do. Kim says that I'm not the same person she married, and she gets upset about that very much. Which I can understand. I mean the way I was told regarding that, as it goes on and on, I'm not going to know much about it. I'm going to go do-lally or whatever it is and so I'm not going to know much about it. It will all be down to Kim. I don't know how she is going to cope. I think she's finding it hard now to be honest, I think I would if I thought there was something wrong with Kim. I just think, I feel sorry for her and my family because, like I say, I'm not going to know much about it, I'm going to forget, and I might end up forgetting to eat and certain things"*
>
> *ROB*

Remaining positive about the future when they know things are already bad and going to get worse can be difficult, as Rob explains, but very few of the participants felt this way. Most of the people with dementia were optimistic about the future and hoped that their dementia would not get too bad. Remaining happy and connected to their loved ones was important to all participants as this allowed them to feel that they had been accepted as a "person with dementia".

6.4 Acceptance

Acceptance is actively embracing one's experiences as a way of moving forward and leading a fulfilling life (Herbert and Brandsma, 2014). The need to be accepted is central to human life (DeWall and Bushman, 2011). Acceptance for the participants with dementia encompasses a desire to be accepted as a "person with dementia" by family and friends. The subthemes within this theme are disclosing their diagnosis, good support systems and being with people in a similar situation.

6.4.1 Disclosing their diagnosis

The participants with dementia were aware that there exists a lot of stigma around a dementia diagnosis and felt that people would treat them differently if they knew; as a result of this, many of the participants did not want to tell people about their diagnosis.

> *"I didn't want to tell anybody when I was diagnosed, I really didn't. I didn't want to tell anybody which is silly because I haven't done any wrong, I haven't done any harm to anybody. It's just unfortunate that it's us and not them you know. But I didn't feel good about it at all and I thought that I can't talk to people, people are going to treat me differently"*
>
> *LYNNE*

Only three participants were comfortable telling their friends and family about their diagnosis. In Rose's case, it had been her friends who were encouraging her to seek help for her memory deficits and telling them the outcome of the appointment with the consultant (receiving a dementia diagnosis) only confirmed their suspicions. Whilst they did not say "we told you so", they were thankful that Rose had listened to their advice and sought out a diagnosis for her memory problems.

> *"I think my friends, it was a bit like, well it wasn't like I told you so, but it was like thank goodness, at least we know now"*
>
> *ROSE*

Similarly, Beverley did not mind telling her friends about her diagnosis as she thought it was only fair that they were told. It took Beverley a while to accept that she has Alzheimer's disease, but once she had got her head around it, she felt comfortable telling people.

> *"I have told most of my friends, well it is only fair to let them know"*
>
> *BEVERLEY*

Alternatively, June felt that her diagnosis was her business and would only tell people if she wanted to.

> *"It was my business so you know, if I wanted to tell them [about my diagnosis] I would and if I didn't, I didn't do it"*
>
> *JUNE*

Feeling that their family and friends may treat them differently because of their dementia influenced a person's willingness to tell people about their diagnosis. Lynne worried about people treating her differently because of her dementia and was subsequently reluctant to tell people. Both Rose and Beverley were comfortable telling their friends as they feel close relationships to them and thought it was only fair that they knew. Similar to June, Lynne and David also decided that their diagnosis was their business and they would only tell people if they wanted to. Being accepted by their friends was a central element of their disclosing preferences.

6.4.2 Good support systems

Some of the participants in this study talked about the support they have received from family and friends in depth. Having their family's reassurance that everything will be ok seemed to help the person with dementia accept their situation and the changes that were occurring within their lives. Most of the participants explained how their relationships with other family members had been strengthened by their dementia diagnosis; for example, Rose's son is now much more involved in her life and is always considerate when planning activities with her, such as going for a meal.

> *"My son in Yorkshire didn't used to come down very often but since this, he comes down about three times a year… is there anything you want? And he didn't used to be like that, but he phones up and he wants to know everything, so he's changed a lot, which is good. So, you know, out of a negative thing, comes a positive. He's coming down this weekend actually so he'll take me somewhere to eat but he always knows somewhere that's quiet because if I go in a café and there's too many people, I won't hear what you're saying and I can't be relaxed. So, you know, that's come out of it"*
>
> *ROSE*

For some, the diagnosis of dementia had resulted in their family distancing themselves, leaving one person to support the person with dementia; this happened to Nancy, whose family do not bother with her, leaving her husband Trystan to be her only source of support. Nancy believes that Trystan's support is keeping her alive.

> *"Trystan's support, without that I think I would have been dead long before now… Without him I think I would have been dead a long time ago. Because as I say, I've had no support other than what I've had off Trystan"*
>
> *NANCY*

Pat has a lot of support from Hannah but sometimes, she must insist that her daughter goes home and lives her own life as Hannah tends to spend more time with her mother than with her friends. Pat knows that Hannah feels conflicted between being with her mother and being in her own home; to try and reduce Hannah's conflicted priorities, Pat spends a few days a week in Hannah's house and has agreed to move in with her.

> *"She's [Hannah] very good to me. I couldn't manage without her. I couldn't cope without her. I had to be adamant about her going back home because she was down here all the time, day and night, and I thought well*

> *she's missing out, she wasn't seeing her friends… Hannah does such a lot…Hannah, she does all my shopping for me and she does a lot of things for me… Hannah reminds me [about appointments] because she takes me… So, she's had a stair lift put in her house so that if I feel like going up there for a couple of nights, I can go up"*
>
> *PAT*

Being treated well by the people around them was a central element of participants' narratives. Having friends who treat them nicely was present within several of the participant's stories. For Nancy, this means having friends who still value her as a person, and do not treat her as someone with dementia. Furthermore, the people with dementia felt most comfortable with those who knew their diagnosis and accepted them regardless. They were aware that not everyone would be accepting and supportive of their diagnosis and value those who still treat them the same.

> *"I tend to bother with the people that I know, know that I have got the dementia and know me other than being a dementia patient. I'll talk to you because you treat me nice and I treat you nice. But I mean not everybody feels that way"*
>
> *NANCY*

Having a good support system of family and friends was present within all the narratives for people with dementia. Being around people who accept them, and their dementia makes the people with dementia feel valued and loved. The participant's lives would be quite different if they did not have someone to help them, particularly Nancy, who relies heavily on a wheelchair; without her husband's help and support, Nancy believes that she would have died long ago.

6.4.3 Being with people in a similar situation

For human beings, the need to feel a sense of belonging is accompanied by affiliating with others in a similar situation and feeling accepted as part of their group (Berry, 2015). This is true for the participants with dementia in this study. Most of the participants explained that they take part in dementia support groups as they enjoy being with people in a similar situation who understand what they are going through. These support groups take many forms, from choirs to curling, and offer an escape where they can just be themselves, not a person with dementia. The organisers of the groups maximise the visual cues for the attendees so that no one feels uncomfortable if they forget a name or the song words. Nancy enjoys the groups because everyone is in the same situation.

> *"Brilliant because everybody was on the same level. They either had dementia or vascular dementia and we just all mixed in you know. Not for us to forget names, they used to pin our names on us so people wouldn't forget the names and make it uncomfortable for them … And we'll go there, and we had a song and we would all sing it"*
>
> *NANCY*

All the people with dementia who attend support groups expressed positive emotions regarding their experiences at the groups. The groups are so helpful to the mental health of the participants, that many attend several groups a week and wish they could go more often.

> *"They are wonderful the people there. You come out feeling, I wish I could go again. It is lovely.*
>
> *Tony: You come out of there with a restoration of your faith in human beings"*
>
> *BEVERLEY*

Attending support groups regularly has led to the participants developing strong friendships with others who attend. The relationships that are built during the dementia support groups leave people with dementia feeling positive about their lives. For Rose, the people who attend the support groups have become family to her.

> *"The singing group that I go to…I feel that they are part of me, and I am a part of them. Because we're all, maybe different stages, it doesn't matter*

> *because we all understand that we've all got some problem and we don't have to worry that we will feel different to normal people. And they can be like a family as well so it's good"*
>
> *ROSE*

Knowing that everyone who attends the dementia support groups are in similar situations can help the person with dementia relax and not have to worry about their dementia. Everyone understands what they are going through, and they have a good time regardless.

> *"We sit down, we chat, we have a quiz and it's all everybody with Alzheimer's and things like that, so we are all in the same sort of boat"*
>
> *ROB*

The support groups are not only a chance for people with dementia to be with others in a similar position, they also promote the wellbeing of those who attend. Many of the participants explained that they leave the groups with positive emotions and often feel that they have achieved something; in particular, those who attend singing groups find that they remember most of the lyrics when singing; "*which is miraculous".*

> *"Singing reconnects everything"*
>
> *BEVERLEY*

Having a dementia diagnosis can make a person feel isolated from society but attending dementia support groups alleviates the isolating feelings and allows the person with dementia to feel like an accepted member of the group. The dementia support groups provide an outlet to relax and have fun, irrespective of their problems with dementia. If they need support, someone at the group will be able to offer it, but more often than not, the people with dementia who attend the support groups do so because their friends are there, and they have fun.

6.5 Isolation

Isolation is when a person feels cut off from their community (Colman, 2009). When a person with dementia feels that they are not accepted by their family and friends, it can lead to feelings of isolation; whereby they notice that people are avoiding them and treating them differently. This can lead the person with dementia to feel that they have to deal with their situation with little support from others. The subthemes within the theme isolation are negative reaction from family and friends, being avoided, problems communicating, feeling like a burden and struggling to cope.

6.5.1 Negative reaction from family and friends

Receiving a negative reaction from family and friends about their diagnosis was a painful occurrence for the people with dementia who participated in this study. Talking about it upset participants who had experienced it and made them feel that their loved ones were not accepting their new identities, as people with dementia. When families react negatively to their dementia diagnosis, it can make the person with dementia feel that they are alone and cannot confide in their family for support. As Nancy explains, her sister accused her of being a hypochondriac; this resulted in Nancy having very little to do with her siblings as they do not understand what she is going through and do not believe her about her diagnosis.

> *"I had to tell my brothers and sisters that I had it, and my sister said oh you stupid thing, you haven't got that, I said that's the trouble, I have….It's as bad as my sister saying I was a hypochondriac. I mean that hurt and she didn't realise, it didn't bother her, she said I'm nothing but a hypochondriac, you imagine these things, I said well I must be very good, I deserve an Oscar"*
>
> *NANCY*

Similarly, David's son thought he was joking when he shared his dementia diagnosis with him. Dementia is a serious diagnosis and not a subject to joke about. As mentioned in David's life story, he uses a lot of humour when talking to people. His son may also have that trait and tries to mask serious conversations by using humour.

> *"My younger son thought I was joking when I said that I had dementia, they were in stitches"*
>
> *DAVID*

Some of the family members did not accept their loved one's dementia diagnosis. As Louise explains, her sister is a nurse but will not accept that Louise has dementia; several of the participants experienced similar situations, whereby their friends and family do not accept their diagnosis.

> *"She [Louise's sister] had been a nurse all her life but she didn't want to accept it [Louise's dementia diagnosis] at all"*
>
> *LOUISE*

This could be due to the societal expectation of what someone with dementia should be like and what the person with dementia is actually like; as Pat explains, her friends do not believe that she has dementia as she is "not too bad".

> *"I think it's because it hasn't materialised like Roy's [husband] did then, you know. I have kept so good, even though I say it myself. Although I know that I'm worse than I was before Roy passed away, I'm still not that bad…But a lot of people have said you wouldn't think that you've got it. But I think they think about people like Roy was, having progressed Alzheimer's don't they"*
>
> *PAT*

For people with dementia, feeling that their loved ones are not accepting of their dementia or do not believe their diagnosis can make the person feel alone in dealing with it. Society generally has an image of someone with dementia, as Pat explains, and if a person with dementia does not resemble the societal image, people will be reluctant to accept it. This was true of the participants in this study, while some were very forgetful and "typical" of society's image of someone with dementia, others were not. For those who were not obviously forgetful, their family and friends were not accepting of their dementia diagnosis, with David's son thinking he was joking and Nancy's sister calling her a hypochondriac. This reaction from their family members resulted in Nancy and David feeling like they could not confide in their family and had to deal with this alone.

6.5.2 Being avoided

In addition to people with dementia feeling that they cannot rely on all of their family for support as they are not accepting of their diagnosis or think it is a joke, people with dementia are also avoided by family and friends because of their diagnosis. While David feels that his family do not accept his dementia diagnosis, he has also noticed that they behave differently around him.

> *"Well I think they think something bad is going to happen to me and that's the impression they give me sometimes you know"*
>
> *DAVID*

In addition to being treated differently by their family, all the participants had noticed that friends now avoided them as they are unsure what to say to someone with dementia or do not want to visit them in care homes.

> *"Just some people believe the stigma about it [dementia]…Lots of friends but you don't see them"*
>
> *MAY*

The stigma of having dementia was noted by all the participants. There was a general belief that those in wider society do not fully understand dementia and hold the opinion that dementia results in the person not being able to do anything for themselves. Friends can sometimes make the person with dementia feel that they have a contagious disease, and subsequently avoid them. Some people with dementia feel that a diagnosis of dementia is like walking around with a sign that says "beware, dementia".

> *"I think everybody is judged on something, and to have this, it's like as if you've got some contagious disease that will jump from one person to the next and then from that person to another one until everybody is infected with it… I feel all the time now is miserable because I've got this and I'm, it's like I'm walking around with a big sign, beware, dementia"*
>
> *NANCY*

Feeling that they are being avoided because of a medical diagnosis can make a person feel isolated from the rest of society. This is true for people with dementia too. People with dementia are very aware of the way that they are treated by those around them. When old friends begin to avoid them, do not visit or telephone, they can only assume that this behaviour is caused by their dementia diagnosis. The loss of friendships can leave them feeling isolated from their social friendship groups. They feel that society will not accept them as a "person with dementia" if their old friends cannot accept them.

6.5.3 Problems communicating

Being able to communicate with family and friends is often taken for granted by those who can do it easily. For people with dementia, maintaining a conversation can be difficult. Remembering what has been already been said can be hard. In addition to memory difficulties causing them to feel self-conscious about having conversations, both Beverley and Rose have difficulty remembering and formulating the words they want to say when having a conversation. This can lead to them feeling frustrated and reluctant to speak to people as they worry what people will think or say.

> *"You get a brain freeze when you're talking, and you just go blank and you can't think when you're talking to somebody and you're explaining something to somebody. I used to be able to have a good conversation and a good laugh and things like that but now it's completely the other way"*
>
> *ROSE*

Being afraid to communicate with people can result in a person with dementia feeling that they have no one to talk to and increase their feelings of isolation. It can also have wider consequences; for example, Rose explained that she can be reluctant to go shopping because she is afraid to ask the store assistants for help in case they think she is stupid or she asks for the wrong thing. Louise feels that holding a conversation with someone takes a lot of effort on her part as she cannot just talk to people anymore.

> *"I'm making an effort all of the time, I can't just talk to people anymore, it's an effort"*
>
> *LOUISE*

The struggle to communicate with people, not just family and friends but store assistants, doctors and so on, can leave a person with dementia feeling reluctant to try and converse with people. Purposely avoiding any situation that may lead to a conversation can be isolating as they limit their daily activities to avoid those occurrences.

6.5.4 Burden

All the people with dementia who participated in this study were independent and did not like relying on others for help. For the participants, independence meant being able to conduct day to day tasks alone. Cooking, cleaning, dressing, shopping and getting out of the house were all tasks that they were beginning to struggle with as their dementia progressed. Many had already noticed that their ability to conduct tasks independently was beginning to deteriorate, and this would only get worse as their dementia progressed.

> *"If I could be a bit better, I would like it. But that's what I wish that my daughter, granddaughter and son in law- make life easy for them. It would be marvellous"*
>
> *MAY*

Similarly, Pat worried that she may become aggressive as her dementia progresses. She has made plans with her daughter to seek out residential care should this happen as she does not want her daughter to have to look after her.

> *“I’m hoping that it will stay and keep it [her dementia] at bay. I don’t want to get any worse, after seeing them [her mother, grandmother and husband getting nasty], you know, I’ve said to Hannah, if I get like that put me in straight away somewhere. I don’t want her looking after me on her own”*
>
> *PAT*

All the participants explained that they did not want to have to rely on their family members as they felt they would become a burden. Despite their families reassuring them that they are not a burden, they still felt they were, and this was associated with negative feelings about themselves. When the person with dementia does not want to ask for help with a certain task, it often leads to that task not getting done.

> *“I’m independent, I like to do my own things and I haven’t been able to, I’m relying on my daughters and that’s an awful feeling. I don’t want them to be burdened by me, they say that I’m not a burden, but I know it’s not true”*
>
> *LYNNE*

Some of the participants had come to terms with needing additional help and support, but others were determined to do whatever they could to help themselves and not become burdensome to their loved ones. Remaining independent was a focus for Rob, who tries to do as much as possible on his own and even hopes to get better.

> *“Not to be a burden on anybody if I can. Because Kim didn’t marry me to look after me like I am now or like I’m going to get and that’s the other thing that upsets me more than anything in my life, I regret this is happening to us because like I said, we had a great relationship, a great few years, really good. And this, it’s not the same now, it’s not the same*

> *and I'm sorry for that and I wish it wasn't. I would love to go back to the way I was but like I say, I keep saying the wrong things and doing the wrong thing and I just can't do that, I've tried to do it and do it right but the more I try, the more it gets worse and I don't know what to do about it, I can't do anything about it. I just don't know what to do. I want to get better; I must get better"*
>
> *ROB*

Apologising for their increasing needs was common amongst most participants. They would apologise to their families for their additional care and support needs. Feeling that they are somehow at fault for their situation can be isolating. Remaining independent and not becoming a burden was a key theme. Feeling that they are burdening people can increase feelings of isolation when they do not want to keep asking their families for help. The need to be independent can lead to people with dementia struggling to cope with daily life without assistance from others.

6.5.5 Struggling to cope

For people with dementia, daily life can be a trial. All the participants explained that they struggle with their forgetfulness, which causes frustration. Struggling to think of what to say also caused stress for the people with dementia in this study. But the real difficulty for people with dementia is with life in general; a combination of the smaller struggles put together. This can make them angry with themselves for developing dementia.

> *"Life, it's just hard, you know, I mean Kim will say a lot for me in that I'm not dangerous but I'm not the same, I know I'm not the same person and I'm so angry inside with myself, so angry with myself. I don't like it. This is what I really struggle with"*
>
> *ROB*

Similarly, Nancy also explained that she struggles with life; from the moment she wakes up until she goes back to bed at night. Nancy feels that this daily struggle is no life at all.

> *"Life. That's true, life. I struggle with it every day when I get out of bed in the morning and my inside is struggling until I go to bed at night, and I go to sleep… when you feel like that, there's just no life at all"*
>
> *NANCY*

Finding it hard to cope with one or two things in daily living can be problematic for anyone but struggling to cope with life generally can result in a person feeling that their lives are not worth living[5]. This was evident with some of the people with dementia in this study. Others in this study felt that they should not be struggling to cope; life should be easy, but it is not.

> *"I shouldn't be trying to cope; I should be me"*
>
> *ROSE*

All the negative emotions towards coping with life with dementia can make a person with dementia feel isolated from the rest of society. The struggle to cope and be themselves is a threat to their former sense of self and their newly evolving self.

6.6 Visual Cues

The video recordings offered additional insight into the participant stories. Some of the earlier cues from the videos that added more understanding to the stories included June showing just how big the strap was when she had been naughty in school[6]. June held her arms right out to the side to highlight the vast size of punishment device as this is how she remembered it as a child. She vigorously demonstrated the power that her teacher had put into the strap as it hit her over the

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[5] None of the participants in this study revealed that they have suicidal thoughts, but some were taking medication for depression.

[6] More commonly known as the cane in Welsh schools.

hand. June explains that this was so painful that she was not naughty in school again. This is a poignant memory from her school days.

Further visual cues included Louise demonstrating one of the tasks that she had to do whilst having a memory test. Louise had not performed the tasks particularly well but remembered what she was asked to do and now, reflecting, was able to do it. She laid different objects on the table in front of her and began arranging them, as she had been instructed during her memory test. Louise was one of few participants who could recall the tasks from the memory test, and no others were able to reiterate with such detail. She admits that the process of having her memory tested was very upsetting and frustrating. She regularly thinks about the day and what she could and could not do. This may explain why she remembers it so well.

In addition to the visual data offering more detail regarding the participants' explanation of things, it also gave the opportunity for their facial cues to be observed throughout the data analysis stages. This is unique to video recorded data. Audio data could allow the listener to hear changes in the participant's voice, for example, laughing or crying, but does not allow that researcher to say, with confidence, that those are the emotions being portrayed. The video recordings do. This additional information was useful when conducting the analysis on the data as it distinguished between general statements and emotive narratives. For example, Rob began to cry when explaining that he feels that his wife hates him. Similarly, Lynne became visually upset when saying that she was no longer the same person. David's face showed wonder when he said that his son found his dementia diagnosis hysterical. There was visual joy on their faces when the participants were narrating their experiences of dementia support groups.

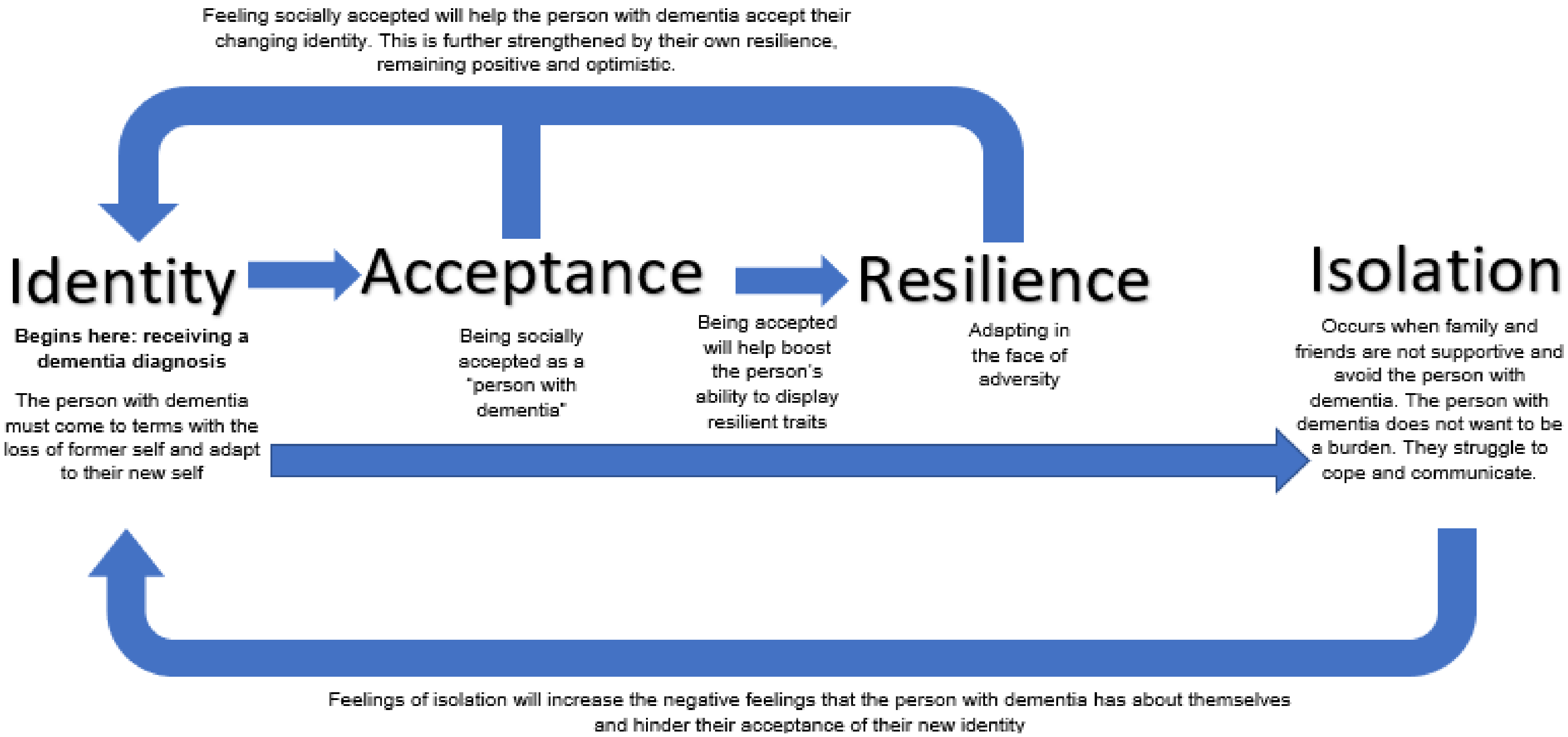
These details, however small, add to the understanding of life with dementia. It helped in the analysis and development of the themes. It highlighted which elements of the narrative meant most to the participants. The details of their life that cause emotional joy or upset were accurately recorded on the videos.

6.7 Model of Living with Dementia

To highlight how the themes for people with dementia interlink, a model was created (see Figure 5). This model of life with dementia illustrates how the person with dementia will experience a change in their identity caused by receiving a dementia diagnosis. Feeling that they are socially accepted can help a person with dementia accept their changing identity but can also support that person in becoming resilient. Resilience can be remaining positive, optimistic and engaged in social activities. For people with dementia, their ability to remain resilient is dependent on the support they receive from those around them; those who accept them. Increased acceptance and resilience will, in turn, help them accept their changing identity.

Feelings of isolation come in many forms, from not being socially accepted, to struggling to communicate and not wanting to be a burden. If the feelings of isolation persist, it can damage the person’s changing identity and result in negative feelings towards themselves.

Figure 5: Model of having a diagnosis of dementia



6.8 Summary and Reflection

These results suggest that people with dementia face many obstacles, but still demonstrate elements of resilience. A key theme for people with dementia was acceptance, whereby they accept the loss of their former self and come to terms with their new self. They may not be able to do the things they used to because of their dementia but they manage to overcome adversity. Being accepted by their friends and family as a “person with dementia” is important. Finally, people with dementia can feel alone and isolated because they cannot accept their new situation or believe that they are not accepted by family and friends. The negative feelings associated with isolation can have implications for the person’s sense of self.

All participants talked about the relationships that they have built with others who also have dementia whilst attending dementia support groups. Within their narratives, the participants painted colourful images of these groups and all their benefits. These support groups offer a safe place for people with dementia, where they are understood and accepted.

The findings suggest that living with dementia can be an isolating experience. People with dementia need to be surrounded by people who understand their situation and who offer support. For those who believe that they are alone, they can develop negative feelings about themselves. Having a good support network can help a person accept their diagnosis and the changes that will occur within their lives as a result of the dementia. Increasing society’s understanding of dementia will help them feel included and not worried when in social situations.

The following chapter presents the themes for the family members who participated in this study with supporting extracts from the participants’ narratives.

Reflection on the Chapter

Despite initially attempting not to concentrate on the negative impact of dementia upon the participants' lives, this proved tricky. It was clear which participants remained positive and optimistic, had accepted their dementia diagnosis and had good support systems. These participants explained life with dementia in a positive light, yet it was equally as distinct who the struggling participants were. By this, I mean those who did not understand their diagnosis, or did not feel comfortable with their diagnosis, like Lynne. They had noticed that they were becoming over-reliant on family and friends for help, and who were realistic about the future struggles for their family, like Rob. For the most part, I was able to offer a balanced definition of each theme, counterbalancing any negative experiences with positive ones.

All those who participated were active members of community social support groups or activity groups within their residential care homes. This is a limitation of the study, as the findings are not representative of those who are not socially active. But equally, shows how vital such groups are for the mental well-being (for example, feeling acceptance, participating in meaningful activities, having support networks) of those living with dementia. This consolidates the controversial theory of resilience and successful aging for people living with dementia which I discuss in Chapter 8 (pp 234).

It took me a long time to create my model of life with dementia. After a few failed attempts, I decided to try and portray it chronologically. With the change in identity coming first, caused by the dementia, which impacted upon acceptance and resilience and could all be hindered by feelings of isolation. All these factors interlink and weigh heavily upon the others, which I portrayed.

CHAPTER 7 RESULTS: FAMILY MEMBERS

"We walk this road together; but for me, it's funny how
It's gifted us with closeness that we never had 'til now"
(Taken from "Dementia Didn't Steal my Dad", a poem by Karen Riddick, 2017)

7.1 Introduction

This is the last results chapter for this thesis and presents the four themes for the family members who participated in this study. These themes are loss, conflict, acceptance and isolation. Isolation and acceptance were identified as themes for both the people with dementia and the family members yet there are nuances between the two; these differences are great enough to justify the presentation of acceptance and isolation separately. Table 14 summarises the themes and subthemes identified within the narratives from family members and these are discussed in turn.

Table 14: Themes and subthemes for family members

Loss	**Conflict**	**Acceptance**	**Isolation**
Acknowledging what has been lost. Acknowledging the loss to come. Loss of awareness. Loss of a spouse. Loss of friends.	Future. Coping. Emotionality. Independent living. Hospital problems. Self-care. Cruel but kind.	Normal part of aging. Genetic predisposition. Positive reaction to loved one's diagnosis. Change of responsibility. Maintaining normality.	Decision-maker. Independence. Withholding information. Remaining strong. Lack of consideration. No support. Criticism. Good support.

7.2 Loss

All participants expressed elements of loss within their narratives. These elements were grouped into 5 subthemes; acknowledging what has already been lost, the loss to come, loss of awareness, loss of a spouse and loss of friends.

7.2.1 Acknowledging what has already been lost

All family members discussed in depth how their situation has changed over time. Comparing their loved one's current health status to how they used to be caused a lot of upset for family members, when they are able to track how the person has changed; what they are to what they have become.

> *"It is more of a worry because you see things that you never thought you would ever see. From what they are to what they have become. Very sad"*
>
> *SARA*

Noticing a temperament change in their loved one was also common. Most of the participants explained that their relative had become shorter tempered but Gail had noticed that her husband had become more subdued.

> *"He is a lot quieter, he doesn't talk so much, he is quite content to just sit in the chair, have the tele on. No, he isn't the person he'd been before. Much more subdued because he was such a lively sort of man, you always knew he was around and he had views on everything, but that changed"*
>
> *GAIL*

For the married couples who participated in this study, reflecting on their marriage relationship prior to the onset of dementia was also a topic they discussed. Despite the decline in their loved one's health as a result of the dementia, they feel that their marriage is stronger than before. For most, living with dementia has brought them closer to their spouse.

> *"It's inevitable that it [their relationship] will change. I have to say that it has drawn us together a little bit more, now what I mean by that is she had a little bit of her life and I had a little bit of my life which were mutually exclusive from each other ..We are sort of joined at the hip"*
>
> *TONY*

As Beverley's dementia has progressed, she has become more reliant on Tony for help and support. They are now together 24/7, whereas before they had separate elements to their lives. Similarly, most of the married couples who participated in this study noted that they will remain committed to their spouse and reiterated their wedding vows, for better or for worse…until death do us part.

> *"Relationships change anyway, people evolve, situations change and the part of being married is that you have got to change with it, it's either you change, or you break. I've got no intention of ever going anywhere else or being with anyone else, as I said to her when I married her, it could have been me in this situation and I know for a fact that she wouldn't have turned her back on me and there's no way that I'm ever going to turn my back on her"*
>
> *DARREN*

For the family members, thinking about the way that things have changed so far and how they may progress caused concern. Most of the married couples who participated in this study were committed to caring for their spouse. Their relationship has been strengthened by life with dementia, despite their loved one being more dependent on them for help and support.

7.2.2 Acknowledging the loss to come

Several of the family members who participated in this study explained that they have compared their situation to other people affected by dementia. This allows the families to understand their loved one's dementia. If the person with dementia whom they are comparing their situation to is at a more progressed stage than their loved one, they realise what is to come.

> *"I mean I've got it easy compared to some of the people whose husbands and wives are really bad, and then I do look at them and I think oh god I've got that coming"*
>
> *DIANNE*

Hannah has previous experience of caring for someone with advanced dementia, her Dad. Hannah found it difficult to cope with her Dad getting annoyed and not understanding what was happening to him. She hopes that her Mam does not get to that stage.

> *"Well with Mam, things haven't changed that much but Dad also had dementia and I found it difficult towards the end when he wasn't talking much and getting annoyed. But I think it was difficult for Mam to cope with as well. I know what is to come from seeing Dad and I hope that Mam won't get that bad but she's doing very well at the moment"*
>
> *HANNAH*

For the people with dementia, attending support groups where they could be with other people who have dementia was a positive experience of acceptance. The family members are apprehensive about allowing their loved one to attend some support groups. For example, Kim does not want Rob to attend any day centre groups as she believes that they are aimed more-so at those with advanced dementia. Kim worries that Rob will become frightened if he realises that he may one day have advanced dementia.

> *"He was offered a place in a day care centre, but we turned that down, I don't feel it would do him any good. Day care tend to be more further on down the line, people with dementia that's further advanced and I think that if you put him in that situation now, it would frighten him. Yes, he knows he's got dementia and yes, he probably knows exactly what is going to happen in the end, but he doesn't need it put in his face"*
>
> *KIM*

Similarly, Gail has the same concerns about her husband being in a nursing home. Whilst the home itself is “*marvellous”*, Gail can see how the residents are at differing places in their dementia journey and seeing what is possibly to come for her husband is difficult to comprehend.

> *“When you’re in a home like this one, which is marvellous, but you see how they are all deteriorating all the time, and how bad some of them are, and I think oh God, it’s around the corner for him isn’t it. He’s bad and he’s going to get even worse…It’s hard to cope with, the fact that I cannot do anything what so ever about it and that it’s going to get worse, it’s very upsetting to see how he is now and how he’s likely to become because you look around and you see how they’re all falling down on the journey, and there’s no rhyme or reason to the time of it, because they’re all different”*
>
> *GAIL*

Comparing their situation to others results in the family members seeing how their loved one’s dementia could progress and how bad it could get. All participants found this frightening, particularly when they consider how things have already changed.

7.2.3 Loss of awareness

The family members in the study explained how their relatives had lost some awareness of their dementia. This was reported more by the family members with a loved one who was unable to participate in this study due to their lack of awareness of their diagnosis.

> *“He doesn’t think he’s got a problem. He says to me sometimes “oh my memory is not what it was” or “I knew I meant to do something but I can’t remember what it was” but if you say to him “Dad it’s your memory, you have dementia” he doesn’t have a problem, he refused to go to the memory clinic because he doesn’t have a problem, so as far as he’s concerned, it’s just absent mindedness”*
>
> *PIPPA*

Like Pippa, almost all the family members explained that they had trouble encouraging their loved one to go to the memory clinic for assessment. After attending the consultation, some of the people with dementia did not understand what diagnosis they had been given.

> *"He knew it was a memory clinic, he knew he had problems, he used to say "I've got problems with my memory. I can't remember things", but he didn't say it was dementia"*
>
> *GAIL*

After receiving their diagnosis, some of the people with dementia struggled to come to terms with it. Several of the family members explained that they had to have long conversations with their loved one to encourage them to accept their diagnosis. Once they had accepted their diagnosis, life became much easier.

> *"I think initially, she has the nature where she tried to block things out, I think there was an element of that to start with and it took quite some time for her to understand that she has Alzheimer's. And I think when that sat with her more comfortably, things were a lot better then, because Beverley would say to somebody, well I've got Alzheimer's"*
>
> *TONY*

The family members not being aware of the signs that their loved one may have dementia can influence if, and when, the person gets a diagnosis. When the person with dementia has a loss of awareness about their diagnosis, it can make things more difficult for family members.

7.2.4 Loss of a spouse

Most of the married couples who participated in the study explained how life with dementia had strengthened their marriage, but for some, life with dementia had resulted in them feeling like a single person again. For Gail, her husband has moved into a nursing home and has advanced dementia.

> *"I think it's changed [her relationship with her friends] because I think a lot of it is with couples, and that if we'd gone out for whatever reason, I wasn't a couple anymore, I'm on my own now, it's like being a single person really"*
>
> *GAIL*

Similarly, Kim explains that her husband is no longer the man that she married. Due to his frontal temporal lobe dementia, Rob is no longer able to pick up on emotional cues. When Kim is having a bad day, Rob cannot identify it. The intimate side of their marriage is gone, and Kim really misses having the emotional support.

> *"Rob is not the person that I married now, that sounds hard doesn't it, sounds horrible. Rob is a different person to the one that I married seventeen years ago. The person that I loved and married is gone, now it's like living more with a friend. It's down to that emotional side of things, that closeness that you have in a personal relationship. …I miss the loving side of it; not so much the sexual side of it. Routine stuff, he'll do it…it's the natural spontaneous stuff that he doesn't do anymore and that's really hard…I was going to say that there's no love, but he does love me in his own way, but it's a different kind of love, there's no sexual relationship … I really miss having somebody to realise I was upset and put their arms around me and give me a cuddle and just sort of make you feel better"*
>
> *KIM*

Additionally, there is a large age gap between Kim and Rob; she feels that she did not sign up to be his carer, especially when she is so much younger than him.

> *"Didn't sign up for this…I think because I am so much younger than him …I said how would you have felt, twenty years ago if your life had just stopped? Because effectively that's what's happened to me…To think that this is my life for the next god knows how many years, and that's the hard thing…My life is basically on hold, what do I do? Like I said, it's not what I signed up for and to some extent, yes Rob is not the person that I*

> *married…Is it wrong for that partner [herself] to have another relationship, a sexual relationship, because that partner is very much missing out on their life. Is it wrong for them to have a life outside of dementia?"*
>
> *KIM*

Feeling that their spouse was no longer the person they married was only disclosed by two of the married women who participated in this study. For Gail, she felt that she was single again as her husband was no longer able to participate in "couple's activities". Kim felt that her husband was no longer the man she married, and she has a right to have a life outside dementia where emotional support is regularly offered.

7.2.5 Loss of friends

All the family members who participated in this study were aware that people would avoid their loved ones because of the dementia. This was noted more by the family members who's loved ones lived within residential care homes. For Gail, she feels that her friends have avoided visiting her husband in the residential care home because they do not want to see how he has deteriorated.

> *"I don't think they [friends] would have taken very kindly to it, coming in here [care home] because they wouldn't want to see him the way he is now, I don't think"*
>
> *GAIL*

Some of the family members feel that their loved one's friends are avoiding them because they do not understand dementia; they are frightened to approach someone with dementia because they do not know how they will act.

> *"His friends distanced themselves, nobody visits him…it is almost like they are frightened to approach him because they don't know how he's going to react or whether he'll remember them but now it is just literally myself that visits"* *PIPPA*

Similarly, Laura noticed that her mother’s friends have started to avoid her and do not visit her within the care home. Laura feels that there is a lot of stigma associated with having dementia and care homes, which is why her mother’s friends have shied away.

> *“There are others, and I understand why, that have shied away. They say they will come and visit but they won’t… there’s also that feeling of not knowing what to say…and there are others that I think have got a mental picture of someone who is sat in a chair, slumped, drooling. Not able to communicate. Because there is a stigma with the word. And it took me a long time to explain to my mother that it is just a word. That the word dementia covers a lot of different areas. It does not necessarily mean that someone is in a position where they can no longer do anything for themselves”*
>
> *LAURA*

Noticing that their loved one is experiencing a loss of friends can cause upset to the family members, particularly when life-long friends begin to distance themselves from the person with dementia.

7.3 Conflict

The theme conflict encompasses the internal conflict experienced by the family members within this study between feelings of struggling and hope. These opposing states co-exist, and the family members oscillate back and forth between the two. The family members explained several instances where things were not very good, and they struggled to get through. Despite this, all family members showed signs of optimism, hope, and positivity. Drawing together these opposing states of mind allowed for the development of a theme which highlights this conflict. The subthemes within conflict are thoughts about the future, coping, emotionality, independent living, hospital problems, self-care and cruel but kind.

7.3.1 Future

The future was discussed by all the participants. Some had an optimistic view of the future, which displayed signs of hope whilst others explained that there is no cure and things will only get worse. When the participants acknowledged the loss that has occurred so far and witness what the future might be like for their loved one, they often concluded that the future will be bleak for themselves and their relative with dementia.

> *"I know what the end is going to be, that he can't survive it, and things are going to get worse than they are now, and that's hard. So, there's no other answer is there really... I was given enough [information about dementia in a care home] to know what the outcome was going to be and how it was going to go, I realised from early on that this is something that's bad and that there's no cure and there's nothing that I can do about it"*
>
> *GAIL*

Gail explains that there is no way their situation can improve; this was also noted by Bethany.

> *"It just seems never ending and you know that there's no way that things will get better, so I think that's in the back of your mind all of the time as well. It's really stressful. I'm constantly worried about her. There's no solution for us either"*
>
> *BETHANY*

Believing that things will only get worse was the opinion of half of the family members who participated in this study; the other half tried to remain optimistic and positive about their loved one's future with dementia.

> *"We just try to stay positive and think positively that we could be fifteen years down the line and she's not much worse than what she is now…all we can do is hope for the best …that's what we hope for, we just try to*

> *stay positive… So far, we've had a fantastic life together and hope to have a number of more years with her, regardless of the Alzheimer's"*
>
> *DARREN*

Darren hopes that Louise's dementia does not progress much; this was also noted by many of the other family members. Laura hopes that her mother will not decline any further but knows that she will always be taken care of. This was also explained by Sara who hopes that her mother does not get to a stage where she is no longer capable of doing things for herself. Both Laura and Sara had to pause the data collection process after discussing their mothers' future. This was a topic that elicited a lot of upset within the participants; trying to remain positive about their mothers' decline acted as a defence mechanism against the reality of how bad things could get. Pippa was the only participant who explained that she was fine with her Dad's condition deteriorating in the future as long as he is being well cared for.

> *"Occasionally now my Dad will use his hands, which is fine by me; if he eats using his hands, as far as I'm concerned, he's eating but he occasionally forgets how to use a knife and fork. So, there's little things that I think, well why is that happening?"*
>
> *PIPPA*

There was a clear divide between the participants who do not think their situation will get any easier; things will only get worse in the future. While other participants explained they did not want their loved one to deteriorate in the future, but when they inevitably did, they hoped they would be well looked after.

7.3.2 Coping

Coping was identified within the data for both the people with dementia and the family members within this study. Both populations explained they find it difficult to cope living with dementia. For the family members who took part in this study whose loved ones were living in residential care, an excessive struggle to cope was the explanation offered regarding the decision to relocate them into residential care when it became too difficult to care for them in their own homes.

> *"My sister said that she couldn't cope anymore in the house with her [June] because it was just too much work … they [social workers] did an assessment and they said that she wouldn't be able to live on her own anyway even if my sister could cope"*
>
> *GERAINT*

This was a common explanation amongst the family members regarding the decision to source residential care for their loved one. Whilst the physical strain of caring for someone with dementia was alleviated by them being in a care home, the emotional strain remained. For Geraint, he struggles to repeatedly explain to his mother that she now lives in a care home; when he visits, she thinks she is going home with him. For Sara, the difficulty comes from accepting that her mother has dementia and lives in a care home.

> *"We had loads of discussions and it was horrible to think that she would never go back home again …she's happy as Larry here. It's us that's the problem, not her, because we get upset that she's in here… It is very hard to think that your Mother is in a home, even now when people ask me, I fill up. I say "oh she's in a home, she's got dementia" but at the end of the day, it is what they need isn't it"*
>
> *SARA*

As Sara explains, the emotional struggle of having a loved one in a care home with dementia can be hard to cope with. For the family members who were caring for their loved one in their own homes, every day holds a new hardship. For Dianne, she struggles to know what mood her husband will be in when he gets up.

> *"Hard, there's no two ways about it, it's not knowing from one day to the next… You feel you're treading on eggshells… He comes downstairs and I think can I say good morning now or? So, I wait. And if he says alright, I think oh we're having a good day today, so I've just got to play it by ear"*
>
> *DIANNE*

The hardship of trying to cope both physically and emotionally was common amongst the family member's narratives. As Sara explains, she struggles emotionally with the situation her mother is in but knows that it is the best thing for her Mam. The family members try to remain hopeful and optimistic whilst struggling to live with dementia.

7.3.3 Emotionality

Mixed emotional responses to their situation were reported by all family members. This ranged from behaviours caused by the dementia that the person finds difficult to cope with, negative emotions regarding their situation and trying to maintain a sense of humour despite the hardship they face. A lot of the participants explained they struggle with their loved one's forgetfulness.

> *"He is forgetting stuff and not remembering stuff now because he will say something and then he'll backtrack and "oh it doesn't matter, don't worry about it" because he can't remember what he was saying and so he covers it up by saying that it doesn't matter. But it's his personality that's changed; that I miss. The memory side of it can be a nightmare, he forgets things, forgets to do things, forgets what he's doing, and he gets frustrated but it's his personality changes that I miss more than anything"*
>
> *KIM*

For Kim, Rob's forgetfulness is a nightmare and causes issues within their relationship, but she particularly struggles with the changes she has experienced in his personality. This was common amongst participants whereby the person with dementia's personality has drastically changed and causes frustration. For a few of the participants, it was not the symptoms of dementia that caused problems, but the behavioural traits associated with co-existing disorders.

> *"She also suffers with Charles Bonnet Syndrome[7]. She sees people, and people tell her that I'm no good and to keep a knife under her pillow, which she's done on several occasions, so I've got to normally check for those"*
>
> TRYSTAN

Trystan experiences considerable stress caused by his wife's Charles Bonnet Syndrome; she takes a knife to bed and hides scissors by her chair in the living room. This causes a lot of tension between the couple and Trystan must be extra vigilant with knives and scissors around Nancy.

In addition to forgetfulness causing annoyance to the family members, some people also explained how the repetition can be a nuisance too. Laura finds it frustrating when her mother is repetitive and becomes irritable when she says things that are not accurate.

> *"Frustrating. I can't think of any other word to describe it. This morning I have sat here, and I have listened to my mother talk to you and I can hear discrepancies in the things that she has said to you. It is hard not to jump in when she says something that is not accurate, I would not say untrue because in her head it is true. It can wind me up the fact that she is very repetitive. I know that she cannot help it but when you have heard the same story over and over it does tend to get to you"*
>
> *LAURA*

Stress was a common emotion described by the family members in relation to their lives with dementia. Trying to juggle all their responsibilities is the main cause of stress for the family members who participated in this study.

---

[7] Charles Bonnet Syndrome is caused when a person's sight deteriorates, they begin to hallucinate. While the hallucinations are not caused by the person's dementia, the dementia can make the hallucinations more bizarre (NHS, 2018).

> *"[Life with dementia is] Stressful, yes, and sometimes hilarious. It is more difficult when you're trying to work and trying to balance everything and fit other things in around it and try and maintain a bit of sanity for yourself, that's the hard bit. But I seem to be doing alright"*
>
> *DARREN*

Experiencing a mix of emotions was something that few participants talked about. During the interviews, the participants' explained life with dementia either in a generally positive manner or negative one. However, both Darren and Gillian explained that their experiences of living with dementia was a complex relationship between love, humour, guilt, stress, loss and anger.

> *"All mixed emotions, of course I still love him, but I get angry and I've got a loss and there's nothing I can do about it and it's so mixed up. And then I still feel guilty because I look at him and I think aww you poor man, why are you like this? And it's all sad…I must admit, I have all these different feelings, I feel guilty because sometimes I think "look at the mess you've landed me in", and other times I feel guilty and I feel really sad and then I think of all the loss and what it is going to be like in the future and how long is it going to go on like this, it's all mixed really"*
>
> *GAIL*

Striking a balance between the negative and positive emotions associated with a life with dementia can be complex. But adding an element of humour can help the family members cope with the stress. Specifically, Darren uses a lot of humour to explain how he feels about more serious situations. For example,

> *"Hopefully she gets run over by a bus or something before that happens [her dementia gets too bad]"*
>
> *DARREN*

This is Darren's way of expressing his hope that Louise will die from something sudden and unexpected before her dementia gets too bad. Similarly, he says,

> *“Nothing surprises me. If I’ve got to wipe her arse, I’ll wipe her arse as well [laughing]”*
>
> *DARREN*

This quote highlights his commitment to care for his wife. However, finding humour in their situation was rare amongst the participants. Gail explains that her husband will sometimes say things to make her laugh despite him now being in the advanced stages of dementia.

> *“He is ever so funny because it’s still somehow lodged in this brain of his and he said to me recently “this place” he said “is costing a lot of money” oh I said is it? “One hundred pounds” now a hundred pounds to him is absolutely nothing but you can see and I sometimes, a lot of them do it here, they have a cup of tea or whatever “how much do I owe you for this?”*
>
> *GAIL*

Sometimes, people with dementia will say or do things that their families find humorous. As Gail explains, her husband worrying about the care home costs and drastically underestimating how much it costs was amusing to her. Additionally, Bethany tries to remain upbeat and find fun within different situations.

> *“We’ve tried to be as upbeat as we possibly can about it so we do laugh as much as we can about things as well. We got lost in the car the other day and my mother ended up telling us the way”*
>
> *BETHANY*

Bethany’s Mam giving her directions when they were lost in the car was particularly baffling for Bethany as she did not know whether to trust her mother’s instructions or not. Dianne also tries to make light of different situations.

> *“He’ll forget which child he is talking to. So, I said to him I’ll write labels out and when they come here, I’ll put them on them, so you know which one*

> *you're talking to. You've got to pass it off as a joke, it's not funny but you've got to try and make it funny haven't you"*
>
> *DIANNE*

Maintaining a sense of humour despite feeling stressed and frustrated can cause an internal emotional conflict for the family members of people with dementia. Striking a balance between the two is essential as they do not want to feel frustrated all the time, nor do they want to make a joke of their whole experience of living with dementia. This can be complex and, as many of the participating family members explained, they tend to feel the frustration and stress more.

7.3.4 Independent living

The theme independent living is about the family members trying their utmost to keep their loved one living in their own home for as long as possible.

> *"I know she wants to stay in her own home for as long as she possibly can, so we want to do that for her"*
>
> *BETHANY*

This desire was discussed more by the adult children who participated in the study as they must commute between their homes and their parent's home to ensure they are safe and well looked after. The possible need for a care home is therefore at the forefront of their minds. Whereas the married couples did not discuss the possibility of needing any care home services.

The family members who were recruited from the residential care home discussed how they came to make the decision about their loved one moving. For some, they did their best to ensure their loved one could stay at home. This included care packages being introduced and considering renovations to the house.

> *"We had assessments done and then we arranged for some sort of package. To start with it was that minimum package where you have shower carers coming in a couple of times, where we had the lady who*

> *was coming in to sit with him for two hours, where he could go to the day centre. That for a little while was ok but then it turned out it wasn't enough. We needed a bigger package. And for the bigger package, I think it would have meant doing renovations in the house"*
>
> *GAIL*

Considering renovations to the house to ensure their loved one could stay in their own home was also discussed by Laura who wanted to give her mother every opportunity to stay at home for as long as possible.

> *"We had hoped that, by the end of the respite, that she might be able to go home…but my mother decided that she wanted to go into full time care… we were making the provisions for her to go home. And while I wanted that to work, I knew deep down that even if she did go home, she wouldn't be at home for long. But I wanted to give her the chance because I know it is possible for people to live with dementia in their own home with the right care"*
>
> *LAURA*

As Laura explains, it was her mother's decision to move into a residential care home. Laura had prepared the house for her mother to go back there after her respite care had ended, a stairlift had been fitted along with other modifications. While Laura desperately wanted her mother to return to her own house, she was realistic about the fact that she would not be there for much longer before needing the extra support from a care home and ultimately, her mother's decision to move there had to be respected. This conflict between what the family member wants for their loved one and what their loved one needs was central to several of the participants' narratives.

7.3.5 Hospital problems

All participants had "horror stories" about some of their experiences with hospitals. Some were around the diagnosis process while others were about hospital procedures failing a person with dementia. Tony, Geraint and Sara explained that they all had trouble obtaining a dementia diagnosis for their loved one; both Sara and Geraint found that the memory clinic staff would not listen to their observations of their loved one's behaviour and only went by the memory test scores that had been obtained.

> *"I took her up there [memory clinic] and I went in with her and the doctor was asking her questions, just general questions and then we had to go sit in the corridor then and he called her back in and he said "I don't think you've got dementia"... So, I said to him at the time, I said well why is she forgetting all these things … We knew there was something not right but it was difficult, because she had a test done, they said it wasn't, they couldn't do anything about it then"*
>
> *GERAINT*

Sara's experience was similar whilst Tony explains that the process of obtaining a dementia diagnosis for Beverley was torturous. As Beverley had a history of depression, the consultant focused on this instead of looking any further.

> *"Torturous [the diagnosis process] because the doctor consistently looked at Beverley's depression, his view was that his diagnosis was pitched at depression and I couldn't see that because I have seen the effects of Beverley's depression... With the doctor…but he takes an awful long time to make a diagnosis"*
>
> *TONY*

Further hospital concerns occur after the person has received a dementia diagnosis. For Pippa, she had to go above and beyond to protect her father when the hospital decided he could go back to his own home after being sectioned for 13 weeks.

> *"He was coming to the end of the 13 weeks [sectioning] where they do the review. The doctor saw him for about six minutes and ascertained that he was of sound mind and capable of going home. Alarm bells went off …that can't be right …I said he'll die if he goes home because he will be looking for my mother, he can't take care of himself …two visits a day from the carers, and I said no I'm not having it…so I had to fight …and it*

> *got to the stage where I would visit my dad and take photographs of his notes; his falls, his aggression, his wandering. Once they didn't tell me he actually got out and went to town in his underpants; I wasn't told, but it was in his notes. So, we went to a meeting…and I said right I've got all day, I've got about 100 pages here and I've highlighted on every page aggression, mood swings, TIAs, escaping, hitting the walls. Now you tell me that he's capable of going home… They adjourned the meeting and they came back and said, "no I think we're in agreement with you, he's not fit to go home". I had to do that and fight for it myself"*
>
> *PIPPA*

To protect her Dad, she had to photograph his hospital notes, replicate them and highlight instances where he displayed behaviour which suggested that he could not go home.

As touched upon in Chapter 1, British hospitals are beginning to adopt the guidelines from John's Campaign (Appendix A, pp. 342) so that when someone with dementia is admitted into hospital, a family member can stay with them to help provide reassurance to that person. Kim was the only participant who had experienced this. When Rob was admitted into hospital, Kim stayed to look after him.

> *"He was in the hospital, and I had to stay in the hospital with him because he didn't want the nurses doing personal care and looking after him, he wanted me to look after him and it was really, really difficult because the nurses wouldn't look after me, looking after him. Half of them didn't even want to give me a cup of tea, it was lousy. And that's where you need more support for carers. If you've got a carer that's caring for somebody, that carer needs to be cared for as well"*
>
> *KIM*

This subtheme, hospital problems, highlights the commitment of the family members to do what is right for their loved one, even if it means going against medical staff. The conflict arises when the family member's knowledge of the person with dementia exceeds that of the medical professionals. They want to accept the medical professionals' views are reliable but something about their actions does not sit well with the family resulting in the family members having to fight to get what is best for their loved one.

7.3.6 Self-care

Some of the family members were spending so much time caring for their loved one they did not have time for themselves and sacrificed activities that they enjoy.

> *"One of the things I should say is I'm an outdoor person …I miss being able to go out in the garden or sit outside for a cup of coffee because I'm always nervous about leaving Beverley on her own… I do get a bit of cabin fever"*
>
> *TONY*

Having to miss out on activities they enjoy was highlighted by several of the participants. Both Tony and Trystan have had to sacrifice their hobbies to ensure their wives are safe and cared for. Whereas others make an effort to put time aside to have "me time" and maintain their hobbies.

> *"I've still got a couple of friends who, I'll go out for a pint and have a bit of release. I sing in a choir, so I still look for other releases"*
>
> *DARREN*

Maintaining relationships with people other than the person with dementia is essential. Striking a balance between spending time with the person with dementia and spending time with other family members and friends can lead to feelings of guilt and worry, causing a mixture of emotions.

> *"I constantly feel bad if I'm not here, if I know I'm going home knowing that she'll be here for hours on her own, I feel awful, and I think I've got to go home because my husband is there, go home if the children are visiting or I've got something else to do I feel really bad so I think there's this*

> *constant guilt and worry all of the time basically, that's my main experience of it"*
>
> *BETHANY*

Spending so much time with the person with dementia can result in other family members being neglected; Bethany explained that she feels guilty for not seeing her husband much because she is with her Mam all the time. If she tries to spend time with her husband, she feels guilty for leaving her Mam. Feeling that their loved one is safe for a few hours can provide essential relief and respite for the family members.

> *"We've been going up there [local dementia support group] now over a twelve month. It's something to look forward to, he goes with the men and I've got two hours when I don't have to worry and that is heaven. Believe you me. That is heaven. And he's fine when he's up there"*
>
> *DIANNE*

When looking after a person with dementia, the concept of self-care can elicit feelings of guilt. It takes a while for the family member to accept it is essential for them to have some time to themselves and it is not a selfish act.

> *"You reach a point where you think I've got a life too and I've got to try and look after myself otherwise I'm not going to be any good to anybody"*
>
> *GAIL*
>
> *"I needed to look after myself too to be able to look after my mother, and that I have a life as well, which you feel selfish about at first"*
>
> *LAURA*

Feeling selfish for taking care of themselves causes conflicting emotions about "me time". The family members need a release from being with the person with dementia all the time, but also feel guilty for doing something else. This can have implications for their mental health and relationships with other people.

7.3.6 Cruel but kind intentions

Some participants shared hopes for their loved one that appear cruel but have a kind justification behind them. The main topic within this subtheme concerned the people with dementia being at the “worse stage of dementia” whereby they are aware that they have it but cannot do anything about it. The people with dementia know what has been lost and what loss is yet to come.

> *“This stage is the crueller stage because he’s still aware. As they progress and they become less aware, less understanding, then it’s not so bad because they don’t know what they are missing”*
>
> *KIM*

Several of the family members feel conflicted between wanting their loved one’s dementia to get slightly worse so that they are not so aware, whilst not wanting the dementia to get any worse. This is a complex state of mind to comprehend.

> *“I think that this stage that she is at is probably the cruellest stage because she is aware of everything … I don’t want her to get any worse, but I hate the fact that she knows so much now… we know that she knows about everything whereas sometimes you think when they get further into dementia, they don’t actually know about things, it seems easier on the person. Harder on the relatives but easier on the person so I think that’s what we find difficult, we want her to just be where she isn’t suffering”*
>
> *BETHANY*

Whilst Bethany hopes that her mother will get slightly worse to reduce her anxiety and awareness, she also acknowledges that the dementia progressing will make life easier for her mother but harder for her. Similarly, Pippa said,

> *“It’s been a journey, and it’s still ongoing and I’m now coming to the stage where I think it’s going to be a slightly harder journey for me but easier for him”* *PIPPA*

Within this subtheme, cruel but kind, the family members illustrated their wishes for their loved one's dementia to deteriorate so that they are less aware of what is happening to them. Wishing their loved one gets worse is not a cruel desire; they want the awareness to diminish so that their knowledge of what is to come can no longer scare them. This is a difficult conflict to comprehend and explain.

The theme of conflict has demonstrated that family member's experience a mixture of struggle and hope. They try to remain positive despite facing hard times. Living with dementia is a rocky road of emotional conflict, as all family members have experienced and explained within their narratives.

7.4 Acceptance

All family members within this study must accept that their lives will change as a result of their loved one's dementia. The subthemes within this theme are normal part of aging, genetic predisposition, positive reaction to loved one's diagnosis, change of responsibility and maintaining normality. These highlight different aspects of the family member's lives that require differing levels of acceptance.

7.4.1 Normal part of aging

All participants referred to dementia being associated with old age. This was given as an explanation for not recognising that their loved one was beginning to show signs of dementia; they attributed forgetfulness to old age.

> *"She just thought it was part of getting old…It is just normal for people, as they get older, to forget things… When I started pushing for Louise to be tested, she dug her heels in and said no there's nothing wrong with me, I'm just getting older"*
>
> *DARREN*

Accepting that dementia is not a normal part of aging can be difficult, especially when society has associated old age with forgetfulness. It is necessary for people to recognise that dementia symptoms, such as forgetfulness, are not a normal part of old age. The ability to distinguish between what is “normal aging” and signs of dementia will influence people seeking help earlier and ensure people with dementia are being diagnosed sooner.

7.4.2 Genetic predisposition

Some of the adult children who participated in this study were concerned about dementia being hereditary. For Geraint, he did not know whether dementia was hereditary and the thinking that he may possibly be developing dementia was of great concern to him.

> *“I don’t know whether it is hereditary…I’m getting worse and worse [forgetfulness] and I don’t know if I’m just joking about with it or whether I seriously am. And it does worry me, it could be hereditary… I don’t know whether I’ve got it, the start of it, and it does worry me… I’m 58, I’ve got my own children, my wife, I don’t really want them to have to go through what I’m going through with my sister…I’m trying to ignore it at the moment and pretend it’s not happening to me”*
>
> *GERAINT*

Instead of Geraint trying to find out more information about the hereditability of dementia, he shuts it out and tries not to think about it as he does not want to consider the impact it will have on his family. Laura, however, is aware that dementia may be hereditary as a lot of people in her family have received a diagnosis. This makes Laura more accepting that she may one day develop dementia.

> *“My grandmother had dementia and my mother has got a cousin with dementia...So the fact that maybe it is in the family has never really been a worry. It is something that you can’t control it is, if you’ve got dementia, you’ve got dementia, it is not something that you can really do anything about”*
>
> *LAURA*

Most forms of dementia are not inherited (Alzheimer's Society, 2017) but for the adult children of people with dementia, there may be a long family history of dementia (as with Laura) that makes them more accepting of the fact they may develop dementia.

7.4.3 Positive reaction to loved one's diagnosis

Reacting positively to their loved one's diagnosis is essential to helping the person with dementia feel accepted by their loved ones (as discussed in the previous chapter). For the family members, a diagnosis of dementia was essential to helping them support their loved one and prepare for the future. The diagnosis confirmed their suspicions that their loved one has dementia.

> *"Relieved [when the diagnosis was confirmed], it confirmed what I was thinking all along…right we know what that is, now we can try and deal with it. There was a certain amount of relief but obviously, what's the word? Trepidation at what's to come. But at least with the diagnosis, we could say right, this is what it is, what can we do about it rather than being in the dark. Yeah so relief and trepidation"*
>
> *DARREN*

The family members recommend accepting the diagnosis as soon as possible as that will help them come to terms with the additional support that may be needed by the person with dementia in the future.

> *"The hospital… they came back with vascular dementia. And I think once it was labelled, it was right ok, we know what it is, we knew all along what it is but now we've got a definite diagnosis on it, where do we go from here? So, I think the diagnosis was the key… Just accept what's going on because you can't stop it once the tidal wave starts coming in, it's coming in and you can't stop it, so you have just got to go with the flow"*
>
> *PIPPA*

For Pippa, dementia is like a tidal wave; it cannot be stopped, and it can cause a lot of difficulties if a person does not accept the changes that are occurring because of dementia. Accepting that the tidal wave is coming is essential for family members to be prepared to support their loved ones.

7.4.4 Change of responsibility

Within a marital relationship, there may be different marital roles. When the person with dementia is no longer able to carry out their role, the other person will have to take over the responsibility for it. For example, Gail's husband is now living in a nursing home and she has had to take on all the household responsibilities.

> *"I've got a lot more responsibility, a lot on my shoulders, having to do things that I've never done before that he would have done, finding that I can do them, which is something, I've found I can do so many things that I'd never thought I could ever do".*
>
> *GAIL*

Gail has found out how to do a lot more things around the house for herself, things that her husband would have previously sorted out. The same is true for Trystan, who has gone from doing nothing to doing everything.

> *"I had to take over everything; do the washing, cleaning, cooking, dressing, I'll bathe her… From doing absolutely nothing, I would just go out to work, come home, food would be on the table, she would do everything. But she does nothing like that now, I've got to do everything… She's got stress incontinence, so I've got to see to all of that now …It's just part and parcel of looking after my wife"*
>
> *TRYSTAN*

Like Darren and Tony, Trystan respects the vows he made to his wife on their wedding day; he will do anything that is required of him to take care of his wife. Trystan also explained that he would not be comfortable having carers looking after his wife; when he does it himself, he knows it is done properly. Tony also explains that Beverley’s needs come above all else.

> *“Well the focus has changed now. It has changed because my role has become supportive, I’ve had to learn to be patient to the point where the first thing I must think about is Beverley’s needs, that always comes first now”*
>
> *TONY*

The adult children who participated in this study also find their new responsibilities a trial. Bethany is struggling to juggle being a daughter and being a carer.

> *“We are taking on the role of carers as well as just daughters, but it is difficult… I feel like I’m nagging her all of the time whereas before she was so independent, she didn’t really need us to do that much for her and now it’s complete role reversal really. She won’t take part or do anything without us. She’s much more dependent… we have to do all of the household things now. Visiting a couple of times a day with meals. It’s changed the whole family dynamics really. It seems to be a constant. Nothing nice, just really hard all of the time, there’s no break from it. I don’t mind doing anything for my mother, that’s not the issue, it’s just pacing everything in your life”*
>
> *BETHANY*

Having to take control over their parent’s lives was noted by all the adult children who participated in this study. All the responsibility is now on the adult children’s shoulders as the parents with dementia are now more vulnerable.

> *“I am not sure that he recognises me all the time as being me. I think I’m more the adult whereas before I was the child, and dad was always there. Any problems I went to my father, now the tables are turning a bit because his behaviours are becoming more childlike and I feel more like the responsible adult. The roles are reversing”* *PIPPA*

For the adult children whose parent with dementia is now living within residential care, their responsibilities have been alleviated slightly. After taking on all the responsibilities for their parent, it can make them feel redundant when the care home staff now become responsible for their parent.

> *"I was going down there, I was putting meals, I was buying convenience meals to try and make life easier for her. I was basically spending more time down there than at home… But I feel redundant because you spend your time running around doing things, and then suddenly it's taken away from you. And while it is nice to start and get your life back, you feel a little bit redundant then. It's a new routine basically"*
>
> *LAURA*

All participants in this study have accepted the increased responsibilities that come with having a loved one with dementia. For some, the responsibility becomes too much, and they must source additional help; but family members still maintain a level of responsibility even when their loved one has moved into a residential care home.

7.4.5 Maintaining normality

Trying to maintain an element of normality was essential for the family members who participated in this study. Accepting that there is no cure to dementia and dealing with it was a key theme for the family members.

> *"We have decided to try and be as normal as possible really and try to talk about any issues that she's got, which she does sometimes, sometimes she doesn't. I've tried to say to her that there's no solution to the problem, we've just got to work with it as it is and we have just tried to take that attitude really of one day at a time, see how you feel and we'll try and do the bits that you can do"*
>
> *BETHANY*

In addition to having an open environment where any issues can be talked about, the family members also encourage the person with dementia to do things for themselves.

> *"I try to step back quite a bit and make Louise get on with things because I think that the more she gets on with life, the better it is because if you step in all of the time, you're just taking that away, you're stopping that thinking process. So, I do try to push her forward and make her do things that she doesn't want to do"*
>
> *DARREN*

As Darren explains, he encourages Louise to think about things that need doing which, in turn, encourage her to remain independent and perform tasks around the home. Similarly, Dianne explains that her children still treat David as their father, not as a vulnerable person.

> *"The majority of the time, they don't treat him as if he's got dementia because some people treat them like children. But they still treat him, well he's their Dad, if they want anything, they can go to him …they don't treat him as if there's anything wrong with him, they just treat him normally"*
>
> *DIANNE*

Still treating David as their Dad is important for maintaining David's identity. Sara explains something similar with her Mam; as a family, they have agreed not to correct her mother when she is incorrect, they just carry on as normal. As the participants with dementia explained, being corrected all the time by their family and friends has detrimental effects on their confidence and self-esteem.

The family members have had to accept their loved one can no longer do some of the things they used to do because of their dementia. But wherever possible, the family members encourage the person with dementia to maintain some elements of normality.

7.5 Isolation

Within the narratives for the family members, self-reliance and “being alone” occurred frequently. Collectively, they form the theme isolation. The subthemes that resonate with self-reliance are decision-maker, independence, withholding information and remaining strong. Similarly, being alone is also within the subthemes lack of consideration, no support and criticism. The last subtheme to be discussed is good support, as good support systems can alleviate feelings of isolation.

7.5.1 Decision-maker

Several of the family members who participated in this study explained that they now must make decisions alone. This was particularly difficult for the adult children who have no siblings; they must be self-reliant.

> *“You can’t have a proper conversation with her…she doesn’t understand whereas she was always there. Completely changed, even though I’ve got other family, it is not the same as your Mother. And being an only child as well, you can’t share the responsibilities really”*
>
> *SARA*

Hannah is also an only child and now finds that the roles of their relationship have reversed; where her Mam was always checking up on her, it is now the other way around. When Hannah is not with her Mam, she regularly telephones to check that she is ok.

> *“I am more responsible, I have to make sure she’s taking the right tablets and rather than her checking up on me, I’m the one who’s checking up on her…. Family members who would originally ring Mam to make arrangements for things will also give me a ring just to check that I have had the message”*
>
> *HANNAH*

Some of the family members explained that the pressure to always make the decisions can sometimes be too much for them and they wish that they could have a break from it.

> *"Sometimes I wish somebody else would decide what we're having for tea and go shopping and cook it… it would just be nice to be looked after occasionally"*
>
> *KIM*

Feeling they have no one to support them with decision making can make the family members feel isolated. The level of self-reliance can span from something as small as cooking dinner to larger decisions regarding finances and care packages.

7.5.2 Independence

The married couples who participated in this study explained that they are self-reliant and try to remain independent. Their adult children have their own lives and they do not like to call on them much for help.

> *"I devote more of my time to Beverley and I am quite content with that so the friends we have got, are mutual friends, and they all know, so with the two boys, it has changed that slightly although I don't call on them much, we try and be independent. We are capable of being fairly independent now"*
>
> *TONY*

Tony and Beverley are independent and rarely ask their children for help. This was also true for Darren and Louise, whose children still rely on them for things while Darren and Louise remain independent.

> *"We have always been pretty independent, we don't have this really tight nit family bond which a lot of families get…They [their daughters] still rely on us for things and they still come to visit us but they are not here every other day. It's pretty much, I'm left to get on with everything"* *DARREN*

Remaining independent and not asking wider family and friends for help was also described by Gail who does not want her daughters to worry about her. Darren acknowledges that everyone has things to deal with in their own lives and so not always want to be asked to help someone else with theirs.

> *"Other people have got other shit in their lives that they have got to deal with. Louise's sister I'm a little bit disappointed in to be honest because she is an ex nurse and she hasn't offered any support in any way…our daughters are around if we want them but we try not to put on them"*
>
> *DARREN*

A determination to be self-reliant was common amongst most of the spouses who participated in this study. They do not like asking others to help. Despite independence being their choice, insisting on dealing with things alone can be isolating for the spouses sometimes.

7.5.3 Withholding information

There is a clear divide amongst the family members who participated in this study regarding their knowledge about dementia; some chose to do as much research as possible while others simply did not want to know about the disease and its progression. For those who have gained as much knowledge as possible, they choose what details need to be passed onto their loved one. They must be self-reliant and decide what is best to share and keep to themselves.

> *"Obviously at the time…the doctor gave us information [about dementia] but it's very much information overload at the time. So a lot of stuff that I have learnt is from reading, internet, the Alzheimer's Society provided a lot of information as well, books, webpages on the internet, that sort of thing, is where I got my information from and then a lot of my information I passed on to Rob. Limited information. Need to know information. He knows that he's got dementia, but he doesn't need to know the bad things about it"*
>
> *KIM*

Similarly, when Gail’s husband received his dementia diagnosis, he did not understand what the consultant had said. When he later asked Gail, she decided that it was best not to tell him.

> *“He didn’t take it in because when we saw the consultant who diagnosed the dementia, and said it was dementia, we came out and it was like he wanted to turn a blind eye, he didn’t want to even talk about it because he said to me “I didn’t understand what he was saying” so I thought he’s not ready to be told, I think this is going to destroy him because he was fit enough to know what dementia was at the time, so I said to him “he told us that the Parkinson’s cells in your brain are gradually dying off, he also mentioned that there are some other cells dying off” but I didn’t say it was dementia because I know him pretty well to know how he would have reacted”*
>
> *GAIL*

Both Gail and Kim withhold information from their husbands to protect them. They are both aware of how bad their situations could get but have no one to share their knowledge and worries with.

7.5.4 Remaining strong

Some of the family members who participated in this study have young families who do not necessarily understand what is happening to their loved one. For those family members, they must remain strong for the whole family and be self-reliant. When things get tough for Sara, she must keep going for the sake of her own family. She cannot let her mother’s dementia get her down.

> *“You have got to go on, for everybody else, you have got to keep going haven’t you. How can you not?”*
>
> *SARA*

This was also true for Kim, who feels that she is the “*king pin*” within their family, she keeps everything together. If Kim is having a bad day, her family offer her no support and hide in their rooms until she has calmed back down.

> *“I tend to be the king pin in the family that sort of holds everything together and if I have a melt down and crack up then the family falls apart and they all look at me as if I’ve grown three heads. You find that they all disappear to their appropriate rooms and hide. But yeah, I tend to be the one that sort of holds everything together and issues instructions and keep things running”*
>
> *KIM*

The mothers who participated in the study all gave the impression that they were the *“king pins*” (as Kim says) within their families; they must maintain a state of calm. It can be difficult for the family members to keep it together, particularly when they feel that they have no support from others.

7.5.5 Lack of consideration

Forgetfulness is a common symptom of dementia and can include forgetting when someone has visited or even forgetting a relative. The family members whose loved ones were unable to participate in the study found that their loved one would regularly forget who they were. Because of this, some of the family members find that their other family members do not understand why they visit their loved one if their loved one will not remember; this can result in them becoming socially isolated.

> *“My husband is a bit sort of, well he won’t remember you love so why are you bothering to go in? Because if I have been in today now and I have spoken to him, if I go back in there now, he wouldn’t remember I’d been in or given him his papers or anything. But I remember”*
>
> *PIPPA*

Pippa insists on visiting her Dad even though he does not remember it. It does not matter that her Dad will forget, Pippa will not. Pippa received little understanding from her husband where her Dad is concerned.

> *"Relationship with my husband, he more or less shuts it out, he'll inquire occasionally how's your father? Have you been to see him today? But if I said to him, we'll bring Dad home for the day, "no, we'll take him out. I don't want him to come here"* …*Regards neighbours and that, they don't talk to me, they've all got my phone number just to ring me and ask how he's doing…they deliberately avoid me"*
>
> *PIPPA*

No one visits Pippa's Dad, only her. As she has explained, family and friends will avoid talking to her about him. This was apparent within most of the narratives for those with a loved one living in a residential care home, their friends and family do not visit and do not understand why the family members insist on visiting when their loved one will not remember.

> *"You've got to keep coming to see her, you can't not, you can't forget about her"*
>
> *SARA*

For the family members who are committed to visiting their loved one, they can experience feelings of isolation, especially when those closest to them do not agree with their actions. For Pippa and Sara, having family who do not understand what they are going through, and why they need to visit their parents, can make them feel as though they are going through the dementia journey alone. Greater consideration from family and friends could alleviate the family member's feelings of being alone and isolated.

7.5.6 No support

In accordance with legislative documents, such as the Dementia Action Plan Wales (2018), family members should always be offered support. This was not the case for most of the family members within this study. Even the family members who's loved one have had dementia for several years did not know where to go for support and information on dementia. Having no support can make a person socially isolated.

> *"I didn't know what's out there, even now I don't know whether there's groups to visit or people you can chat to. I joined on Facebook, the Alzheimer's Society, and found a lot out on there and I've asked a lot of questions on there, I've been in to see my Dad today, I don't think he actually knew who I was today, he can look right through me and I don't think it registers who I am …I have sort of stumbled through as I have gone alone and looked on the internet… so it is only what I have read on the internet and my journey with my father really as to I have sort of found things out by asking along the way"*
>
> *PIPPA*

For Pippa, the most horrific incident that sticks in her mind regarding a time when she desperately needed information and support, but none was offered, was the night that her Dad was sectioned.

> *"There were times when I think I don't know what's going on like the evening he was sectioned, I just saw them as taking him away in an ambulance. Nobody told me what's going to happen, where is he going to go, where is he going to end up and all I was told is wherever there is a bed available, we'll be in touch. And I'm thinking but you've taken my Dad away and he is going to be on his own and frightened and can't I come? And I was told no because he's sectioned I can no longer see him and I felt very much out in the wilderness as to well what happens now? I was scared for him and I was upset, and people were saying "oh it's the best thing" and I'm saying well I don't agree with you at the moment"*
>
> *PIPPA*

Pippa was the only participant who had experienced their loved one being sectioned; the ordeal of that night is still vivid in her mind. The other family members suggested that they need information and support on a more day to day basis, not necessarily when extreme measures are taken, like being sectioned.

> *"Sometimes you just need the support when you're having a bad day"*
>
> *KIM*

The participants explained that there is little support being offered to the family members of people with dementia, as Darren explains, all the support is aimed at the person with the dementia diagnosis.

> *"It would have been nice to have been approached by professionals who said right this is for you, because you will need support but no, I haven't had any contact with anybody basically. The support that seems to get put in place, seems to be for the person who is suffering with it rather than the people who have got to pick up the pieces after it… at the start [of the dementia], there doesn't seem to be anything in place for the partners so I think that can be improved...We have had a number of people come to the house…which is for Louise but for me, nothing. I don't mind, I've got broad shoulders, I can get on with it but when I do need help, hopefully there will be some there"*
>
> *DARREN*

Feeling that there is no support for the family members at the beginning of their dementia journey was common amongst participants. As Darren says, he hopes that if there comes a time when he does need more help, it will be available. Isolation is caused by not being connected to others; being offered no support to ease the stresses of living with dementia can cause severe feelings of isolation, particularly when there is no clear means of obtaining support should it be needed.

7.5.7 Criticism

As previously mentioned, some of the people with dementia often become agitated and short tempered. They can often take out their frustration on their family members making them feel as though their efforts of caring for their loved ones are not good enough.

> *"Inadequate. Sometimes I feel that I've let him down in some way. I know I haven't but it does make you feel like that, makes you feel useless…but I do feel like I've let him down in some way or I've done something to make him go like that but I haven't"*
>
> *DIANNE*

Trystan also explains how he can become stressed when Nancy criticises him.

> *"I can't say a little word to her now and she flies off the handle… she's a lot more aggressive now…It's stressful at times, you get frustrated because you can't do right from wrong"*
>
> *TRYSTAN*

For Geraint and his sister, Angie, June was more argumentative when it came to personal hygiene. Angie found this difficult to deal with as Geraint explains:

> *"She was forgetting to bath and she obviously thought she'd already had a bath; she would say to Angie "I don't need a bath. I had one earlier" and Angie would say "Mum that was yesterday when I bathed you" "No I bathed" she would argue that she had already had a bath, it was quite difficult. Mum was getting quite aggressive with it at times because she felt that Angie was just picking on her"*
>
> *GERAINT*

Several of the family members explained that they have had to learn to bite their tongues when their loved one is inaccurate or criticising them. For Dianne, she feels that this will only be effective for so long.

> *"I'm quite prepared to shut my mouth most of the time and get on with it but my daughter says Mam one day you're just going to let rip at him and it's no good saying you're not because you will and god help when you do.*

> *I said well I hope it never comes to that, but she said it will Mam because he's pushing"*
>
> *DIANNE*

There is only so much criticism a person can take, especially when they are trying to do their best for a person that they love. Feeling that their best efforts are not good enough for their loved one can result in the family members feeling down and alone. Sharing these negative experiences with another person can reduce feelings of isolation.

7.5.8 Good support

Good support systems are the most effective method of preventing feelings of isolation within the family members of people with dementia. Support from family members when the person with dementia is being a little bit difficult can reassure the family member.

> *"They [family] are very supportive of me, if they think he is a being a little bit, say bombastic then for want of a better word, they won't let him get away with it, they will tell him and then he'll go and sit in his corner and he'll have a little think about it"*
>
> *DIANNE*

Dianne's children will tell their father when his behaviour is unacceptable and make him realise what he is doing. For Laura, the family support comes from her husband allowing her to spend as much time as she needs with her mother while he sorts out everything else.

> *"I have got a brilliant husband… His view was "you look after your mother; I will look after everything else". And he has"*
>
> *LAURA*

The best support that Bethany has received came from the memory clinic which her mother attends. The memory clinic nurse manages to encourage Lynne to participate in different activities whereas Lynne will tell Bethany that she does not want to. Bethany often feels that she is nagging her mother, but the memory clinic nurse is able to alleviate some of that pressure.

> *"Then they sent us one of the memory clinics nurses, he's absolutely brilliant, my mother loved him straight away. Completely different attitude, she'll do whatever he asks her to do, we can argue all week, he will come and say well why don't you try it and she's gone… it gives us sort of a break as well because sometimes we feel like we're constantly nagging her"*
>
> *BETHANY*

A good support system can create an element of solidarity when coping with some of the difficult elements of dementia. For Dianne, her family help her show a united front against David's "bombastic" behaviour. Laura's husband has allowed her to focus on her mother completely while he sorts out everything else and Bethany has found that the memory clinic nurses can intervene and stop her "nagging" her mother. Feeling a sense of solidarity can prevent feelings of isolation when living with dementia.

7.6 Visual Cues

Similar to the participants with dementia, the visual cues were also noted for the family member stories. Unlike the people with dementia, the family members did not convey additional details using hand gestures. They did, however, offer many emotional cues whilst narrating their stories. These emotional cues allowed for deeper understanding of the significant explanations they were offering. When acknowledging all the loss they have experiences, Kim and Gail became visually upset. Similarly, Sara and Dianne became upset when explaining the struggle they experienced with hospital care, and having to deal with things alone. Laura began to cry when thinking of the future. Instances such as these highlight the elements of life with dementia that are particularly poignant for the family members.

When Darren made jokes about Louise (for example, being hit by a bus) he would smile at her and wink as he said it. These visual signs would have been missed by audio recording but provide much understanding of Darren's character and relationship with Louise. Furthermore, they held hands throughout the interview for moral support. This again would have been missed by solely audio recording the interviews.

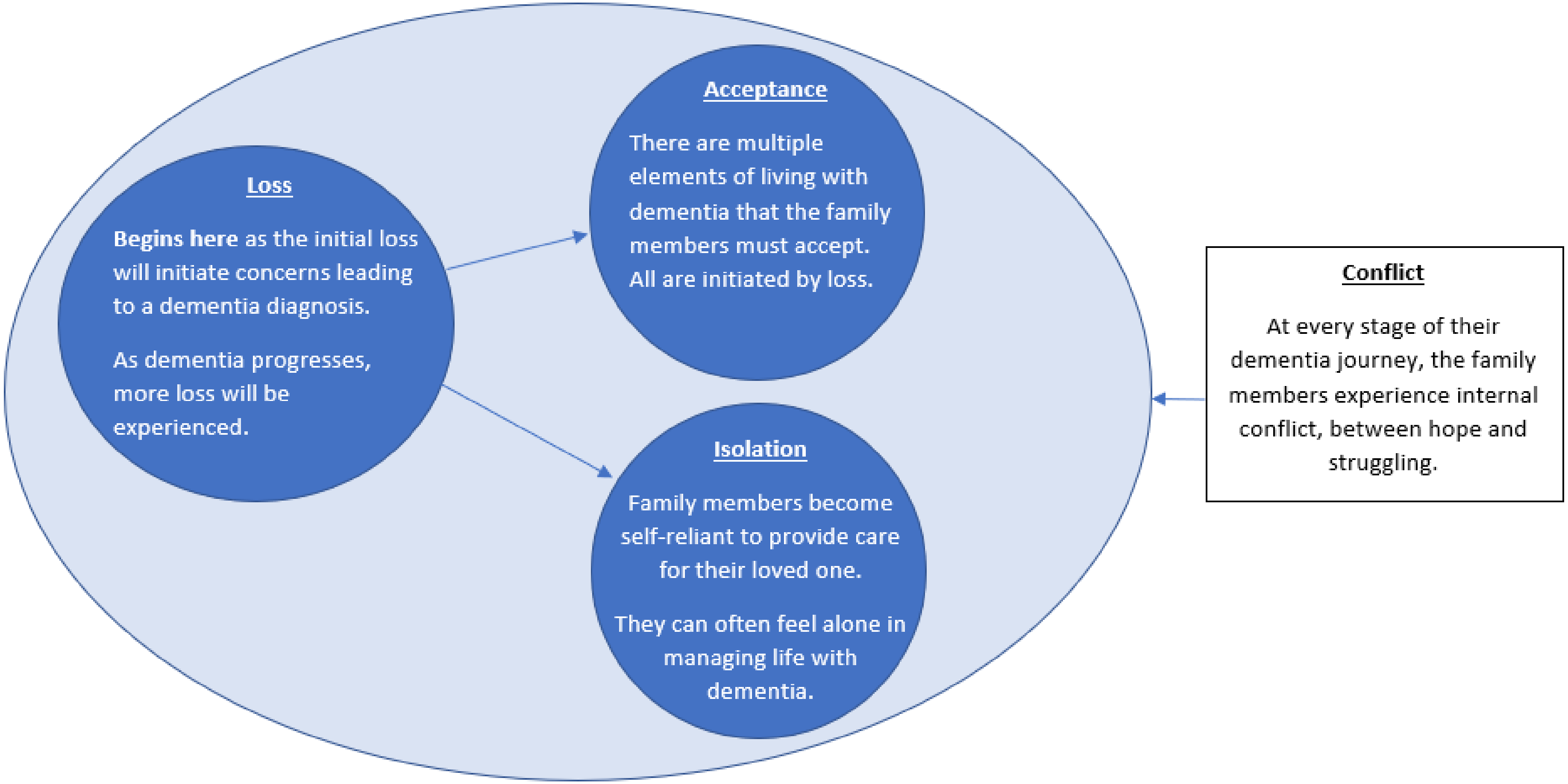
7.7 Model of Living with Dementia

To explore the connection between the four themes, the model below was created (Figure 6). The family member's journey of life with dementia will always be sparked initially by a feeling of loss. The initial loss in cognitive ability will be noted when the family members acknowledge what has already been lost and seek medical advice. After their loved one receives a dementia diagnosis, the family members have to accept the diagnosis, the changes that may happen in their lives and the possibility of there being a hereditary link. The dementia diagnosis will also result in the family members becoming self-reliant and having to deal with things alone.

Living with dementia is not a one-off experience of loss; dementia is a progressive condition that worsens over time. Acceptance cannot be a one-off occurrence; it is an ongoing process as their situation changes, and they experience more loss. As the person with dementia's ability decrease, and their care needs increase, so does the family member's sense of isolation. Whilst acceptance and isolation are more so thoughts and feelings (internal processes), the loss the participant experiences can be observed as their loved one's condition deteriorates and will be noted within their medical records as evidence of the dementia progressing. As the diagram explains, acceptance and isolation are dependent on the person experiencing loss. The loss will occur regardless of the other factors. As the dementia progression varies from person to person, so will the frequency of the family member experience of the sense of loss, and the severity of that loss. Therefore, for some, this process may only happen once or twice, with only one or two incidents of loss. For others, they may experience many losses whilst living with dementia and will restart the model multiple times.

Conflict is present at every stage of the family members’ dementia journey and encompasses all the other themes. Throughout their lives with dementia, the family members will experience highs and lows, struggles and hope. Sometimes, these mixed emotions will co-exist and occur simultaneously.

Figure 6: Model of living with a family member with dementia



Loss

Begins here as the initial loss will initiate concerns leading to a dementia diagnosis.

As dementia progresses, more loss will be experienced.

Acceptance

There are multiple elements of living with dementia that the family members must accept. All are initiated by loss.

Isolation

Family members become self-reliant to provide care for their loved one.

They can often feel alone in managing life with dementia.

Conflict

At every stage of their dementia journey, the family members experience internal conflict, between hope and struggling.

7.8 Summary and Reflection

These results suggest that family members of people with dementia struggle daily to live with the condition; these struggles are both emotional and physical. All participants talked about an internal emotional conflict that they face every day. Some were more negative about their loved one’s dementia while others remained optimistic and positive. Discussing the future elicited mixed emotional responses in the participants with some becoming upset and having to pause their story telling.

All the family members who participated in this study displayed a fierce determination to do their best and get the best possible care for their loved ones. For some, this involves providing care themselves, home renovations and fighting the health boards or social services to get what they believe to be the best for their relative.

All participants have accepted the changes in responsibility that occur as a result of their loved one’s dementia. Several participants talked about relationship changes that had occurred since their loved one had developed dementia; for some, the intimate relationship of their marriage had diminished, leaving them to feel like single people again. For others, they have lost friendships and their need to care for the person with dementia has put a strain on their relationship with other family members.

A key theme for the family members who participated in this study was isolation. Self-isolation was apparent within several of the participant’s narratives whereby they want to remain independent and not ask for help. The family members were very aware that they were being avoided and had lost friends because of their loved one’s dementia. The findings suggest that the family members of people with dementia need more support. Emotional support would help the family members come to terms with the loss of a spouse, feelings of isolation, changing responsibilities and coping with life with dementia.

The next chapter of this thesis offers a discussion on the results of this study. It draws on all the previous chapters and considers the results of this study in relation to the literature, perspectives of dementia and legislation, policies and frameworks. It is split into three sections, the discussion on people with dementia, family members and joint perspectives. Commentary is made on the use of digital storytelling as the data collection tool too as this is rare and not well documented.

Reflection on the Chapter

I struggled to put together a model of life with dementia for the family members. I became preoccupied with the grief curve as all their experiences could be mapped against that. But living with dementia is not a linear progression. As the condition deteriorates, more levels of loss will be experienced. Thus, making the grief curve obsolete. I needed to represent the unity of the themes and how acceptance and isolation are dependent on loss whilst conflict is ever present. I feel that I have portrayed this coherently within the model (Figure 6).

The hardest theme for me to label was “conflict”. I wanted a theme that encapsulated the emotional turmoil experienced by family members. Feeling optimistic and pessimistic about their life with dementia. To try and label this theme, I spoke with my academic supervisors and decided on “conflict” to portray the emotional conflict experienced. It is only since having my VIVA that an examiner suggested its similarities to ambivalence.

As I have previously said, I tried not to follow the norm seen within the literature and only highlight the negative aspects of living with dementia. While I feel I was successful in providing a balanced portrayal for the people with dementia, this was much more difficult for the family members. The family members shared some positive stories about their lives with dementia, but these were greatly outweighed by struggles, upset and worry. Although rare, participants did share stories about humour, acceptance and optimism. The videos were useful for identifying these instances as I could see a clear change in their facial expressions, between seriousness and amusement. I do not think I would have been able to tweeze out these scarce moments had I only audio recorded the data. Whilst I am aware that the family member themes are more negative than the participants with dementia, I stayed true to the narratives of the participants. These narratives were primarily more negative and this chapter represents that.

CHAPTER 8 DISCUSSION

“Dementia is the only disease or condition, and the only terminal illness that I know of, where patients are told to go home and give up their pre-diagnosis lives, rather than to fight for their lives”

(Kate Swaffer, 2015, pp. 3)

8.1 Introduction

This chapter draws together the results from chapters 5, 6 and 7 to address the research aims and discuss the links between these findings and the relevant literature, policy and perspectives of dementia. This study has generated rich data about the lived experiences of people affected by dementia. Their narratives have highlighted the journey that the participants have taken, from childhood through to the present day whilst the family members’ narratives explored a shorter journey, focusing as they did primarily on their lives after the dementia diagnosis. This chapter is divided into three sections, initially beginning with a discussion on the experiences of the participants with dementia. It goes on to explore and understand the lived experience of the family members who participated in this study while the final section will highlight any similarities between the two populations. Throughout, commentary on the observations made whilst using the video recordings and life story work are also made in relation to the literature.

8.2 Lived Experience of People with Dementia

Four themes were identified within the narratives of the participants with dementia; these are identity, resilience, acceptance and isolation. These themes are all present in studies found within the pre-existing literature. As the literature review demonstrated, many studies have focused on the identity and sense of self for people with dementia while the resilience of people with dementia is a developing area of research within gerontology with theorists (Baltes and Carstensen, 1996; Harris 2007; Keady *et al.*, 2007) proposing that resilience is essential to successful aging. Elements of acceptance and isolation resonate with pre-existing studies uncovered within the literature review. These are discussed further below.

8.2.1 Identity

Identity was a key theme for the people with dementia who participated in this study as they all felt their sense of self had been altered by their dementia. All participants explained they had lost a part their identity due to their dementia and had to come to terms with their new sense of self. As Lynne said, *“it takes a bit of accepting because part of you is gone and you’re losing that part that you want desperately to have”*. This is only one example of a participant explaining their deteriorating physical and psychological health causes changes in their identity that results in negative feelings towards themselves. This emulates with findings from Nordtug *et al.* (2018) who suggests that people with dementia will grieve for their former selves as their condition alters their cognitive abilities. The methodology utilised by Nordtug *et al.* (2018) resembled the personal history elements of this study whereby the participants discussed their life history, not just their life with dementia. It is possible that comparing the two phases of the person’s life within the same interview could lead the participant to directly compare the two and elicit feelings of grief towards their former self. This possible causation is further strengthened by the findings from Hedman *et al.* (2012) who did not apply life histories to their methodology, and solely asked about life with dementia. Their findings suggest that *“overall, they perceived themselves as being the same people as they were before the onset of Alzheimer’s Disease”* (Hedman *et al.,* 2012, pp 730).

For the people with dementia who participated in this study, most did not understand the diagnosis they had been given; for example, *“I still don’t know what the difference is between ordinary, vascular dementia and just plain dementia”* (Nancy). Similarly, Karnieli-Miller (2012) found that people with dementia in Israel did not understand their dementia diagnosis either; suggesting that this is a problem in other countries. Until recently, people with dementia were not told their dementia diagnosis as health professionals felt that the news could elicit depression or suicidal thoughts (Lee *et al.*, 2014; Scott, 2001). Yet, Lee *et al.* (2014) argues that health practitioners should ensure the person with dementia understands their diagnosis. *“Participants* *were glad they had been told as it had helped them understand and make sense of their condition"* (Lee *et al.,* 2014; pp. 302). They may initially feel distressed, but after a period of time, they will begin to adjust and learn to cope with their diagnosis (Lee *et al.*, 2014). This was apparent in the current study as those who had received their diagnosis within the last year were upset (Lynne, Louise and Rose) while those who had been diagnosed with dementia for a few years were more accepting of their diagnosis (June, May and Pat).

Ryan *et al.* (2009) found that people with dementia often identify themselves as "*educators to those who do not understand dementia"* (pp 150). This is also true for those who participated in this study as the purpose of this study was to explore the lived experience of people affected by dementia. It is why all participants chose to disclose their stories; to share their experiences and aid people in understanding life with dementia. The importance of recognising people with dementia as "*educators*" who can help researchers understand life with the condition has also been noted by the Prime Minister's Challenge on Dementia 2020 (2016) which acknowledges that research into improving knowledge of dementia is vital to creating a dementia friendly Great Britain by 2020.

8.2.2 Resilience

"Resilience is defined as a dynamic process encompassing positive adaptation within the context of major adversity" (Cicchetti, 2010, pp. 145) and is central to "successful aging" theories proposed by critical social gerontologists (Harris, 2007; Keady *et al.*, 2007; Harris and Keady, 2008) as described in chapter 2. All participants' narratives displayed elements of resilience regarding their lives with dementia whereby they have positively adapted to their situation despite living with this challenging condition. Harris and Durkin (2002) considered accepting the diagnosis, maintaining a positive attitude and disclosing their diagnosis to others to be resilient traits. These were all apparent within the narratives of the participants with dementia. Furthermore, remaining connected through community activities was deemed to be central to a resilient personality type (Harris, 2008). The need to remain connected to family and friends was also noted by Christie (2016), Karlsson *et al.* (2014), Surr (2005) and Steeman *et al.* (2007).

The participants with dementia explained that they try to remain independent and maintain a sense of normality within their daily lives, although this is not always possible due to their deteriorating physical and psychological health. For example, Rob enjoys looking after his smallholding but is aware that he will have to give it up as his dementia progresses. This is one of many examples whereby the participants explained that they try to maintain normality, despite the increasing struggle to do so. Maintaining normality in the face of declining health is central to successful aging theories (Havighurts, 1961; Rowe and Kahn, 1998; Bonanno *et al.,* 2001). However, not all participants were able to maintain normal activities and this inability made them feel angry and upset. For example, Nancy feels that she is no longer a *"housewife"* as she cannot maintain their home or cook their meals. This is consistent with findings from Hellström, Eriksson and Sandberg's (2015) who found that women with dementia often explained their identity in terms of their role within the home; when their husbands had to take over the role, the women were not accepting of the change.

All participants within this study attend dementia support groups or care home activities and most found that these support groups provided them with a sense of belonging; *"we all understand that we've all got some problems and we don't have to worry that we will feel different to normal people. And they can be like a family as well so it's good"* (Rose). Participating in meaningful activities is essential to "*successful aging*" (Havighurst, 1961) and is directly linked to quality of life (Giblin, 2011; Reynolds, 2015) .The benefit of community social support groups has been acknowledged since the 19th century with the British government encouraging the community to support people with dementia (Clift *et al.,* 2008). Furthermore, participating in a dementia support group was found to "*have an equalising effect and to inspire confidence and to reduce isolation"* for people living with the diagnosis (Bungay and Skingley, 2008, pp. 6). Being a part of a dementia support group offers social benefits and a sense of connectedness (Clift *et al.*, 2008) that was apparent within the stories of the participants in this study who explained they enjoyed being around people in the "same boat". Being with people in a similar situation offers people with dementia a sense of acceptance.

8.2.3 Acceptance

For the participants with dementia within this study, a need to feel socially accepted was common, yet this was more prevalent for the people with dementia who are still living at home. Since being diagnosed with dementia, Nancy, Louise and Lynne felt that they have no self-worth; for example, Nancy says *"I don't feel that I've got any worth at all"*. Whereas June and May, who live in residential care homes, felt that their friends' acceptance did not matter anymore. As Surr (2005) found, people in care homes feel accepted by the other residents and staff within the home, and therefore, may not feel the desire to be accepted by people outside of that home. This may offer an explanation for May and June not feeling the need to be accepted by family and friends, as they are accepted by the people they see every day; that is the staff and residents within their residential care home. This is a topic for further research, and a recommendation of this study. If this is a wider occurrence for people living with dementia, it could challenge the current guidelines to keep people in their own home for as long as possible as the care home environment benefits the psychological wellbeing of people with dementia.

The participants in this study explained how good support systems helped them accept their changing identities; for example, *"I tend to bother with the people that I know, know that I have got the dementia"* (Nancy). This is illustrated within the model of living with dementia (see Figure 5, pp 167) that shows how being socially accepted as a person with dementia can strengthen their resilience levels, which, in turn, helps them adapt to their changing sense of self. This is reaffirmed by Svanström and Sundler (2015) who demonstrated that strong relationships are essential for people with dementia to remain connected to their wider communities, prevent them living a vague existence and helps them adopt a positive attitude. *"Other people's presence is needed in order to create a sense of meaning and to avoid the situation where everyday life becomes fragmented and more and more vague"* (Svanström and Sundler, 2015; pp 160). As previously highlighted, this positive attitude is linked to resilience. The importance of a good support system or support group for people with dementia has been recognised and formulates one of the recommendations for this study. For those who feel they are not accepted by friends and family, life with dementia can become isolating.

8.2.4 Isolation

Feelings of isolation were apparent within the narratives of most participants and this seems to stem from the lack of acceptance they feel. For some participants, their families did not accept their dementia diagnosis; for example, David's family thought it was a joke, while Nancy's family accused her of being a hypochondriac. Furthermore, several participants discussed being avoided by their friends and family; as Nancy said, "*it's like I'm walking around with a big sign, beware, dementia*". This is echoed by Sterin's (2002) case study who found that the lady was either dismissed by her family and friends, much like David's experience, or became invisible and ignored, avoided like Nancy.

Feeling isolated as a result of declining independence is common in older people generally living in their homes (Hillcoat-Nallétamby, 2014). For the people with dementia who participated in this study, their declining independence, due to their condition deteriorating, was associated with worries about becoming a burden on their families. For example, Lynne explained *"I'm independent, I like to do my own things and I haven't been able to, I'm relying on my daughters and that's an awful feeling. I don't want them to be burdened by me".* This resonated with the findings from Chen and Lin's (2019) study whose participants were aware of their increasing dependency but did not want to burden their families with their additional care needs.

Rowe and Kahn (1998) suggest that feeling lonely when living with dementia can increase the person's chances of developing a co-morbid mental health disorder and even their chances of early mortality. Combined with the findings from this study, it suggests that people with dementia should be encouraged to participate in social activities where they can feel accepted, as this will reduce feelings of isolation and ultimately, improve their quality of life.

8.2.5 Further observations

Of further note are the observations made during data collection. Discussing life with dementia was an emotive subject, with several participants becoming visually upset (tearful) during data collection (Nancy, Lynne, Louise, Rob and Rose) when discussing the differences between their lives prior to dementia and their current ones with dementia. It is common for life story work to evoke negative emotions within its participants due to its reflective nature (Desalvo, 2000). During the interviews, the participants were confronted with their changing identities, a need to be accepted and feelings of isolation; some of which they would not have given much thought to previously (for example, *"this is the first time that I have said it out loud";* David). It is therefore understandable that they became upset. Nevertheless, a procedure for dealing with upset caused by the data collection process was considered as part of the ethical safeguards of this study.

All participants made reference throughout their narratives to the medications that can be taken for dementia. Their experiences of dementia medication ranged from Nancy not understanding why medications were not available for her vascular dementia, to Pat believing that her Alzheimer's Disease medication has prevented her dementia from progressing appreciably in the past 10 years. Despite all participants trying to remain active members of the community (comparable with the social model of dementia; Bartlett and O'Connor, 2010; Brooker, 2004), they placed a lot of reliance on a medical intervention to slow down the progression of their dementia; this resonates with the medical model of dementia and is similar to the Irish American participants in Hinton and Levkoff's (1999) study who favoured the medical model of dementia over the social one. This may be attributed to the western culture ideals of medicine that can be identified within the Irish American and Welsh communities whereby emphasis is placed on medical interventions (Rapple. 2010).

Despite their cognitive impairment, all the participants in this study provided articulate narratives about their lived experiences. This supports the scarce literature which suggests that dementia does not prevent people from taking part in research and sharing their stories (Digby *et al., 2016;* Lee *et al.*, 2014). Excluding people with dementia from research only serves to *"reinforce negative stereotypes and contributes to social exclusion"* (Novek and Wilkinson, 2017, pp 2). The importance of including people with dementia in research was expressed by Black *et al.* (2012), who demonstrated that the caregiver's proxy accounts do not mirror the experiences of the person with dementia; therefore, giving the person with dementia a chance to share their wisdom is essential to understanding life with the condition as one person’s life narrative can never be truly conveyed by another. Bartlett *et al.,* (2018) states that “*recruitment is a challenging and an often disregarded aspect of research”* (pp. 2) as researchers primarily focus on ethical approvals. But for this current study, the two went hand in hand. The ethical issues linked with dementia research influenced the recruitment and therefore, it is important to note that this study recruited participants who had awareness of their life with dementia; people at a later stage of dementia may not be able to participate in qualitative research. It is worth noting however, that there has been an increase in the number of people with dementia taking part in drug trials as these do not require the same ethical processes and it is unethical to claim a treatment works for dementia, if it has not been trialled on people with dementia (Bethell *et al., 2018).* There are several modifications and considerations to be addressed when trying to ensure people with dementia can take part in research; these have been discussed at length within the methodology chapter of this thesis. A personal reflection of this can also be found in the last chapter of this thesis (pp 274). Highlighting these factors can be used by other researchers and therefore, have implications for future research, which are discussed later in this thesis (pp 270).

8.2.6 Summary of the lived experience for people with dementia

This section has demonstrated what life is like for a person living with dementia. The results suggest that a change of identity will be experienced by people living with the condition; some will adapt quickly to this change whilst others will resist it and try to maintain a sense of their former selves. Despite the adversity experienced, those affected can still display elements of resilient personality traits as they try to maintain normality, remain positive and optimistic, and participate in meaningful activities.

Living with dementia can become an isolating experience as they may be avoided by friends, struggle to cope with the changes they experience in their physical and psychological ability and try to remain independent not to burden their loved ones. Feeling socially accepted through good support systems and spending time with people in similar situations helped alleviate the feelings of isolation for the participants in this study and helped them come to terms with their changing identity.

A change in identity when living with dementia cannot be prevented as the condition deteriorates; however, resilient traits can be encouraged through resilience boosting programmes. Feeling socially accepted can be emphasised through dementia support groups which can also alleviate loneliness. The model of life with dementia (Figure 5, pp 167) illustrates how these all tie together and improving the one, can have an impact on how the person with dementia experiences the other. This all resonates with successful aging theories. Despite the controversy surrounding this theory in regards to those living with dementia (as discussed in Chapter 2, pp 24), the findings from this study support the premise of older people remaining socially active, self-sufficient and resilient to help them live better with dementia. These all tie into the recommendations made in the following chapter of this thesis (pp 267). The next section of this chapter will offer insight into the lived experiences of the family members.

8.3 Lived Experience of Family Members

Within this section, the lived experiences of the family members of older people with dementia are explored and discussed. Four themes were identified within the narratives of the participants; these are loss, conflict, acceptance and isolation. These themes are present in studies found within the pre-existing literature. The theme conflict has the most supporting literature as this theme encompasses the turmoil experienced by the family members regarding the roller-coaster journey they are undertaking; balancing hope and despair.

8.3.1 Loss

Loss was a theme in all the participating family members' narratives as the reflective element of the data collection process resulted in the participants comparing their loved one's previous lifestyle to their current one. Within chapter 7, this subtheme was entitled "*acknowledging what has been lost*" as all participants explained that their loved one had already lost some cognitive or physical ability and they worried about the further loss to come. As Gail explained, her husband was a lively man, who held opinions on everything; now he is a lot quieter and does not speak much.

Participants comparing their current position to previous ones has been noted within other research studies with Robertson (2010) explaining that this social comparison served as a means of judging quality of life.

Comparing their loved one's situation to another with dementia was also common amongst the participants as they tried to make sense of *"how bad"* their position is. As Kim explained, she does not want Rob to attend day centre as she fears that it will be too confrontational for him; he will be surrounded by people at a later stage in their dementia and he will see what the future could possibly hold for him. Alternatively, Dianne uses the comparison to establish that her husband is still "*doing well*" and not deteriorating as much as others they know from the dementia groups. This phenomenon was also found by Robertson (2010) who noted that this comparison allows people to make sense of the world that they live in.

Having a spouse with dementia can sometimes make the family member feel that they are a single person once again, as their husband is no longer the man they married. This was experienced by Kim and Gail, as Kim explains the spontaneous affection and reassurance from her husband when she is upset is something that she misses most from Rob; *"the person that I loved and married is gone, now it's like living more with a friend. It's down to that emotional side of things, that closeness that you have in a personal relationship"*. Contrary to this, the husbands who participated in this study (Trystan, Darren and Tony) felt that the relationship with their wives had strengthened since she had dementia. This gender difference reaffirmed conclusions made by Hayes *et al.* (2009) who found that female participants were more likely to experience a loss of spousal connection because of the lack of kissing, hugging and saying *"I love you*" from their spouse.

Feeling the loss of a spouse highlights a clear gender difference in the relationship dynamics between the male and female participants. These opposing frames of mind can occur within one person, with an internal conflict between hope and despair, optimism and pessimism. These have been encompassed within one theme for the family members, entitled conflict, and is discussed next.

8.3.2 Conflict

A major theme for the family members who participated in this study was conflict; this encompassed the emotional conflict all family members experienced whilst living with dementia. Kim differed from the other family members as she strongly feels that her husband is no longer the man that she married; because of this, Kim is trying to decide if it would be ok for her to seek an intimate relationship with someone else as she "*did not sign up for this*". Kim is experiencing a different type of conflict to the other participants; she is conflicted about the way she feels about her relationship with Rob. There is a 20-year age gap between Kim and Rob which may contribute to Kim's feelings but there is no supporting literature to reaffirm her experience. This is a clear gap in the knowledge base of living with dementia and sexuality, and is subsequently, a recommendation for further research (pp 267).

Emotionality was a subtheme within conflict as all family members frequently referred to experiencing a mixed emotional response to their lives with dementia, as Gail explained that she felt, *"all mixed emotions"*. This resembled findings from Shim *et al.* (2012) in which family members would often lose their temper with the person with dementia but then feel guilty and apologise. Guilt was a common emotion experienced by family members; due to feeling resentment towards their loved one and for having time away or respite. Guilt was also a common theme noted by Mullin *et al.* (2011) and Hellström *et al.* (2017) whose participants felt guilty for spending time away from their loved ones while Hennings *et al.* (2013) found that family members felt guilty for moving their loved one into residential care as *"caregiving is full of contradictions and ambiguity"* (Hennings *et al.,* 2013; pp 689). This is contrary to the findings of the current study as the family members who were recruited through the residential care homes (Pippa, Laura, Geraint, Sara and Gail) did not share similar feelings of guilt for seeking out residential care for their loved ones; they understood that residential care was the best option for their safety.

The idea of self-care was common amongst the participating family members in this study, with most saying that having time alone, "*when I don't have to worry… that is heaven"* (Dianne). The link between time alone, and wellbeing has also been acknowledged by Oliveira *et al.* (2020) who found that the mental health of family caregivers was significantly influenced by the amount of time that person spends doing things they enjoy. As Laura explained, having time to herself initially made her feel selfish but she was also aware of how essential it was to her mental wellbeing. Family caregivers missing out on "*me time*" due to their increasing responsibility has led health professionals to label them "*the invisible second patient*" as they often experience physical and psychological ill-health as a direct result of their caregiving responsibilities (World Alzheimer's Report, 2019; Brodaty and Donkin, 2009). This has also been recognised within the Social Services and Well-Being (Wales) Act (2014) which states that local authorities must meet the needs of carers and they are entitled to an assessment of need in their own right[8].

Several participants spoke about struggling to cope. The primary cause of this struggle was the person with dementia's changing temperament; for example, *"you feel you're treading on eggshells"* as Dianne said. For some, the struggle to cope became too great and they had to seek out additional care and support for their loved one; as James explains, his sister could not cope with their mother's aggression regarding personal hygiene. Aggression from the person with dementia was a common stressor for the family members who participated in Jayalath *et al*'s (2016) study too, along with incontinence and forgetfulness. Incontinence was only reported as a problem by Sara in this study; this does not mean that the other participants do not struggle with this, they just did not talk about it although Darren made a joke about providing toileting support to Louise in the future.

There is a small body of literature which suggests that caregivers will use humour as a defence mechanism when living with dementia (Polenick *et al.*, 2020). This is certainly true of Darren, who uses humour to express his commitment to his wife; *"if I've got to wipe her arse, I'll wipe her arse as well"*. While others try to find humour in different situations; for example, *"we do laugh as much as we can about things as well"* as Bethany stated. Whilst the use of humour was common amongst the family members' narratives to cope with the condition, there is little research exploring the

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[8] The Social Services and Well-Being (Wales) Act (2014) defines a "carer" as a person who provides care for another adult.

use of humour amongst people living with dementia. There is an array of literature for the use of humour when living with other terminal conditions, such as cancer (Morris and Page, 2018) and AIDs (Pandey and Tripathi, 2017). This is an area for future research to explore and has been made as a recommendation based on the results of this study (pp 267).

Making services clear to people in Wales in order to obtain timely diagnoses was an aim of the Dementia Action Plan Wales (2018) yet the participants in this study highlighted several problems concerning healthcare services. The problems ranged from obtaining a diagnosis (as explained by Geraint, Sara, Tony and Laura) to lack of support (as explained by Pippa and Kim). Not being satisfied with the outcome of a memory clinic appointment was a key finding for Karnieli-Miller (2012) too despite this study being conducted in Israel where their memory clinic structures may differ. The findings resonate with the results from family members in this study whereby they felt that the memory clinic appointment had not provided them with the information they needed regarding the aetiology of their loved one's type of dementia, support resources and future needs. Regardless of the lack of information they had received about their relative's condition, all family members were accepting of the diagnosis.

8.3.3 Acceptance

The family members all explained that they had been accepting of their loved one's diagnosis. This differs from the acceptance theme for the participants with dementia as they wanted to be socially accepted, whereas for the family members, acceptance represents for them an internal accepting of their relative's diagnosis. For participants, the dementia diagnosis confirmed their suspicions, that their loved one had developed dementia. They all spoke about their positive reaction to their loved one's dementia diagnosis within their narratives; for example *"just accept what's going on because you can't stop it once the tidal wave starts coming in, it's coming in and you can't stop it, so you have just got to go with the flow"* (Pippa).This is a rare finding as there was no supporting evidence found within the literature search and is therefore, a recommendation for research. Further research could focus on the reaction of caregivers to their loved one's dementia diagnosis to understand their process of accepting the condition. This would have implications for interventions whereby support could be offered to help people come to terms with the diagnosis more quickly.

Changes in role and responsibility were key aspects of the family members' lives with dementia that needed to be accepted; for example, "*I've got a lot more responsibility, a lot on my shoulders*" (Gail). The increased responsibility was a feature for all family members with most spouses agreeing that "*it's just part and parcel of looking after my wife"* (Trystan). This echoed findings by England (2017) with the case study of Mr Cassidy, who highlighted his marital commitment to care for his wife until she passed away, despite his own health problems; *"he aspires to be the kind of person who keeps his promises yet feels helpless in caring for his wife"* (England, 2017; pp. 964). Mr Cassidy's wife often became violent towards him, but he maintained that she was still the woman he married. This is consistent with the findings from this study as Trystan, Darren and Tony emphasised their commitment to their wives, despite their diagnoses.

The male participants were more accepting of their increasing roles and responsibilities than the females who participated in this study. The women spoke more about struggling to cope (for example, *"it's hard to cope with",* Gail), whereas the males explained that their increased responsibility was part and parcel of taking care of their wives. This gender difference resembles outcomes from Jayalath *et al.* (2016) and Uei *et al.* (2013) who found that male caregivers underplay their struggles when living with dementia while female caregivers are more likely to report feelings of burden. Jayalath *et al.* (2016) suggests that this gender difference may be because *"men normalise more of the behaviours associated with dementia than the female caregivers*" (pp 97). Studies have suggested that women tend to spend more time providing care for their loved one with dementia. Time spent providing care is positively correlated with caregiver burden (Uei *et al.*, 2013; Casado and Sacco, 2012), while wellbeing is negatively correlated with burden (Lethin *et al.*, 2020). Several studies uncovered in the literature review explored caregiver burden (Jayalath *et al.*, 2016; Uei *et al.*, 2013; Hasselkus and Murray, 2007), yet none of the participants in this study expressed feelings of burden whilst caring for their loved one. Instead, the family members try to help their relative as much as possible.

Helping their loved one maintain a sense of normality was common amongst the family members. Darren ensures that Louise still performs tasks around the house, while Dianne's children still treat David as their father, and Kim encourages Rob to maintain his hobbies (learning guitar and tending to his animals on the smallholding). Maintaining hobbies and a routine is central to preserving the identities of people with dementia. The literature also suggested that family members will aid in maintaining the person's identity through a sense of normality and engaging them in meaningful activities (Cronfalk *et al.*, 2018; Johansson *et al.*, 2014; Hutchings *et al.*, 2011). These studies also noted that family members were worried that residential care homes would not encourage their loved one to participate in stimulating activities. Contrary to this, the participants in this study explained that there are so many activities within their loved one's care home they struggle to know when to visit and not interrupt activities, for example, in Laura's biography. This difference could be attributed to the individual care home organisations as they offer different services. Despite family members accepting their loved one's diagnosis, and remaining hopeful, they also explained their life with dementia made them feel isolated.

8.3.4 Isolation

Family members felt disconnected from support services and information which has resulted in them becoming self-reliant and isolated. Despite the Mental Health (Wales) Measure (2010) emphasising that family caregivers must be provided with plenty of information and support to manage living with the condition, the family members' narratives suggest otherwise. Several explained that they had not received enough formal information about their loved one's diagnosis and had to seek out the information for themselves on the internet. For example, *"I have sort of stumbled through as I have gone alone and looked on the internet"* (Pippa). Furthermore, some family members were not aware of what support was available to them. For example, *"it would have been nice to have been approached by professionals who said right this is for you, because you will need support but no I haven't had any contact with anybody… when I do need help, hopefully there will be some there"* (Darren). Supporting the family members of people with dementia is essential to preventing them becoming isolated and over-whelmed with the demands of their caregiving role. Feeling disconnected from support services is common with Strommen *et al.* (2020) finding that families living with dementia in America were not aware of the support that was available to them, while Gorska *et al.* (2013) found that families in Scotland were in need of post diagnostic advice, information and assistance to help them adapt to living with the condition. This suggests that, internationally, there is a clear need for families to be provided with more information, in a variety of ways, and at different points in time, about the support that is available to them.

Withholding information is a subtheme within isolation, as the family member will protect the person with dementia from the reality of their diagnosis. Both Gail and Kim explained that they have purposely not told their husbands certain information about their condition. Gail chose not to reiterate to her husband that he had been diagnosed with dementia; *"I thought he's not ready to be told, I think this is going to destroy him because he was fit enough to know what dementia was"*. Yet, as Lee *et al.* (2014) and Scott (2001) suggest, people with dementia must be told their dementia diagnosis; initially they may be upset but will eventually come to accept it. However, Kim also admits to withholding information from her husband and only shares "*need to know information"* with him. She will seek out information about her husband's diagnosis but will only relay limited information to him. Kim feels that her husband does not need to know how bad things will get. This is equivalent to Hellström and Torres (2013), who found that the family members in their study would seek out information about their loved one's dementia diagnosis but would not share that information with them. Further inquiry by Hellström and Torres (2013) found that the people with dementia typically did not want to know how their diagnosis would impact on their futures, they were solely interested in the here and now. Withholding the reality of the condition from their families can be isolating for the family members, as they know what the future may hold but cannot share their anxieties.

Remaining strong was an important element of the family members' life with dementia as they do not want their wider family to worry. For example, as Kim explained, "*I tend to be the one that sort of holds everything together".* Similarly, most of the family members try to remain independent and not ask other people for help as "*other people have got other shit in their lives that they have got to deal with"*

(Darren). Having to cope with life with dementia alone, can be an isolating experience, even if the person chooses to be independent. There was not any evidence found within the literature search that echoed these findings, suggesting that this is an under explored area that research could investigate.

8.3.5 Further observations

Of further note are the observations made by the research student during the interviewing process. All the family members are committed to doing their utmost to support and protect their loved one with dementia; this was apparent throughout their biographies and their narratives, mirroring the findings of Palmer (2013) whose family members kept the needs of the person with dementia central to all the decisions that were made. This was clear within all the narratives in this study; for example, Tony says, *"Beverley's needs, that always comes first*" and Paula photographing her father's hospital notes to prove that he was not safe to go home. This validates a previous paragraph regarding the increasing responsibilities of the family members, also how committed they are as caregivers.

8.3.6 Summary of the lived experience for family members

This section has shed light on what it is like to live with dementia as a family member of someone with the condition. The results suggest that there are multiple losses experienced whilst living with dementia, including a comparison of what has been lost, the impairments to come, decreased friendship groups and the diminishing of a marital relationship. Throughout their life with dementia, the family member will experience a turmoil of emotions related to many aspects of their situation. They will have to balance their own well-being with their caregiving demands. This is all acknowledged within the model of life with dementia (Figure 6, pp 211) whereby conflict encompasses the entire experience of living with dementia. Training courses are available to help caregivers cope with this and is acknowledged within the recommendations from this study (pp 267).

Family members will help alleviate some of their loved one's struggles by accepting their diagnosis, maintaining a sense of normality and increasing their responsibilities within the relationship. However, these increased caregiving roles can result in the family member feeling isolated as they have so much to deal with on their own. Some choose not to ask for help, while others do not know where they can turn for support. The experiences of people with dementia and their family members are exclusive of one another, yet there are some similarities.

8.4 Joint Lived Experience

This final section explores the commonalities between the experiences of the people with dementia and the family members who participated in this study. Exploring the similarities between both groups of participants offers a holistic view of life with dementia. The shared subthemes are good support, relationships, making comparisons, knowledge of dementia, stigma and the future.

8.4.1 Good support

Having a good support system was important to all participants within this study; for the people with dementia, good support from family and friends made them feel socially accepted. For the family members, good support systems prevented feelings of isolation. Both illustrate the psychological advantages of having a good support system. The benefits of such while living with dementia has been observed by Elnasseh *et al.* (2016) who found that good communication with the wider family can help them develop resilience against the struggles of living with dementia. This was also reiterated by Keyes *et al.* (2016) who found that strong support systems are beneficial to both the person with dementia and their family members, to reduce feelings of isolation. Despite the Global Action Plan (2016) emphasising the importance of people with dementia remaining mainstream members of society to prevent segregation (World Health Organisation, 2016), isolation was a theme within the narratives of the people with dementia and the family members in this study. More can be done to prevent people affected by the condition feeling alone and increasing the support available to them. This could be as simple as clear signposting to already established support groups and formulates one of the recommendations made from this study (pp 267).

8.4.2 Relationships

Many studies explored marital relationships when one spouse has dementia (Daniels *et al.*, 2007; Hayes *et al*., 2009; Hibberd *et al.,* 2009; Robertson, 2010; Shim *et al.*, 2012*;* Swall *et al.*, 2019; Polenick *et al.,* 2020). A changing spousal relationship was also a finding of this study, as Trystan explained, *"we are a lot closer now than what we used to be"*. Feeling that their marriage had improved since their spouse began to develop dementia mirrors findings from Swall *et al.* (2019), who concluded that life with dementia will enrich the couple's sense of us. Tony also noted how his relationship with Beverley had become closer since she has dementia; *"I have to say that it has drawn us together a little bit more, now what I mean by that is she had a little bit of her life and I had a little bit of my life which were mutually exclusive from each other ..We are sort of joined at the hip"*. Hernandez *et al.* (2019) found something similar in their study whereby married couples explained that the increase in doing things together had improved their sense of couple-hood and drawn them closer together. This is one of the benefits of exploring both perspectives of life with dementia.

For the married couples who participated in this study, most (excluding Rob and Kim) believe their relationship has been strengthened since one half of the couple has dementia. *"Relationships change anyway, people evolve, situations change and the part of being married is that you have got to change with it, it's either you change, or you break"* (Darren). It is essential for a couple to transform their relationship as the dementia progresses to maintain a strong partnership (Hibberd *et al.*, 2009). A strong partnership is consistently shown throughout dementia literature as well as other long-term conditions, as being essential to the wellbeing of the person with dementia and their spouse (Lethin *et al.*, 2020).

8.4.3 Making comparisons

Throughout the participant narratives, all spoke about comparing their situation to others living with dementia. This has two purposes. For the people with dementia in this study, the comparison often served as a means of illustrating that their dementia was still in the early stages; for example, *"I have got a bit more up here [points to* *head] than them"* (May). While the family members often used the comparison to try and understand what the future would be like for them; for example, *"some of the people whose husbands and wives are really bad… I do look at them and I think, oh god I've got that coming"* (Dianne). This resembles findings from Robertson (2010) who found that those living with dementia would often compare their situation to societal expectations of how a person with dementia should be. Similar to the people with dementia in this study, those who participated in Robertson's (2010) study used the comparison to measure how well they were doing.

8.4.4 Knowledge of dementia

The participants admitted to having a deficit in knowledge about dementia. Some participants (Pippa, Laura, Kim, Darren, Hannah and Tony) explained that they had pro-actively sought out information about dementia while Lynne, Louise, Bethany and Pat had worked in a nursing capacity and had learnt about dementia through their careers. All other participants admitted to knowing little about dementia. This is consistent with studies by Andrews *et al.* (2018), Stokes *et al.* (2014), Kjallman-alm *et al.* (2013) and Werner (2005) who all found that the families of people with dementia did not understand the nature of the condition; most thought it was a normal part of aging. Similar to Zhan's (2004) findings, Louise felt that her dementia was a punishment for wrongdoing, Nancy felt that she was going insane and most participants felt that there was certainly a stigma with having dementia that would prevent them from being socially accepted. There are two recommendations that can be drawn from this; firstly, families need to be provided with more information, in an easily accessible and understandable format, about dementia when they receive their diagnosis and secondly, more members of society need to be educated about dementia. These recommendations are explained further in the next chapter.

8.4.5 Stigma

The societal expectation of what it is like to live with dementia was made explicit within several of the participant's narratives and throughout the dementia literature. *"There are others that I think have got a mental picture of someone who is sat in a chair, slumped, drooling. Not able to communicate. Because there is a stigma with* *the word"* (Laura). Within the literature, Katz (2013) highlights the importance of seeing a person with dementia, not a "*diseased brain*". While others have referred to people with dementia as *"the living dead"* (Behuniak, 2011) or "*zombies, bodies without minds*" (Walrath, 2016). This societal stereotype of a person with dementia has implications that were noted by all participants. Firstly, if the person with dementia does not personify the societal expectations, their diagnosis will be questioned; for example, *"a lot of people have said you wouldn't think that you've got it. But I think they think about people like Roy was, having progressed Alzheimer's"* (Pat). Secondly, people living with dementia become marginalised from society as their friends do not know what to say and therefore, often avoid them altogether; for example, *"they deliberately avoid me"* (Pippa). Being deliberately avoided was also a result from Clarke and Bailey (2016), who found that people living within a secluded village community avoided the family of a person with dementia upon learning about their diagnosis, as they did not know what to say. Dementia education is essential to keeping people affected by the condition as mainstream members of society.

8.4.6 The future

Due to the biographical nature of this study, all participants were asked about their lives prior to dementia and their hopes for the future. The hopes for the future were mixed, with some family members being hopeful and optimistic. For example, Darren said *"all we can do is hope for the best",* while others felt that the future looked bleak. Like Gail, who stated that *"I know what the end is going to be, that he can't survive it, and things are going to get worse than they are now, and that's hard"*. The participants with dementia all explained that they hoped not to get much worse, to remain happy and be surrounded by people who love them. The desire to remain connected to family and friends was also noted by Karlsson *et al.* (2014) while Spigelmyer *et al.* (2018) found that family members had significant worries about an increase in caregiving demands as their loved one's condition deteriorated. None of this is unusual for people living with a long-term condition, however it does highlight the importance of being aware that dementia progresses and accepting this will allow people to plan for the future. This may include the making of wills, agreeing power of attorney and advanced care planning, to name a few.

8.4.7 Narrative dynamics

Of further note are the observations made during data collection. Six pairs of participants chose to stay together for data collection as the person with dementia felt that their loved one may be able to offer support if they "*got stuck*" on what to say. A loved one "*filling in the gaps*" within the memories of the person with dementia had been observed within the literature previously. Phinney (2002) found that the family members' input in the person with dementia's interview would often prompt them into adding something of their own or would provide more in-depth data by offering additional explanations that the person with dementia had forgotten. For those who participated in this study, only Hannah "*filled in the gaps*" for Pat's narrative when Pat could not think of the right word to say. The remaining family members would intervene only to correct the person with dementia.

Both Tony and Darren dominated their wives' interviews. This diluted the experiences of Beverley and Louise and disempowered them to share their stories. Tony admitted that he tends to answer any questions when he is with Beverley; *"to be honest, if any questions are asked and I am with Beverley, I tend to answer the questions".* Louise would often divert the question onto Darren so that she did not have to answer; this often resulted in Darren rewording the question and pushing Louise to give an answer. Daniels *et al.* (2007) also observed this dynamic within their participants' recording whereby the husband would overshadow his wife with dementia. The likely reason for this behaviour within the couple's dynamic are the problems conversing that the participants with dementia referred to; instead of watching their loved one struggle to think of something to say, the family members intervene. The more confident participants were interviewed alone or, in Nancy's case, would tell their husband to *"shut up"* and stop interrupting.

Furthermore, Daniels *et al.* (2007) found that the narratives from their participants were primarily positive, but occasionally, there would be a slip in the positive terminology and negative elements of life with dementia would begin to appear (for example, loneliness). Researchers refer to this as "*demand characteristics*" whereby participants will alter the way they behave to appear socially desirable (Reese *et al.,* 2013) and this has been recognised as a limitation of this study. This highlights that there is often more to a story than what is being portrayed and sometimes, having the other person in the room prevents the participant from speaking honestly about their experiences. This is certainly true for Tony who explicitly says *“yeah a difficult one to answer, that, candidly”* several times throughout his interview. When Tony did answer “*candidly*”, Beverley would often interrupt him, especially if he was talking about her care needs. It has been suggested that this phenomenon is common amongst couples living with dementia; when both people are present, they will only share information that the person with dementia is comfortable with others knowing (Hellström and Torres, 2013). Unlike this study, Hellström and Torres (2013) also found that the person with dementia dominated the conversations so that they could control what information was shared. It is worth noting that Hellström and Torres (2013) recommended further research explore the longitudinal effect on couples’ disclosure preferences as they noted discrepancies amongst their participants based on how long they had been diagnosed with dementia. This may explain why the participants in this study prompted their spouse to answer on their behalf but the participants with dementia dominated the conversation in Hellström and Torres’ (2013) study. It is possible that Beverley interrupted Tony because she has only recently received her dementia diagnosis; those who have been diagnosed longer may have felt comfortable sharing more personal information.

The literature suggests that there is a psychological benefit to participating in life story work whilst supporting someone living with dementia (Novy, 2018; McKinney, 2017; Tamura-Lis, 2017; Thompson, 2011; Moos and Bjorn, 2006). Yet the use of life story work as a data collection tool for people with dementia is scarce (Benbow and Kingston, 2016). Whilst it was not the intention of this study to explore any psychological benefits of life story work as a data collection tool, a few participants spoke about the therapeutic effect of participating in this study; *“it’s been therapeutic to talk about it”* (Darren).

8.5 Summary and Reflection

For people with dementia, a changing identity and sense of self is prominent, both for the participants in this study and within the dementia literature. Despite resilience being a relatively new concept for people with dementia, it was a key theme for the participants with dementia who, despite facing adversity with a dementia diagnosis, maintain a sense of normality and a positive outlook on life. A desire to be socially accepted was also common amongst the literature and the participants' narratives. This study suggests that there may be a difference in levels of "wanting to be socially accepted" between those living in their own homes and those living within residential care homes, but as there were only two participants recruited from the care homes, this is uncertain.

The family members experience a multitude of losses within their dementia journey and many conflicting emotions, yet they always manage to prioritise their loved one's safety and well-being. The family members explained they have an increase in roles and responsibilities since their loved one developed dementia and accepting this can sometimes be difficult.

All participants experienced isolation and were aware that friends and family often avoided them due to the stigma associated with dementia. The literature suggests that isolation is a common experience for people living with dementia but attending dementia support groups can alleviate the sense of isolation and increase support for those affected. The benefits of social support groups have been acknowledged and is recommended strongly in a range of Welsh dementia policies.

The video recordings offered insight into the participants' relationships. Some offered support throughout their narratives by holding hands and comforting one another. For others, the recordings shed light on the dominant partner, usually the person without dementia, who takes over the conversations and answers on behalf of their loved one. Some participants with dementia felt able to stand up for themselves and stop their spouse disclosing information they did not want shared whilst others openly invited their spouse to take over the conversation.

The next chapter of this thesis summarises the research findings and makes the original contribution to knowledge explicit to the reader. The limitations of the study are discussed followed by recommendations for policy, practice and research.

Reflection on the Chapter

This chapter was difficult to assemble. I had to draw together everything previously said within this thesis and unpick the policies, models, literature and my own findings to figure out exactly where my thesis sits. Drawing out any similarities or differences between the participants' experiences and those within the literature or models of dementia, and critique that using the policies and legislations from Chapter 1 combined with a comparison of the methodological implications of all studies.

Whilst the experiences of living with dementia are unique for the person with the condition and the family members, there were elements within the narratives that were experienced across the board and these warranted their own, separate discussion. For example, noticing how the stigma of dementia led to social exclusion.

One of the original contributions of this study was the use of video recordings to capture the data. As the participants were primarily sitting still for the duration of their videos, it did not warrant the same commentary as an observation study may have. Nevertheless, where poignant visual cues were present within the data, I have added details of this and highlighted the importance of such distinction.

I am sure I am not the only one who wrote their thesis chapters in a random order. For me, I started with perspectives of dementia, methodology, results, literature review, introduction, discussion, conclusion and then reflection. It was only when I came to this discussion chapter that things started to slot into place. I was able to see how everything included in this thesis fits together and its relevance to people affected by dementia. It was frustrating when the legislation, perspectives of dementia and literature all support truly person-centred care and yet the participants shared many examples when this was not the case. Based on my own experiences as a care worker and the participants' narratives, I have come to realise that "person centred care" is a term that gets used a lot, but it not necessarily integrated within day to day practice.

CHAPTER 9 CONCLUSION

“Dementia is important to all of us, as individuals, as professionals and as a society”

(Allistar Burns, 2010, pp. 2)

9.1 Introduction

This chapter offers a summary of the research findings and makes the original contribution to knowledge explicit to the reader. This is followed by an outline of the limitations of this study. Based on the findings, recommendations for policy, practice and research are offered and conclusions are made.

9.2 Key Research Findings

The research question for this study was “what is it like to live with dementia?” and the two objectives were (1) to explore and understand the lived experience of older people living with dementia, and (2) to explore and understand the lived experience of family members of older people living with dementia. These are discussed below in relation to the findings of this study.

9.2.1 The lived experience of older people living with dementia

The first objective of this study was to explore and understand the lived experience of older people living with dementia. The participants’ narratives illustrated the impact of receiving a dementia diagnosis on their identity and sense of self. This diagnostic label is essential to all other experiences they have of living with dementia. The participants’ reaction to their dementia diagnosis was strongly influenced by their previous lived experiences; for example, those who had cared for people with dementia (through work or a family member) had a negative reaction to being diagnosed while those who were unaware of what dementia is, were more accepting of their diagnosis. Despite this, people need to understand the diagnosis they have been given at it is essential to future planning and accepting their new identity. As the literature suggests, those who have been newly diagnosed may initially feel distressed but will come to accept their dementia in time.

The participants with dementia expressed a desire to be socially accepted as a "*person with dementia*" and found that the best place for this was within the community dementia support groups that most participants attended. Being with people in a similar situation helped them to feel supported, accepted and created a sense of extended family. It is not unusual for people attending support groups to feel this way, despite this, most participants with dementia felt that their dementia diagnosis had isolated them from wider society; some had received a negative reaction from family and friends when they shared their diagnosis while others were aware that people avoided them. Dementia support groups should not be the sole place for someone living with the condition to feel accepted. All social spaces should be accepting of people with dementia.

Adversity was experienced by all participants with dementia, yet they all demonstrated elements of resilience within their lives and tried to remain positive and optimistic, despite struggling to cope with life with dementia. Most participants were determined to maintain an element of normality and independence as they did not want to burden their families. A key argument of this thesis is that older people with dementia can articulate and share their experiences of living with dementia, regardless of cognitive impairment. Giving people with dementia the opportunity to socially share their experiences can aid society to better understand what it is like to live with dementia; their voices can be heard and used to advise on policy and best practice.

9.2.2 The lived experience of family members of older people living with dementia

The second objective of this study was to explore and understand the lived experience of family members of older people living with dementia. Loss was palpable within all their narratives. Their loved one's loss of ability was the initial indicator that sparked the dementia diagnosis process and since then, they experienced a multitude of losses, from ongoing loss of cognitive ability, to loss of friends and a spousal relationship. The family members sought information to establish what sort of loss is yet to come, in order to prepare themselves. Loss in various shapes and forms, is present throughout the family members' journey with dementia.

The family members accepted their loved one's dementia diagnosis with all its implications. As their loved one's dementia progresses, the family members must accept a changing level of responsibility for them and an increased caregiving role towards their loved one. Akin to the people with dementia, the family members experienced a sense of isolation as they lack support from family and friends as their caregiving role increases. Furthermore, they explained how their increased responsibilities resulted in them having to remain strong for the rest of the family, they made all the decisions regarding what was best for their loved one, including withholding information. In particular, what the future may hold. Being criticised by the person with dementia was particularly isolating for the family members and often made them feel like their caregiving efforts were not good enough. This could have negative consequences for the family members' mental health.

It became evident within the family members' narratives that they had experienced an internal conflict of emotions regarding life with dementia. They all tried to remain optimistic and positive while being faced with a hard reality; that their loved one's condition would deteriorate, that their situation could not improve. Whilst there were vast differences amongst the participants' narratives, with some like Kim only sharing the negative elements of their lives with dementia, most others acknowledged that they felt mixed emotions. For the family members who participated in this study, it is clear that living with dementia is a *"rocky road"*.

9.2.3 What is it like to live with dementia?

The two previous sections have explored what it is like to live with dementia from both perspectives: the older person with dementia and the family member. The similarities between the two groups provides an overall understanding of life with dementia. The participants' narratives suggest that life with dementia is isolating, as all participants felt that they were avoided by friends, family and neighbours due to the stigma associated with “dementia” and people not knowing what to say to them. Dementia support groups were important aspects of the participants’ lives as they gave the family members a chance to relax and those with dementia a chance to be socially accepted and have fun.

Maintaining a sense of normality and accepting the changes in roles and responsibilities was also common amongst both sets of participants. The people with dementia were coming to terms with their family members taking over some of their roles within the household and having to accept assistance with personal care. The family members felt an increased responsibility for their loved one’s safety and wellbeing, whilst taking over household roles. All participants were trying to maintain a sense of normality as this was an essential coping strategy for all participants living with dementia. Whilst some elements of the findings of this study were present within literature, others were not.

9.3 Original Contribution to Knowledge

“Originality is a major ingredient of doctoral research” without which, a doctorate cannot be awarded (Gelling and Rodriguez-Borrego, 2014, pp. 6). Original research should result in the production of new knowledge (Gill and Dolan, 2015). This is one of a handful of studies that has created original and enlightening data which adds to the body of literature on the lived experiences of people affected by dementia. The use of a multimedia data collection tool (video recording) to explore these experiences through life stories is unique and rarely seen.

9.3.1 Methodology

Life story work as a therapy for people affected by dementia is widely documented (Novy, 2018; McKinney, 2017; Tamura-Lis, 2017; Thompson, 2011), yet it is seldom used as a data collection tool. This study has demonstrated that researchers can gain an additional understanding of life with dementia if they recognise what life was like before dementia. Understanding someone’s educational attainment, employment and family relationships can help a researcher appreciate how that person’s life with dementia has been shaped by prior experiences, for example, Lynne's nursing career has increased her fear of living with dementia as she knows how difficult it can become. Life story work has proven to be an effective and insightful data collection tool when used with participants affected by dementia.

This study has demonstrated the usefulness of video recording the participants' narratives instead of simply voice recording them. The videos allowed the researcher to identify any non-verbal cues, such as the body language of the narrator or holding hands for support (Louise and Darren), that offers insight into the relationship dynamics between close family members. It also offers the opportunity for the researcher to give something back to the participants; all participants in this study will receive a copy of their life story on DVD to keep. No other studies uncovered within the literature search seems to have done this. This is a key element of originality; giving the participants a copy of their story in an accessible format (DVD) that can be kept and cherished for years to come. The participants' gratitude at receiving these DVDs has been acknowledged and discussed further later in this chapter.

9.3.2 Results

Whilst some of the results from this study were supported by literature, some were not and appear to be seldom researched. The intimate sexual relationship diminishing when a spouse has dementia was a unique contribution to knowledge, as was the comparison between the acceptance levels of those within care homes and those in their own homes. The family members' reaction to their loved one's diagnosis has also rarely been researched previously; this is an original finding. Furthermore, the stories shared by participants in this study are unique to those accessing services within South Wales.

9.3.3 Presentation

The presentation of the participants' narratives, particularly in chapter 5, is novel. Introducing the reader to the participant is rare when reporting the results of a qualitative study, yet it was essential to the personal, biographical nature of this research.

This study had four originality ingredients that contribute to new knowledge. These contributions are useful to understanding life with dementia and alternative methodologies. Despite their importance, there are some limitations to this study.

9.4 Limitations

This study has explored the lived experience of older people with dementia and their family members. In doing so, valuable insights into these personal narratives have been gained which contribute to the pre-existing literature on life with dementia. Nevertheless, there were some limitations to this study. These can be divided into generalisability, sample, methodology and the use of video recordings.

9.4.1 Generalisability

Generalisability in research is the ability of the researcher to apply their findings to other populations or situations (Ovretveit *et al*., 2011). This has been noted as a major limitation within qualitative research which can impact upon the usefulness of research findings (Povee and Roberts, 2014). Yet others argue that qualitative researchers do not aspire for their findings to be generalisable; they aim to gain unique insights into a phenomenon (Yardley, 2008). The same is true for this study as its’ focus was on the participants’ individual experiences. Despite their differences, there were similarities within their experiences which may be attributed to the homogeneous socio-demographic pool from which the participants in this study were drawn.

All participants within this study were working class, white, British and living in South Wales. As Hinton and Levkoff (1999) demonstrated, different cultures within the same country will have a diverse understanding of dementia. It is possible that class, culture and nationality will alter the experiences of people living with dementia; therefore, the results from this study are not representative of all people living with this condition.

All participants were registered with memory clinics within South Wales. There are differences within the organisational structures of the memory clinics that were involved in this study; it can therefore be assumed that memory clinics in alternative parts of the UK or the wider world will have differing structures. The experiences of those who attend memory clinics in South Wales may differ from the experiences of those who attend alternative clinics as Welsh memory clinics are governed by Welsh policy. For example, in China, Nigeria, India, Iran and Ghana, the lack of dementia recognition by governments and health authorities is a key contributor to fragmented diagnoses and failing care and treatments (Chan *et al.,* 2020).

As highlighted within Chapter 5, the participants had varying levels of academic achievement with some having university degrees (Gill, Lynne, Pat) and others leaving school at fifteen (David, Rob). As Hedman *et al.* (2012) illustrated, those with higher educational attainment levels will be able to articulate their experiences better during their interviews than those with lower education levels who may have different experiences. The varying education levels achieved by the participants suggest that the results from this study can be generalised to all socio-economic groups because the experiences of living with dementia do not depend on educational achievements, and may therefore, also not depend on wealth.

9.4.2 Sample

All studies conducted in Wales must offer the participants the opportunity to complete the study in the Welsh language (GOV.UK, 2018). Despite the participants being aware that this was available to them, none enquired about this. The National Survey within Wales revealed that approximately 22% of respondents prefer to speak Welsh than English (GOV.Wales, 2020), therefore, it is possible that some of the participants spoke Welsh as their first language and could have different narratives had they been able to share their stories in Welsh.

Whilst it was not part of the criterion for recruitment, all the participants with dementia attend various dementia support groups within their local community; this may have influenced their participating in the study as they were willing to remain socially active. Dodge *et al.* (2014) illustrated that those who volunteer for research will generally live an active lifestyle and report feeling higher levels of loneliness, thus, impacting on the generalisability of the findings of a study. It is therefore possible that people with dementia who do not participate in social activities would have very different experiences of living with dementia.

All participants were identified and approached by the memory clinic or residential care home staff; only when they had agreed to participate in the study, were their names and contact details passed onto the research student. This is termed purposive sampling as the memory clinic and residential care home staff used their judgement to assess which people were likely to participate in this study. It is possible that the staff recruiting the participants purposely chose people that they knew had good experiences of the services they access and would portray the health board/residential care home in a positive light. Had the participants been recruited by someone independent of the memory clinic or residential care home, the narratives being shared may have been completely different.

The Research Ethics' Committees required participants to be introduced to the researcher through the services they access. This links the researcher to the professionals within that service and may hinder the participants from speaking openly about their experiences (Hughes, 2014). Despite the assurance of anonymity, they may still feel that they cannot freely express their opinion of a service that they access in fear of it being reported back to the professionals and impacting on the support they receive. For example, the Parliamentary and Health Service Ombudsman (2015) found that 56% of older people are afraid to complain about a problem they experience in case it impacts upon their future treatments.

9.4.3 Methodology

Despite encompassing "bracketing" into the methodology for this study, it is possible that some researcher bias was encountered, especially when the participant needed prompting for additional information. Additionally, the research student's demographics (female and in her early twenties) may have altered the responses given by the participants, particularly the men, who may have withheld some information that they were not comfortable with a female/younger person knowing; for example, sexual activity or continence issues.

During the ethical permissions process for this study, it was noted that people with dementia can sometimes lose the ability to control what they are saying; for example, family secrets can often be disclosed (Capstick and Clegg, 2013). Where the participants are able to choose what information to share and what to withhold, it can sometimes bias their narratives whereby they base their story on what they think the researcher wants to hear (demand characteristics) or what they think will portray them in a positive light (social desirability) (Daniels *et al.,* 2007; Reese *et al.,* 2013). For this study, this was a double edged sword. The participants being able to control their narratives and their representation of themselves was, of course, a good thing and gave them control over their life story (Gubrium *et al.,* 2014). At the same time, this control could have resulted in the participants disclosing a sanitised version of the truth or a positive explanation of the situation for a stranger (the research student), instead of sharing anything negative about their life with dementia. Whilst this is possible, and may have occurred with a few participants, most appeared to be sharing the true reality of their experiences, including details about their struggles, intimate relationships and experiences of healthcare services. From a research perspective, these demand characteristics and social desirability are a limitation of the study. From a humane perspective, it is a good sign that the person with dementia is still able to control their representation.

The participants were given the option to participate in interviews alone or with their loved one in the room. The reason for this was that the family members could offer the person with dementia some support if they became stuck for something to say. However, for some of the participants with dementia, their loved one dominated the conversation and diluted their narrative. Ensuring the person with dementia was able to contribute to the conversation can be difficult when they have their loved one in the room, answering the questions on their behalf (Parker, 2015). For the family members who's loved one with dementia remained in the room, their answers may not have been as truthful as they would have been if they were interviewed alone. Tony admitted to this within his narrative, saying "*difficult to answer that, candidly";* it is possible that this was also true for the other family members in the same situation.

To overcome these sanitised stories about their lives, more visits with the participants may have elicited deeper layers to their narratives but given the time and resources available to a PhD, this was not possible. Despite this difficulty, interviewing some of the couples together offered insight into the dynamic of their marriage when one party has dementia.

9.4.4 Video recordings

Swall *et al.* (2019) suggests that participants will often alter their behaviour when they are being video recorded. Whilst it is possible that the participants changed their behaviour because of the video recording, the research student feels it is unlikely. It was noted that the participants were initially aware of the camera as they kept looking at it but soon their narratives began to flow, they stopped looking at the camera and began having a conversation with the research student.

A common limitation of observation studies is the Hawthorne effect (Gross, 2010). Whilst this was not an observational study, the same limitation applies whereby people may alter the way they behave when they know that they are being video recorded (Asan and Montague, 2014). For example, when Louise and Darren were holding hands throughout their video, giving the assumption that it was a form of emotional support, it may actually have been staged for the video recording. In addition to staging behaviours, Snell (2011) suggests that video recorded data may produce a “sensory overload” when the researcher comes to analysing and coding the data. It is suggested that the visual data collected can weaken an analysis if the researcher becomes over-reliant on the visual data to describe the phenomenon being explored (Jewitt, 2012).

Despite these limitations, the data collected during this study offers valuable insight into life with dementia. From this increased understanding of what it is like to live with dementia, several recommendations can be made regarding policy, practice and research.

9.5 Recommendations

The following recommendations are made from the data collected during this study and while the experiences of 22 people living with dementia is not generalisable to the wider population, their experiences can offer useful insight into areas where policy, practice and research could be expanded.

9.5.1 Policy

Universally, the participants in this study experienced isolation and a desire to be socially accepted. The government could do much more to enhance societal understanding of dementia. Therefore, the first recommendation for policy, based on the results of this study is for dementia education programmes. Many have been trialled within schools, such as “dementia for schools”, “generations working together” and “dementia resource suite”, and whilst these proved successful, they were one-off sessions conducted in a limited number of schools (Dementia Action Alliance, 2020). Adding dementia awareness to the core curriculum within schools will aid societal awareness and ease the isolation experienced by people living with the condition. This needs to be entwined throughout every year group, with the information becoming more detailed as the children get older. Something similar to the Good Work: A Dementia Learning and Development Framework for Wales (2016) but aimed at school children not NHS staff would be ideal. Whilst it is unlikely that the ethics committees will approve any stories generated through research to be used as an education tool[9], this study has demonstrated that people living with dementia are willing to share their stories, and therefore, can be presumed that they will be equally as willing to share their stories for educational purposes. Observations made whilst shadowing the services prior to data collection suggest that health boards regularly collect patient stories to share with other patients and staff members. This could easily be adapted to share with school children. The users of the stories must be aware that the patient or participant should always own their own story and should be in full control over where it is shared. For example, participants

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[9] Based on my experience of the committees.

from this study are the owners of their videos and can therefore give permission to the health boards for their use. However, the research team cannot share these videos with anyone else.

This study has demonstrated that people with dementia can reliably participate in research and can therefore reliably advise on legislation and policy. Therefore, the second recommendation for policy is to give people with dementia the opportunity to advise on what they need instead of using proxy accounts. Empowering people with dementia to be ambassadors for others with the condition would refine the governmental legislations and policies and ultimately, provide change within society that can make life with dementia easier.

The final recommendation for policy, based on the results of this study is that the Welsh Government should increase funding for dementia support groups as these provide great psychological benefit for all those affected by dementia. The implication is not prohibitive, yet the benefits of such groups have been recorded without exception both within the literature and the results for this study. To function, the groups need a venue to rent for a few hours a week[10], refreshments and budget for entertainment (bingo, quiz, singing and games). The memory clinic staff are willing to hold fundraising events and the patients are happy to contribute to the costs, but they need additional and stable financial input.

9.5.2 Practice

This study illustrated how people affected by dementia do not always understand the differing diagnoses. This is particularly poignant for those who do not understand the diagnosis that they themselves have been given. Based on this finding, the initial recommendation for practice is for memory clinics to ensure that the patient and their family understands the diagnosis that they have been given. Memory clinics need to take the time to ensure that people understand what their form of dementia means; the aetiology and treatments (if any). This may be as simple as an online story bank

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[10] Some memory clinics have their own space for groups within the memory clinic building and would not need a rented venue.

of videos from other people living with dementia[11]. These videos would contain the "need to know" information about their diagnosis, how it varies from other forms of dementia and additional "*tips and tricks"* of living with the condition. This information needs to be given alongside the diagnosis and later reiterated at follow up appointments. The patients and families can also be signposted to third party organisations (Alzheimer's Society) who may help them come to terms with, and understand, their diagnosis. As previously outlined, people need to understand their diagnosis and to accept it to be able to move forward.

In terms of information about dementia, some sought out their own information online while others asked questions as they went along. People affected by dementia who do not understand its' terminal nature cannot plan for the future. Power of attorney, wills and advanced care plans are a few of the tasks that people living with dementia need to be aware of. The second recommendation for practice, based on the participants' narratives, is for memory clinics to provide timely information regarding the terminal nature of dementia. If the patient receives significant information about their form of dementia upon receiving their diagnosis, then the clinic staff should offer additional information about future planning at a second appointment a few weeks later. To support this, third party organisations could be introduced (for example, the Alzheimer's Society) or an online story bank of videos from other people living with the condition who can offer additional information and support to the families and the person with dementia.

Elements of resilience were present within the narratives of the participants with dementia; memory clinics should encourage positive coping strategies to enhance resilience levels of those living with dementia. There are several interventions in existence to support resilience in people living with dementia (Whelan *et al.,* 2020); most of these are community support based. Therefore, the final recommendation for practice is clear signposting to support groups, which highlight the benefits of

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[11] When "story bank of videos" is mentioned, these story banks must consist of videos that have been made specifically for that purpose. The owner of the story needs to know that their video will be used for this bank of information only. A storyteller cannot be in full control of their story when the uses are muddled. For example, research or education or advertisement.

attending for the person with dementia and their families. This signposting can be as simplistic as posters in the waiting rooms at the memory clinics or leaflets given to patients registered with the memory clinic.

9.5.3 Research

The data collected within this study was rich and informative. The use of stories and narratives as a method of exploring life with dementia was very successful and encouraged participants to share their experiences through more creative means. The participants with dementia were able to engage fully in the study after some simple modifications were made to the methodology, for example, an alternative format for the information sheets. The full inclusion of people with dementia should be at the core of all dementia research and future research should endeavour to optimise this. Therefore, the first recommendation for research is for more qualitative research, using stories and narratives, to explore life with dementia from different parts of the world, but always ensuring people with dementia can partake.

A small number of participants in this study touched upon the changes they have experienced in the intimate relationships with their husbands. This would be an area of interest for future research to explore, especially regarding sexual intimate relationships between married couples when one has a dementia diagnosis. This would likely cover sensitive issues such as consent and infidelity but would provide useful insights that could influence policy and practice. This is something that will become increasingly more important as people are now living longer with varying relationships. Thus, the second recommendation for research is for an exploration into the intimate relationship between couples when one has dementia.

Several areas were uncovered within the results of this study that had little or no supporting literature. Therefore, recommended areas for future research include the family members' reaction to their loved one's diagnosis, the use of humour as a defence mechanism when living with dementia and the difference in levels of life satisfaction/quality of life between people living with dementia at home and in residential care homes. These were significant experiences for the participants in this study and additional research into these areas would increase the knowledge base on life with dementia. This additional information can only be a force for good to inform policy and practice.

This study has offered supportive evidence towards the concepts of personhood (as proposed by Tom Kitwood), resilience and successful aging when living with dementia. In line with the offered definitions of these theories (Chapter 2, pp 24), the participants in this study demonstrated how remaining socially active, having accepting support systems and being optimistic can help strengthen their sense of personhood (or identity). This study falters as all participants are regular attendees of dementia support groups. This was not an intention of the study, but a coincidence from the array of people who agreed to participate. The likely reasoning for this has already been discussed. To offer further support for these theories of living with dementia, the life experiences of participants with varying levels of social inclusion should be explored.

This study had many ethical considerations to overcome as the methodology is unique and required sound justification before the ethics committees would approve it. Future research should push ethical committees further and begin to introduce modern, multimedia data collection methods. Research needs to keep up with technological advances and these “new” methods of data collection are beneficial for the research team and the participants; this study is proof of this as the video recorded life stories were very successful data collection tools. Therefore, the last recommendation for research is for studies to include modern methods of data collection that push ethics committees to approve studies that are not traditional.

9.6 To Conclude…

The Dementia Action Plan (Wales) (2018) vowed to have information, support and advice readily available to all those affected by dementia to prevent feelings of isolation, increase their knowledge and help them cope with living with the condition. Dementia friendly societies, where everyone is aware of the means by which they can help those living with dementia, are listed as a priority by the Global Action Plan on the Public Health Response to Dementia 2017-2025 (2017). People living with dementia should be empowered to remain mainstream members of society. Yet, the testaments of the participants in this study suggest otherwise. Life with dementia is isolating. People do not understand their diagnosis and do not know where to turn for information and support. Feeling connected to society is imperative for those living with this condition, yet they feel left out, unaccepted and lonely. The resources to help people live with dementia are available from third party and charity organisations, yet the signposting to these facilities is not clear. Posters and information leaflets containing the details for organisations, outside of the NHS, that can help are relatively cheap to produce but can have a massive impact upon the lives of people who need them. This study has already initiated some small changes within the care homes who participated in this study. They have introduced information stations within the reception area of their homes for people to find out more about life with dementia and where they can go for advice and support. Relative support groups have been established along with dementia friends training for anyone and everyone who wants to attend.

Despite the struggles they face, people affected by dementia try to remain positive, hopeful and optimistic. Mostly, their relationships to close family become strengthened throughout this journey but more could be done to help people display resilience and overcome adversity brought on by a diagnosis of dementia. Families should not be financially penalised due to the high costs of residential care homes when they can no longer provide the care that their loved one needs. If they are better supported to provide care for their relative in their own home, with improvements in the home care sector, there would be less demand for dementia beds within residential care homes, less caregiver burnout and less anxiety about the future.

> *"I, who had ever been surrounded by amiable companions, continually engaged in endeavouring to bestow mutual pleasure. I was now alone. In the university whither I was going I must form my own friends and be my own protector"*
>
> *(Mary Shelley, Frankenstein, pp. 44)*

This thesis concludes with a personal reflection, written in the first person, regarding the journey undertaken whilst completing this study and thesis.

CHAPTER 10 PERSONAL REFLECTION

"The knowledge that you have emerged wiser and stronger from setbacks means that you are, ever after, secure in your ability to survive. You will never truly know yourself, or the strength of your relationships, until both have been tested by adversity. Such knowledge is a true gift, for all that it is painfully won, and it has been worth more than any qualification I ever earned."

(J. K. Rowling's 2008 Harvard Graduation Commencement Speech)

10.1 Introduction

This is the final chapter of this thesis and offers a personal reflection, presented in the first person, on the process of conducting this research and writing this thesis. *"Reflexivity is a continual process of engaging with and articulating the place of the researcher and the context of the research"* (Barrett *et al*., 2020, pp 9). Reflexivity is an essential element to qualitative, narrative enquiry (Holloway and Freshwater, 2007). The act of reflexivity not only explains any relationships between the researcher and participants, but also allows the reader to understand the work better (Dodgson, 2019). Found particularly in qualitative dissertations, it makes the research process and decisions transparent to explain how the research findings are shaped by the experience of the researcher (Davis, 2020).

10.2 Background

I will admit that when I chose my psychology degree, I was naively hoping to graduate and work for the Behavioural Analysis Unit, much like the TV show, "*Criminal Minds". *Like so many others on the course, I wanted to be a forensic psychologist and assist in the arrest of serial killers. I knew very little about other branches of psychology but was eager to learn. It was during this three-year BSc, that my interest in older people with dementia was initially sparked. To fund my way through my degrees (BSc and MSc) I worked as a home carer. Approximately 80% of the clients were older people with dementia at varying stages. The care company I worked for used to have "*standard dementia packages*" where they would copy and paste the care plans from one client to the other. All instructions for the carers were the same and so were the "*all about me*" sections of their care plans:

> *"Born in mining village. Likes tea, one sugar, milk. Toast for breakfast. Watches channel one on TV. Enjoys seeing family."*

The blasé attitude of the staff within this care organisation, whereby all clients were referred to a series of tasks, did not sit right with me. Whilst I have many stories about these clients, two I remember very clearly as examples of the sheer power of marital commitment, and the terrible way the social care sector failed them. Both ladies had late stage dementia and lived at home with their husbands, all in their eighties. Both couples had adult children who refused to visit as they did not agree with their father's decision to keep their mother at home. Over the course of my four years caring for these ladies, both husbands had heart attacks. Their children refused to care for their mothers regardless of their father's health which resulted in one man discharging himself from hospital on the same day he was admitted, to return to his wife, while the other lady was admitted into emergency respite. Once he had recovered, he then had to fight for 3 months with social services to have his wife returned home to him as he had promised her that she could die in her own home. I did not understand why their children would not help and why social services made it so difficult for that gentleman to have his wife back home, as per her wishes.

This was my fundamental motivation for a change in career. I wanted to understand more about the people receiving care; where they had worked, where they had met their spouse, what they enjoyed doing and what commitments they had made to each other which endangered their own health. I wanted to know why my peers and superiors in the care organisation had taken such an impersonal approach to caring for these older people. They were not a series of tasks to be completed and ignored, they were people with thoughts and feelings, abilities and memories. I have heard carers say, *"she has got dementia so there is no point asking her what she wants for breakfast".* I do not know if this ignorance was from lack of understanding, lack of dementia training (which we had not received) or just that carer's attitude to everyone in general. I wanted to understand what the older person and their family were going through, help wherever possible and then help other people to understand. Within the remits of the company that employed me, there was no scope for me to build my knowledge and stance to the point where I could educate others about life with dementia. I therefore decided to return to academia, build on my MSc and obtain a PhD. I have always been realistic about the impact that my PhD could have and that it will be relatively small, but if I could gain understanding into life with dementia and use that to educate a handful of people, or suggest a means of improving the lives of those affected by dementia, then it would all be worth it.

Dr Fothergill was offering a MRes studentship exploring the lived experience of older people living with dementia, it was the perfect fit. The MRes began in October 2017 and was upgraded to a PhD in October 2018, after which I had to submit my transfer report and successfully transferred onto PhD. This also explains the change in recruitment site, from care homes to memory clinics. I remember the day of my transfer VIVA very well. I was very nervous, felt sick and was shaking. Imposter syndrome is real! And despite Dr Fothergill and Dr Genders reassuring me that I could do a PhD, self-doubt was beginning to emerge but my examiner’s interest in me and my study reassured me that I was good enough to obtain a PhD.

I have considered these three years as a journey, with highs and lows, but always with a PhD as my ultimate destination. To explain my route through this PhD study, I have divided my reflection into several different aspects of the research process. Beginning with methodology, ethics, shadowing services, recruitment, data collection, data analysis and ending with dissemination. I hope that by the end of this thesis, the reader will not only be familiar with the research participants but will feel a sense of knowing me.

10.3 Methodology

I consider myself fortunate that I came straight through from BSc, to MSc and onto PhD as I was still in a learning frame of mind. I had knowledge of research methodologies, but more so of quantitative methods than qualitative. I had to do a lot of reading to gain understanding of qualitative methods but quickly came to realise that the skills I had learnt as a carer, would aid me in the process. I was already good at communicating with older people and their families and was somewhat familiar with what their experiences may be regarding the care services they receive. I was careful when recording my prior knowledge of dementia as this is an essential element of descriptive phenomenology and I had to put aside my own preconceptions. I now realise that I knew very little about this phenomenon.

Phenomenology was a new concept for me at the beginning of these three years. I had come across grounded theory and content analysis within my previous studies but never phenomenology. It took me a long time to come to terms with the philosophy and how that translates into a methodology. After much reading of textbooks, articles and websites, I began to realise that descriptive phenomenology would be the best methodology for me as it focused completely on the narratives of the participants with minimal researcher input. This helped in my understanding of phenomenology, as I was now able to hone in on appreciating the principles of descriptive phenomenology and no longer get confused trying to come to terms with the seven different types. I also wanted to merge descriptive phenomenology with alternative methods of data collection to add to the originality elements of this PhD and to explore how life story work could be incorporated into a research methodology.

I believe that you cannot truly understand a person’s situation if you do not appreciate how they came to be there. This applies to myself and my thesis, hence this chapter, but also applies to wider society too. Within the literature, life story work as a therapeutic intervention for people living with dementia is widely explored (Novy, 2018; McKinney, 2017; Tamura-Lis, 2017; Thompson, 2011) but few studies have used life stories within research. This, combined with several articles stating that research methodologies need to explore the use of alternative methods of data collection, led me to decide to video record the participants’ narratives instead of the typical voice recording. Consequently, using video recordings also offered me the opportunity to give the participants something in return for their help. I was able to give them copies of their videos, as a keepsake. This was important to me as they had been given their time to share personal stories about themselves, to repay this generosity, I was determined to return their videos as they may like to watch them later or gift them to their families. Engaging the participants in the editing of their videos gave them a sense of ownership over the stories that they had created.

The National Institute for Health Research is encouraging researchers to engage members of the public in research projects (Involve, 2015). I often sought advice from people within the community to inform the decisions I made regarding the direction of my study. I respected the knowledge of the steering committee members (two care home managers and two NHS staff) and often incorporated their suggestions into my study design and outputs. All steering committee members had the opportunity to change conference posters, presentations, the report and the manuscript I am drafting. They suggested the recruitment sites for this study as they knew best where people matching my criteria could be found, and they granted me access to those sites. Without the steering committee members, this study would not have progressed, and I am so grateful for their input. Liaising with these different organisations came as second nature to me as I would often have to contact district nurses, catheter teams, day centres, social workers, chiropodists, meals on wheels and so on, as a home carer. However, my liaising skills were not so efficient when it came to recruitment, but I will talk about that later.

I also sought advice from members of the public on my study documentation to ensure that a person with dementia could understand it. There is a free guide online by DEEP (Dementia Engagement and Empowerment Project, 2013) that suggests using larger text, bold colours and putting important text in boxes, but this did not offer insight into the terminology that should or should not be used. Therefore, I placed an advert online asking for people with dementia to read over my documents and suggest alterations. This was such an enlightening process for me. I was not aware that some of the words I use day to day (for example, confidentiality), may not be suitable for a person with dementia to understand. The DEEP (2013) guidance did state that a seven year old should be able to understand the information being provided and I initially thought that this would be patronising to an older person but the feedback I received on my documentation reassured me that I was not being patronising, I was trying to be inclusive. This realisation does not solely apply to research, it is relevant in all settings; using academic or complex jargon does not help a general member of the public to understand the information being provided to them.

When I began this PhD, I was not aware of the controversy my study would cause. I faced disapproval from many regarding the video recordings I wanted to use for this study and the demographic of the participants I needed. I was often reluctant to tell people what my study was out of fear for the confrontation that sometimes followed. For example, at a care home managers' meeting, when I was new to the study, I was flooded with comments regarding capacity of people with dementia. Some managers insisted that no one in a care home had capacity as they all had DoLS[12]. At the time, I did not know what a DoLS meant, felt way in over my head and desperately wanted a hole in the ground to swallow me up. But one man, clearly sensing my discomfort, intervened. Mr Morgan stood up and announced, "*we can take their liver or kidneys, but God forbid if we ask them about their experience".* His speech about the rights of people with dementia in care homes was inspiring and he immediately had my respect. I have since had academic superiors, peers and general members of the community tell me that my study is unethical as I should not be asking people with dementia to take part. I used to shy away from such criticism, but the further into my journey I get, and the more enthusiastic people I meet, the more my confidence has grown. I am grateful to those who criticised my decision to conduct research with people who have dementia as it has helped me develop resilience and a determination to prove them wrong. Further doubt came from the first conference that I attended. I was talking to a lady from the Centre for Aging and Dementia Research[13] about my study and she said, "*good luck getting ethical approvals for that".* This immediately filled me with apprehension and anxiety about my upcoming ethics application and the future of this study.

10.4 Ethics

"Students often feel quite lost in tackling their ethics application" (Petillion *et al.,* 2017, pp. 139). The ethical approval process was a considerable contributor to the "lows" experienced during my PhD journey. My first application to USW ethics, to

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[12] Deprivation of Liberty- residents in the care homes were under constant supervision and not free to leave. These are applied when someone goes into a care home or hospital and cannot make decisions regarding their treatment (Mind, 2019).

[13] CADR is the Centre for Aging and Dementia Research in Swansea University.

recruit through the care homes, was relatively straight forward. When I reapplied to recruit through memory clinics, I assumed that it would simply be a minor amendment as I was only changing the recruitment site, not the methodology. But as the second application had to go through IRAS (NHS Ethics), it was decided that it should be treated as a new submission. It took me a long time to obtain ethical approval for this second submission. The main concern for the committee was around the video recordings, which I must admit, baffled me as they had already approved their use for the care homes but this second application had been sent to different reviewers who had very different concerns to those who approved my first application.

I think all researchers are aware of how disheartening the written feedback to accompany the “not approved” response can be. From February 2019 to June 2019, I made changes and resubmitted then made more changes and resubmitted. I was getting frustrated and upset, and often contemplated removing the use of the videos from my study. Eventually, the Chair of the ethics committee offered to meet with me to discuss the application and in retrospect, I should have requested this much sooner. Admittedly, I was very nervous about meeting him as I thought he was going to criticise the study, much like I had experienced before from other academics. But being able to sit down and talk about my study and his concerns, resulted in ethical approval the following month. I was misunderstanding their written feedback and thought that they were asking for more justification for the use of videos. But they were asking for clarification on the ownership of the videos[14]. I recommend every PhD student request a meeting with the Chair if their submission is not approved; this has also been recognised by Shore (2009) and Snowden (2014) who suggest that students who develop relationships with the research ethics committee have a better understanding of what is required of them. I could have saved so much time and stress, had I just understood what was being asked of me. I feel proud of myself for not changing my data collection tool during this period of confusion. I stood by my decision to keep the videos and it paid off.

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[14] The participants own their videos, but they are copyrighted to USW and can never be published.

My original plan was to use the videos for all outputs related to this thesis, and I had permissions to do this for the participants recruited through the care homes. But after going through NHS Ethics to recruit from memory clinics, they only gave permission for the videos to be used in defence of my PhD thesis, to be shown only to my examiners on USW property. I had presented the videos from the care homes at conferences prior to this decision and the impact these have upon the audience is significant. People can relate to a video far better than segments from a transcript on the screen, so I was disappointed at this decision. But I am grateful they let me continue to use the videos for my PhD. Without ethical approval, my study would not exist. Limiting my use of the videos is a small compromise for obtaining my PhD. Once I had amended my use of the videos on the ethics application form for the NHS, the approval letters followed quickly afterwards.

Despite the adversity that I have encountered over this study, I maintain a desire to conduct older persons' research after the completion of this PhD and hope that everything I have learnt while obtaining approvals for this study, can be applied in my future research career. I honestly believe that sitting down and talking through my application with the ethics committee was an essential step. Sending emails back and forth, trying to interpret what each other is saying can be a long and frustrating process. Once I had sat down with the Chair of the committee and talked through the options and the next steps of what I needed to do, I no longer felt that I was banging my head against the wall. I understood what they wanted, they understood what I wanted, and we worked together to meet in the middle. The research ethics process helped me strengthen my research design, which in turn, added to the quality and credibility of my study. For me, this justifies the time and effort that I put into this lengthy process.

10.5 Shadowing Services

Prior to conducting data collection, I shadowed staff at the care homes and memory clinics from which I would recruit participants. One observation from within the care homes that I shadowed was that they pride themselves on all residents having a "this is me" document (Alzheimer's Society, 2010). Yet these documents are locked away in the office filing cabinet, only seen when requested. The purpose of "*this is me"* was for staff and visitors to the home to be able to learn some personal information about the resident which they could use to start a conversation with that person. I thought this was strange; why take the time to complete this document and then lock it away? New staff, in particular, would benefit from reading these documents, and whilst they are aware they exist, the staff I spoke to have never read them. Confidentiality may also be a reason that they are locked away, but then how can visitors to the home who are not granted access to the document, be able to learn something about that person which allows them to sustain a conversation? Alternatively, one of the homes I visited had collages on the residents' bedroom door containing their name and images of their hobbies; whilst this is not as detailed as the "this is me" document, it serves the same purpose for visitors and new staff members, and helped me to initiate a conversation with the residents whilst I was shadowing within that care home.

I had never worked in a residential care setting before and was eager to learn how they differed from supported living. I will admit, much like Laura suggested in this study, I thought care homes had all the residents sitting in a semi-circle around a TV. How wrong I was. I can only speak for the care homes I visited, and others may differ, but the residents were encouraged to maintain hobbies and interests, and even learn new skills whilst living in the home. Some are encouraged to make their own meals or are escorted to the local pub for dinner. They have singing, chair Zumba, parties and animal visits. They go to the seaside, cinema and bowling. Whilst this was all fantastic to see, it saddened me when I thought back to some of the older people I had cared for whose only visitors were the carers and who never left their homes. Pippa commented that her Dad is having a more fulfilled life in the care home than he has had in the last few years of being in his own home and I also believe this to be true. People view care homes as a signifier of the end (Aminzadeh *et al.,* 2009), yet they are more enjoyable for many people, than being in their own homes.

An observation from the memory clinics where I shadowed was that there was no consistency on the dementia pathway being followed by the clinics. For example, some clinics gave the patients masses of information about dementia straight after they are diagnosed, while others wait 9 weeks before giving the person with dementia any information about their diagnosis and condition. Similarly, some clinics offer a variety of dementia support groups while others offer very little. Some people are given every opportunity to live well with dementia while others are left wading through the unknown. It seems unfair to me that the quality of the services they receive is dependent on their postcode and which clinic they attend. Despite these differences, all memory clinics have a uniform assessment test for dementia, which I was able to observe being used. I was also allowed to shadow the doctors while they confirmed the diagnoses. I assumed that people would be more upset at having their diagnosis confirmed than having the initial assessments, but I stood corrected. To me, the patients appeared far more agitated when they could not answer the questions on the verbal test than when their diagnosis was confirmed by the doctor.

Shadowing the staff at the services allowed me to pick up useful information and names of staff members which I could later use during data collection to prompt the person. It also allowed me to meet key members of staff who could facilitate my access to possible participants. Prior to shadowing the staff members, I had been computer bound, reading and completing different applications. I really enjoyed being back in the "*real world*", meeting older people, instead of sitting at a computer. My prior work as a care worker allowed me to feel comfortable talking at length with a stranger. Through my care work, I learnt how to enter someone's home and immediately start a conversation with them. I was able to bring this skill forward and apply it to the services I shadowed and through data collection. Some of the people I met whilst shadowing the services participated in my study, this also helped me prompt them for more information as I already knew a little about them and had begun to build a rapport.

10.6 Recruitment

Despite my pessimistic personality, I was hopeful that recruitment would be a smooth process and I would have plenty of participants. I could not have been more wrong. Initially, I recruited from the care homes and tended to shy away from asking the care home managers who had intimidated me at that initial meeting and focused on the managers who had been supportive and enthusiastic towards my study. Despite their enthusiasm, they were struggling to identify possible participants. When participants were identified, the person with dementia did not have the required levels of awareness about their dementia diagnosis or could not give fully informed consent to participate. This is likely my own fault for not being clear enough with my requirements for the inclusion and exclusion criteria. Whilst I had written down the criteria clearly and presented it on the handouts, I had not emphasised it enough in my verbal communication with the managers. For a few weeks, I had care home managers contacting me to say they had someone who was interested, and when I went to meet with them, they did not meet my inclusion criteria. I felt awful about this; I had wasted my time and more importantly, the older person's time. I felt deflated and stuck. I considered changing my study to solely explore the experiences of the family members since I was sure the care organisation had some who would like to take part. I had come so far, had the approvals and equipment ready and desperately did not want to change my study.

In a final attempt to find someone with dementia to take part, I became relentless. I emailed, phoned and met with the care home managers. I emphasised that the person had to know that they have dementia, it must be a confirmed diagnosis from the health board and not staff suspicions, and they had to provide fully informed consent to participate (in accordance with the Mental Capacity Act, 2005, guidelines; Department of Health, 2005). After everything I had been through to get to this point, I did not want to fail at this stage. Eventually, I had a phone call to say that a lady with dementia and her daughter wanted to meet with me to find out more about the study. The pessimist in me began to take over again; would this be another let down? May and Laura were the first participants to give fully informed consent to participate in this study. The remaining four pairs from the care homes came shortly afterwards. Due to ill health, three of the people with dementia became unable to participate and their family member participated alone as they had already given fully informed consent.

I had a much easier experience when recruiting through the memory clinics. When I met with the senior staff members whom I had asked to identify participants on my behalf, I explained the inclusion criteria and their response was *"is that all?".* I was thrilled that the memory clinics would find me countless participants. I was a little too optimistic. The relentless approach that I had taken with the care homes was put into use again. I phoned, emailed and arranged meetings with the senior nurses from the memory clinics. I was very specific about the levels of awareness the person with dementia needed to have. I had been prewarned by my steering committee members that NHS staff need deadlines to work towards; if I did not specify a date that I needed people by, they would take their time and possibly forget about me. I initially felt out of my league giving senior nurses a deadline for my recruitment, but on the odd occasions I forgot to say, they asked. They seemed willing to help and appreciated the simplicity of what I was requesting. Between December 2019 and February 2020, they found me fifteen participants who all eventually participated in the study. I have attributed the vast difference in recruitment to the stages of dementia of people living in care homes; generally, the residents have later stages of dementia whereas the memory clinic has every dementia patient on their systems.

I came to understand the influence the sender of an email has over the response that is received from the workforce; when I emailed to ask for participants, I seldom had a response. Perhaps this is due to research fatigue or perhaps it is easy to ignore an email from a research student who is unknown when working in a busy hospital environment? Yet, if I asked one of my steering committee advisors to email on my behalf, many would respond. This is one to remember for future research. Perhaps a university email address in a health board inbox gets overlooked or not given priority and a different approach is necessary to gain the desired results. I did find that staff members who had met with me in person were much more likely to answer my emails than those I had not met yet.

10.7 Data Collection

Data collection was by far my favourite part of this whole journey. I loved meeting the participants and getting to know them by hearing their stories. It amazed me how open and honest they were with a total stranger. I like to think that my years of care work have helped me develop a trustworthy persona and that I can quickly make people feel comfortable in my presence. From my care work, shadowing the services, the conferences I had attended and the literature I had read, I had acquired knowledge of dementia but mostly the factual elements; the diagnosis process, the different types of diagnoses, the medications available and how it progresses. But during data collection, I had to put all this knowledge aside and almost plead ignorance. The participants, naturally, assumed that I knew all about my area of research and would often ask me questions about things they did not understand. I was not in a situation to answer; I was no longer a carer and not responsible for that person's care. My role was research student and while it was difficult for me to resist helping the person understand their condition, I knew that I could not. I either had to say that I did not know the answer, for example, Nancy asked me why she could not take medication for her dementia, or explain that I did not know enough about their situation to be able to comment. Whenever this occurred, I asked if they would like me to contact their dementia advisor and let them know there was some uncertainty; all agreed to let me do this. There were exceptions when I deemed the question to be simplistic and answered. For example, Geraint asked me what the difference between Alzheimer's and dementia was, so I told him that Alzheimer's was a form of dementia and he seemed satisfied with this answer. The participants assumed that I was the expert on life with dementia, yet the basic principles of descriptive phenomenology emphasise the participant is the expert. Prior to conducting this study, I knew very little about living with the condition.

Some of the participants became upset whilst sharing their stories, particularly when speaking about their hopes for the future. During the ethics applications, I had pre-empted that some of the topics may be emotive, but I was not prepared when the first participant, Laura, become upset. Dr Fothergill had prewarned me to take tissues to my interviews, but I had forgotten in the eagerness of my first participants. When Laura began crying, I stopped the video recording and scanned the room frantically for some tissues (there were none) but managed to find a roll of toilet tissue next to May's bed. I offered this to Laura who burst out laughing and immediately stopped crying. I think she sensed my panic. Through my care work, my clients would regularly become upset about different elements of their life, so I was accustomed to offering reassurance and listening to their worries, but Laura took me off guard. I was concerned that she would think me unprofessional or childish, and "what if she reported me?" But she just laughed and resumed telling me why she was so concerned about the future. I did not handle Laura's upset particularly well, but luckily for me, she understood that she was my first participant, and I was still finding my feet. She was patient and reassuring that I had done a good job of interviewing her and her mother. Nevertheless, I learned from that first experience, and always took extra packets of tissues to the remaining interviews and managed other participant’s upset calmly and considerately.

I think sometimes I am so determined to get a PhD, do a good job, and become a researcher; I can be too hard on myself. I am overly critical, and when things go wrong, like forgetting the tissues, I automatically assume I have ruined everything. As a care worker, I faced scrutiny every day and I often forget I am no longer in that environment. When working with people, there is room for minor errors. Laura’s encouraging response helped me realise this and when some things go wrong, laughing it off can be the best course of action. I still need reminding of this occasionally.

I have acknowledged my age and gender as a limitation for this study as it is possible that my demographic profile altered the way the participants spoke to me. I was considerably younger than all the people who participated in this study which may explain why, for example, only Kim shared details of her intimate relationship. The participants and I were all white British, and currently living in South Wales. The commonalities between us made the interviews flow easier. I was familiar with most of the places that were central to interviewee’s stories which saved them from having to try to explain where, geographically, for example, a particular place was. Similarly, I knew the key staff members who were spoken about within the narratives, but this was also a double-edged sword. I understood a particular staff member’s role and relationship with the participant but did not want them to think I knew the staff member too well in case they thought we were friends and therefore, worry about the information they shared with me getting back to the service. I reiterated their narratives would remain confidential and that they were in complete control over what happened to their data. I was open and honest with the participants, and I would like to believe they were the same with me.

Most of the participants showed a united front when I met them for the first time, they answered the door together and sat together while I went over the study and answered any questions. Kim and Rob were the only participants who did not want to meet me at their own home. When Kim arrived at the memory clinic, Rob was playing a group activity at the clinic and they did not acknowledge each other. After Kim's data collection was complete, she left again without saying hello or goodbye to Rob. When it was Rob's turn to participate in the study, he arrived at the memory clinic alone. I felt it was odd for a married couple to not say "hello" when the other arrived in the same place. This behaviour was explained by Kim and Rob during their narratives when they spoke about the way their relationship had changed because of Rob's dementia. Being newly married myself when I collected data from Rob and Kim, I found it difficult to listen to her narrative when she was explaining that her husband was no longer the man she had married; she was no longer in love with him, she had not signed up to take care of him and thought it was ok to seek an intimate relationship elsewhere. Even now, months after talking with Kim, I still think about what she said. I often try to comprehend Kim's rational for this attitude towards her husband; I think there was more to her reasoning than she shared with me and whilst I have kept these thoughts out of my analysis, I still ponder over them occasionally.

Whilst transcribing the videos was essential to this study, it was far from stress free. I always say that time management is one of my skills and coming from my MSc straight into this PhD led me to believe that I could manage the workload easily. I naively put on my ethics application that I would transcribe and return the videos to the participants within a week of collecting them. Some weeks, I met with four participants and having to transcribe four sets of interview data by the following week was unmanageable. Luckily, once the transcripts and videos were returned for editing, I could then take my time making the changes. The transcripts were edited straight away but the videos took much longer to change. In hindsight, I should have edited the videos with the transcripts and returned them to the participants as soon as possible. Instead, I have been editing videos whilst writing this thesis which has been something of a distraction. The other implication of my slow video editing is that the participants have to wait for their DVDs to be returned and whilst I know that they do not mind waiting, I feel like I am somehow letting them down for taking too long over the task.

When Nancy and Trystan's videos and transcripts were returned for editing, Nancy became very upset watching her video. Listening to herself explain the bullying that she endured as a child for being "*fat"* caused her considerable upset. She did not however want it removed from her video, as it was all true and she felt it had shaped elements of her personality, making her as self-conscious about her dementia as she had been about her weight. Bethany experienced something similar when she watched the videos with her mother; Lynne had told me about her feelings regarding her diagnosis but had not told Bethany. It was not only the interviewing process that upset the participants, but also the video editing and for some, receiving their DVD afterwards. I am pleased with my ability to handle upset participants; I did not lie and say "*everything will be ok"* because the reality of living with a progressive condition, like dementia, suggests that life will become increasingly more difficult and worrying. Instead, I attentively listened to their concerns, reassured them that becoming upset was normal, and offered to contact their dementia support worker on their behalf. I think this stemmed from my care work as I would often care for palliative patients and calmly and considerately relay information onto their loved ones, district nurses and other care workers.

I pride myself on the number of positive outputs that can be returned to the participants. They felt the psychological benefits of talking about their experiences; when Darren said that the interview had been therapeutic. The DVDs were received with gratitude and offer a tribute to their loved one's life. The relationships I built with the participants during the data collection and editing for this study allowed me to remain a part of their lives long after data collection was complete. Pippa's father, who was unable to take part in the study, sadly passed away and she later emailed me to say that this study is a legacy to him and his battle with dementia. I received a card from Gail wishing me luck with the remainder of my education and Laura offered similar reassurance; "*I think under the circumstances with my mother and her hearing aids, I thought you were very patient with her…I would just like to say that I am glad you are doing it. I hope you do well, and you are welcome to come and talk to us any time".* I like to think this is evidence of my trustworthiness and likability as a researcher and it gives me confidence that I can become a professional researcher in the future.

10.8 Data Analysis

Deciding on my analysis was easier than I thought it would be. There are limited analysis options for descriptive phenomenology, as I discussed within chapter 4. I was familiar with qualitative analyses from my BSc and MSc, but these courses tended to focus on quantitative analysis instead. Therefore, after a lot of reading, I favoured Colaizzi's (1978) descriptive phenomenology analysis framework as it had clear steps to follow, offered a table to help complete the analysis and kept the participants' narratives central to the process. I did not want to interpret the narratives as this would put my own spin on the stories and that is not the nature of descriptive phenomenology. I decided to use Colaizzi (1978) early on and this was included in the ethics application. I later discovered Burnard's (1991) analysis framework for analysing interview data; this was similar to Colaizzi (1978) but with some helpful additions. I therefore decided to merge the two. Had I been more accustomed to carrying out qualitative analyses, I may have favoured alternative analysis options but as I was not confident in my ability to do this properly, I opted for the clear guided method. This was the right choice for me, and merging Colaizzi with Burnard, allowed me to elevate my analysis while still keeping it relatively simple. My confidence in using qualitative methodologies and analyses has improved vastly in the last three years and I now prefer those methods over quantitative ones as I like the personal nature of one to one conversation.

I was led to believe that PhD analyses had to use a computer software package to assist in their inquiry. I tried to use computer software (NVivo) to analyse my data and got as far as identifying significant statements. I then found that the statements that I had removed were out of context and I had to keep referring back to the whole transcript to find out what the statement was in reference to. I was becoming increasingly stressed over this. I thought maybe I was doing something wrong and so attended multiple training sessions on NVivo but still could not use the package with ease. After sharing my concerns with my supervision team, I was reassured that it was not essential to use a computer software package. If the software could offer no further benefits than arranging by hand, then I did not have to use it. I followed the pre-defined steps that I had created by merging the two analyses and incorporated the analysis table to present the statements within their subthemes but pinpointing the specific title for each theme was challenging. Lengthy conversations with fellow PhD students and my supervision team helped, and as a team, we came to a consensus on the themes. I had these themes validated by some of the participants who felt their situation would be isolation, if they were not able to attend the support groups[15]. Therefore, “good support” is a subtheme within the Isolation theme for the family members, as they suggested. Having the themes validated by the participants was helpful for me. Researchers can never be sure they are capturing the true experiences of a phenomenon without validation from the experts (the person living with that phenomenon). Receiving this validation, and the minor suggestion from the participants allowed me to recognise the accuracy of my analysis. This, in turn, boosted my confidence in this study.

10.9 Dissemination

I feel proud of myself and this study for encompassing something different into the methodology (video recordings) and I did not want to resort back to the norm when presenting the results for this thesis. I had ethical permissions to show segments of the video recordings to my examiners in defence of my thesis; only to show them on the day of my examination, on university property. But due to COVID-19, a face to face VIVA is in doubt. I decided that I wanted to give my examiners as much information as possible about the participants so that their experiences were more than words on a page. I had seen one thesis (Nicky Genders, a previous supervisor) that had a chapter on participant cameos, to introduce the reader to the participants, and decided this would also suit my vision for this thesis. Justification of my chapter 5 was tricky as it was not the norm for dissertations, but I really feel strongly that this study would not have been possible were it not for the participants. Their experiences are more than the few extracted quotes I have used to defend my themes; they are adults with unique personal histories which have shaped their experiences of living with dementia and I needed the reader to see this. As Holloway and Jefferson (2011) emphasised, research needs to be done differently and presenting research also needs to be done differently. I took the time to understand

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[15] Not all participants were able to/wanted to contribute anymore of their time to the study.

the participants’ personal life histories; this time and effort (both my own and the participants’) warrants a section of this thesis.

The very few studies within the literature which had used video recordings to collect their data had only dedicated a sentence to them within the manuscript. I now understand why. It is difficult to add visual analysis to a video of someone sitting still. One of the articles within the literature review had followed the participant around their home and was therefore able to comment more on the content of the video. In hindsight, this may have worked well for this study. Walking around the participant’s home would have produced many more visual cues to prompt the person’s story, although I am not sure about the health and safety of doing this. Single handily trying to hold a video recorder whilst ensuring the older person did not trip over the microphone leads or power cables and so on, could prove problematic, but would have offered significantly more visual data to add to the analysis. Nevertheless, I feel that I have added additional details where appropriate. For me, the biggest gain in using the videos was my own understanding of the stories. I have since transcribed audio data for a different study and have really struggled to understand the participant’s experience. Without the facial cues, my understanding of their life is greatly flawed. Something as simple as a frown or a smile on a recording can make all the difference in the listener’s interpretation of the situation. I therefore understand why articles barely make reference to the use of the videos, particularly in the analysis. Yet they are an invaluable resource when appreciating and interpreting the participant’s experiences.

I often undersell myself and my work. Whilst writing this thesis, my supervisors often commented that I was underselling the vast amount of work I had put into this study. I struggle to “sell myself”; I excel at selling other people and their studies, but not myself. Whether this is due to self-doubt, my pessimism, or my fear of criticism, I am not sure. Nevertheless, this has been present throughout my education. But after seeing the impact that my study has had on the lives of the participants, the audience at conferences and the setting where the services are being delivered, my confidence has grown. My desire is for a career in research and I now feel that I can achieve this. I can talk at length about my own study, using examples from legislation, literature or my participants’ narratives and experiences to reinforce what

I am saying. With the encouragement from my participants and my supervision team, I believe I can make a difference to peoples' lives through research and whilst my study is relatively small, it offers invaluable insight into life with dementia which can, hopefully, be used to inform policy, practice and research.

10.10 Concluding Comments

Pippa's definition of life with dementia also summarises my journey with this PhD; *"a rocky road. A very steep learning curve".* I have celebrated milestones, both personal and study related, and wept during tough times. I have laughed and cried with the participants whilst they shared their stories and have gained new friends, new skills, and invaluable insight into life with dementia. I have tested the boundaries of ethical committees and had an alternative method of data collection approved for this study. Now that these three years are coming to an end, I feel both relieved that it is almost over but also reluctant to finish. I feel confident and knowledgeable within this study. I have spent seven consecutive years as a student and to leave that status and join the "real world" is terrifying. I feel secure within the academic setting and only hope that my career will bring me back to academia in the future. As for what comes next in my journey…

> *"Go back?" he thought. "No good at all! Go sideways? Impossible! Go forward? Only thing to do! On we go!" So up he got and trotted along with his little sword held in front of him and one hand feeling the wall, and his heart all of a patter and a pitter."*
>
> *(Taken from The Hobbit, by J. R. R. Tolkien, pp. 82)*

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APPENDICES

A: Timeline of policy, legislation and frameworks

Date	Policy and Government Initiative	Relevance for Older People with Dementia and Family Members
1986	Living Well into Old Age (King's Fund Centre)	This study was the first to be funded by the government to explore the factors influencing well-being and quality of life in 1500 older people living in London. Contrary to popular beliefs about people living with dementia in 1980's London, the study found that overall, people were satisfied with their quality of life and felt supported by family and friends. Participants in this study reported that they often felt depressed as a result of their worsening ability to perform tasks, not due to isolation or loneliness. To improve the wellbeing and quality of life for older people living in London, this report suggested that older people should be encouraged to participate in social activities and support with daily activities should be offered.
1998	European Convention on Human Rights (ECHR)	The ECHR outlines 16 fundamental human rights; below are the articles deemed particularly relevant for people with dementia and their families. Article 3: No one shall be subject to degrading treatment. Article 5: Everyone has the right to liberty and security. Article 14: Freedom from discrimination on the grounds of a disability (i.e. dementia). The legal framework of both the ECHR and HRA require all health and social care workers to respect the dignity of people using their services.
1998	The Human Rights Act (HRA)	Emphasises that everyone has equal rights. People with dementia have the same civil and legal rights as everyone else. Protects people with dementia from physical, psychological, financial, emotional and sexual abuse. The HRA allows individuals to enforce the 16 fundamental rights outlined in the ECHR through court proceedings if necessary (Social Care Institute for Excellence, 2013). The HRA allows people with dementia and their family members to challenge the "professionals" about what is best for them (Social Care Institute for Excellence, 2013).

		Adherence to both the HRA and ECHR should be evident in the day to day policy and practice of health and social care workers.
2001	National Service Framework for Older People	Standard 1: Older people should never be unfairly discriminated against because of their age when accessing NHS or social care services. Standard 2: Older people should be provided with individualised person centred care. Care should be introduced promptly when needed. Standard 7: Promote good mental health in older people, in particular, effective diagnosis, treatment and support for elderly people with dementia and their family members. Standard 8: Promote a healthy and active lifestyle for older people.
2005	Mental Capacity Act	The Mental Capacity Act empowers people to make decisions for themselves wherever possible. People with a dementia diagnosis still have the capacity to make their own decisions unless it can be proven otherwise. The Mental Capacity Act allows people with dementia and their family members to challenge the "professionals" about what is best for them (Social Care Institute for Excellence, 2013).
2006	United Nations Convention on the Rights of Persons with Disabilities (CRPD)	Provides a social model of disability that gives people with dementia equal opportunity to "non-disabled" people. This includes: Equal access to information, transport, services and work. Support when making decisions. Helping the person with dementia to remain within their community for as long as possible and allowing the person to decide where they want to reside.
2009	The Use of Antipsychotic Medication for People with Dementia: Time for Action. (A.K.A. The Banerjee Report)	The Banerjee Report explored the use of antipsychotic mediation for people with dementia. The report concluded that antipsychotics were overused for people with dementia. Antipsychotics should only be used when a patient really needs it. There needs to be an increase in the use of non-pharmaceutical treatments for dementia symptoms (i.e. behavioural therapy). Access to psychological therapies should be made easier for people with dementia.
2009	National Dementia Strategy	This was the first national dementia strategy for the UK (GOV.UK, 2009). The strategy had 3 objectives; to drastically improve dementia services through earlier diagnosis and intervention, a higher quality of life and improved awareness.

		This strategy resulted in 94% of primary care trusts having a dedicated memory service for dementia (GOV.UK, 2012). The prescribing of antipsychotic medication for people with dementia had been reduced by two thirds (GOV.UK date).
2010	Equality Act	The Equality Act (2010) states that no one is to be discriminated against due to race, gender, religion, sexual orientation of disability. The Equality Act (2010) protects disabled people from unfair discrimination. The Equality Act (2010) defines disability as "a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities". This definition applies to many people with dementia. The Equality Act (2010) is believed to use the law to benefit people with dementia (Mental Health Foundation, 2015).
2010	Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia	This document has accumulated evidence based and person centred practices to guide health and care providers for people with dementia (GOV.UK, 2010). This document recognises that people with dementia are often refused full control over their lives as there are too many "risks" (Clarke *et al*., 2009). This document offers ways for clinicians to overcome these risks to ensure the person with dementia is fully enabled to take control over their lives. This document encourages positive risk management by focusing on the person's strengths, developing a system to manage any risks, taking a tailored person centred approach, always trying to find less restrictive alternatives and understanding a person's past to inform their experiences of risks.
2010	Mental Health (Wales) Measure	The Mental Health (Wales) Measure (2010) enacts many provisions about primary mental health services, coordination and planning within secondary mental health services and the assessment of needs for people within mental health services within Wales. The Mental Health (Wales) Measure (2010) consists on fifty-six provisions. Article 5: primary mental health services must conduct assessments, provide treatments to improve or prevent deterioration, make appropriate referrals and provide information, support, advice and other assistance to both the person with dementia and their carers. Article 14: every patient within secondary mental health services should be appointed a care coordinator, the care coordinator is responsible for

		ensuring there is agreement between the patient, carers and mental health services about the desired outcomes (Article 18). Furthermore, the care coordinator has to record a written care and treatment plan for the patient (Article 18) and ensure this care and treatment plan is reviewed and revised regularly (Article 18).
2011	National Dementia Vision for Wales	The National Dementia Vision for Wales has identified four key areas to target for improvement to increase the quality of life for people affected by dementia. These four areas are: improved service provision improved diagnosis rate and interventions better access to information and support improved training for people delivering care to people affected by dementia. This document sets out how the lives of people with dementia living in Wales has improved thus far and the plan for continual improvement for the future. This plan was accompanied by a raise in funding for dementia services from the Welsh Government (GOV.Wales, 2011). Through this plan, the Welsh Government has committed to: Improve services Improve access to information Raise awareness of dementia Improve training of health care professionals Support more dementia research being undertaken
2011	Dementia Commissioning Pack	The first NHS guide for practitioners to provide the best possible outcomes for people with dementia for the lowest costs. The pack contains practical resources for health and social care workers to provide integrated care and person-centres services. The pack contains guidance on: Early diagnosis and intervention Community and care home based services Mental health liaison services within hospitals Reducing the use of antipsychotic medication Cost/benefit template Needs assessment tool Patient information A full copy of the items provided within the dementia commissioning pack can be found at Dementia Partnership (2011).
2012	Prime Minister's Challenge on	This document was devised under David Cameron and builds on the standards created in the 2009 National Dementia Strategy.

	Dementia 2012-2015	The aim of this challenge was to make the UK a world leader in dementia care and research. To achieve this, an increase in dementia research was encouraged, more dementia friendly communities are to be developed that understood how to help people affected by dementia and improvements in health and social care were recommended. This dementia challenge incorporated a financial reward to any hospital routinely screening for dementia in any over seventy-five year old admissions in an attempt to increase diagnosis rates. Financial rewards were also offered to NHS staff who demonstrated innovative ideas for improving dementia care. Funding for dementia research was increased to £66million by 2015. A nationwide scheme to increase awareness of dementia was launched along with the aim of creating 20 dementia friendly cities, towns and villages.
2013	Framework for delivering integrated Health and Social Care for Older People with Complex Needs	This is a pan Wales, cost effective framework to ensure that older people and their families live well into old age. It aims to provide older people with help when and where they need it, in multiple formats (telephone, face to face, online) and access to community-based support services. These improvements should result in older people and their families feeling well-informed and engaged in the services that are available to them.
2013	Quality Standards for Supporting People to Live Well with Dementia (NICE 2013)	This is a NICE document for assessing quality standards. This document consists of ten statements, each of which are aimed at high priority areas affecting the lives of people with dementia. Each statement is specific and measurable to assess quality standards for people with dementia in all settings (e.g. hospital, at home, care homes). Here are a selection of the statements in this standard: Statement 2: People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support. Statement 4: People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

		Statement 5: People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships. Statement 8: People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
2013	G8 Dementia Summit	This was the first G8 summit, held in London, with ministers, researchers, pharmaceutical companies and charities in attendance. The summit discussed how to stimulate more dementia research, how to improve the treatment and prevention of dementia and how to increase the quality of life for people affected by dementia. The summit agreed to: Find a cure or disease modifying therapy for dementia by 2025 Increase the amount of funding for dementia research Increase the number of people with dementia taking part in research Share information and data from dementia research across all G8 countries Have a large database containing all dementia research free of charge for easy access.
2014	Social Services and Well-Being (Wales) Act	Supersedes the Mental Health (Wales) Measure (2010). The Social Services and Well-Being Act imposes regulations on health boards, local authorities and Welsh ministers to ensure their work promotes the well-being of those who need care and support, and carers. The Act ensures: People have control over the support they need Assessments are focused on the individual Carers have equal rights to support whilst they provide care Information and advice is easily accessible to all Safeguarding powers are stronger A preventative method of support is supplied were possible Local authorities are to work with local health boards to create an innovative, integrated service change The Act obligates ministers to release annual reports on the progress made towards achieving well-being. For people with dementia and their family members, this act allows them to have control over their care and support and ensures everything revolves around them.

2014	The Care Act	This is a highly influential Act impacting on the lives of people with dementia and there family members. Some of the most influential articles follow. Article 1: Promoting wellbeing Local authorities must not make assumptions about a person with dementia. Strategies to prevent or delay the progression of dementia must be investigated. The person with dementia must be involved in decision making about their care. The well-being of the family members must be considered. Article 2: Preventing, reducing or delaying needs Local authorities must try and prevent the person with dementia and family members needs from escalating. Provisions need to be implemented to ensure the person with dementia remains a part of their community i.e. through social activities. Article 3: Information and Advice Receiving a dementia diagnosis should immediately allow access to information. People with dementia and family members should be granted access to a wealth of information and advice about services available to them. People affected by dementia should be given a pathway to raise any concerns. Article 4: Commissioning of Care and Support Care services should be based around the needs of the person with dementia and their family members. Fifteen minute carer visits to a person with dementia should only be used on request, otherwise, the visits need to be longer. People with dementia and their family members should be able to choose which services they want to access. Article 6: Assessment Assessments must be appropriate, effective and comprehensive to ensure people with dementia and their families receive timely and appropriate support. Assessments should be used to help people with dementia and their families understand their situations better. Article 14: Safeguarding All people with dementia and family members must be protected against abuse or neglect. People with dementia must be supported to make their own decisions.

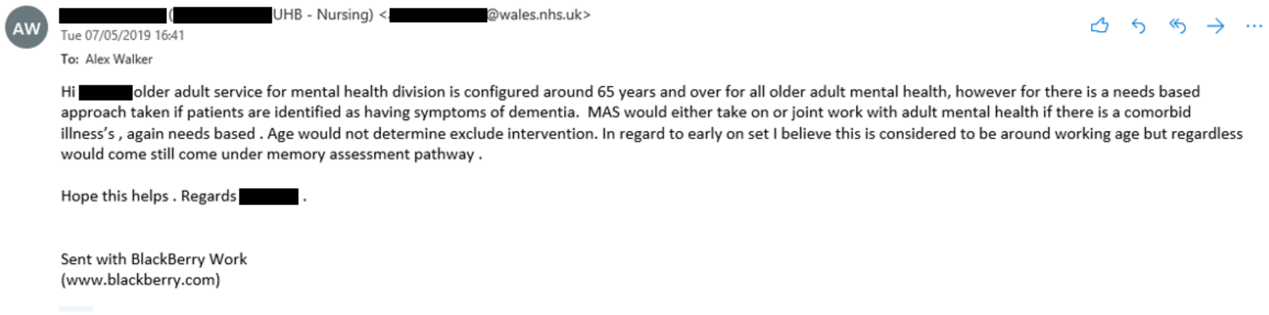
		Family members need to be protected from challenging behaviours displayed by people with dementia.
2015	1000 Lives	The 1000 Lives initiative is working within Welsh NHS organisations to ensure that people with dementia have a good quality of life. 1000 Lives aims to: Reduce referral times for people with dementia accessing memory services. Improved quality of care for people with dementia when admitted into hospital and reduced stay time. Reducing the use of antipsychotic medication for people with dementia. Improved support for caregivers. Additionally, 1000 lives share examples of best practice within Welsh health boards and has developed a dementia training programme to enhance the skills of those working with dementia.
2016	Good Work: A Dementia Learning and Development Framework for Wales	This framework was developed by Care Council for Wales, NHS Wales, Public Health Wales and the Welsh Government. This framework ensures that people within Wales are kept central to all Welsh policy, legislation and guidance. This framework is aimed at health and social care workers and gives them free reign to identity their own learning and development needs. The first section of the framework offers generic information about dementia. The second offers a summary of learning and development topics and the third is aimed at senior managers and commissioners. The framework is devised to build on the strengths of the health and care worker, not their deficits.
2016	Making a Difference in Dementia: Nursing Vision and Strategy. Refreshed edition.	This strategy sets out guidelines for nursing to provide quality and compassionate care to people with dementia and their family members within all settings; including within their own homes. The models of care outlined by this strategy incorporate both the social and medical model of dementia; whereby nursing needs to be person centred whilst delivering medical assistance. The nurse should understand the unique experiences of the person with dementia, build and maintain a relationship with the person with dementia and their family members, treat both with respect and dignity, take the time to understand the person with dementia's life history, develop a dementia friendly environment, identify and report any abuse and offer

		alternative methods of support (i.e not pharmaceutical). All NHS staff are to have completed Tier 1 dementia training by 2018. Any nurse working with people who have dementia need Tier 2 training (active involvement, anticipate, respond and understand). Specialist dementia nurses and palliative care nurses must have Tier 3 training (specialist skills).
2016	Joint Declaration on Post-Diagnostic Dementia Care and Support	This declaration sets out a joint ambition to achieve better quality post diagnostic care among health boards, social care, government, third sector and all other relevant parties. The aim is to deliver integrated and effective services to everyone affected by dementia. The declaration's aims are: The accounts of people affected by dementia need to be taken fully into consideration when planning services and care. These services need to be in line with the individual's preferences. Support needs to be holistic, effective and timely, and takes age, ethnicity, co-morbidity and diagnosis into consideration. The health, physical and emotional needs of those affected by dementia need to be taken into account. Those affected by dementia need to be made aware of the services and support available to them. Families and carers need to receive appropriate information and training to properly care for a person with dementia People with dementia and their family members are given the opportunity to take part in research.
2016	Prime Minister's Challenge on Dementia 2020	This document sets out the government's key aspirations to achieve by 2020, these are; improved public awareness of dementia a national average referral time for an initial dementia assessment (6 weeks) continuity of care *easily accessible information, advice and support *all NHS staff dementia trained all hospitals and care homes become dementia friendly dementia research to become a career choice *funding for dementia research to increase *cure of disease modifying treatment available by 2025 *all dementia research to be accessible on a database *increased numbers of people affected by dementia taking part in research.

		(*these aims were previously outlined in the G8 Summit, 2013).
2017	Global Action Plan on the Public Health Response to Dementia 2017-2025	The Global Action Plan on the Public Health Response to Dementia identified 7 action areas to improve life with dementia, these are: Dementia as a public health priority Dementia awareness and friendliness Dementia risk reduction Dementia diagnosis, treatment, care and support Support for dementia carers Information systems for dementia Dementia research and innovation To achieve these action points, the Global Action Plan aims to build on existing systems of information rather than creating new ones from scratch. By 2025: 75% of countries should have developed or updated their national policies, strategies and frameworks for dementia 50% of countries will have at least one dementia friendly initiative to create a more inclusive society for people with dementia worldwide A minimum of 50% of countries worldwide will have a diagnosis rate of more than 50% for people with dementia 75% of countries will offer training and support programmes for families of people with dementia Dementia research will be doubled
2018	Dementia Action Plan Wales	Prior to this document, the Welsh Government had made several advances in dementia care within Wales; this includes introducing dementia support workers, OTs on older persons' mental health wards, specific dementia teams within district hospitals and increased funding. Furthermore, the Welsh Government has focused attentions on dementia risk reduction through raised awareness. The 2018-2022 Dementia Strategy for Wales aims to: Increase awareness of dementia risk factors so the individual can reduce their risk or delay onset Increase awareness of dementia for communities to be able to provide support to people with dementia Increase a timely diagnosis after symptoms begin and make services clear Enable newly diagnosed people with dementia to plan for their future Person-centred and flexible care for all those who need it (people with dementia and their family members)

		Increase dementia research, including collaborating with people affected by dementia Increased staff dementia training To support this vision, the Welsh Government will: Invested a further £10 million into dementia care for 2018/19 Standardise the role of dementia support workers Develop support teams around the individual Employ an All Wales Dementia Allied Health Practitioner Consultant to provide support and guidance to all health boards across Wales Increase timeliness of diagnosis Improve care and support to ensure people with dementia remain in their own homes as long as possible Ensuring everyone who works with people with dementia has sufficient training to properly support people affected by dementia Introduce the principles of John’s Campaign across health boards. This action plan will be formally reviewed after three years by the Dementia Delivery Assurance and Implementation Group.
Timeline of policies and government initiatives affecting older people with dementia and family members		

B: Email confirmation of Health Boards' older persons services



[redacted] ([redacted]UHB - Nursing) <[redacted]@wales.nhs.uk>
Tue 07/05/2019 16:41
To: Alex Walker

Hi [redacted]older adult service for mental health division is configured around 65 years and over for all older adult mental health, however for there is a needs based approach taken if patients are identified as having symptoms of dementia. MAS would either take on or joint work with adult mental health if there is a comorbid illness's , again needs based . Age would not determine exclude intervention. In regard to early on set I believe this is considered to be around working age but regardless would come still come under memory assessment pathway .

Hope this helps . Regards [redacted] .

Sent with BlackBerry Work
(www.blackberry.com)

C: Types of dementia

Type of Dementia*	**Characteristics/Symptoms**	**Organic Structure**	**Interventions**
Alzheimer's Disease	The most common cause of dementia (National Institute on Aging, 2017). Symptoms of Alzheimer's Disease can include: Forgetfulness Visuospatial problems Disorientation Concentration, planning and organisational difficulties Struggling to follow a conversation Generally, patients have a life span of 10 years after receiving a diagnosis (Budson and Kowall, 2011).	Can identity amyloid plaques and neurofibrillary tangles within the brain of the patient (National Institute on Aging, 2017). Damage can initially be found in the hippocampus, but as the dementia progresses, the damage will become widespread and the brain tissue will have significantly shrunk (Braak and Braak, 1991).	Drug therapy has been shown to slow the progress of the disease for up to 18 months for approximately 60% of patients (Draper, 2011). Cholinesterase inhibitors are the drugs used to slow down the progression of Alzheimer's disease; these include galantamine, rivastigmine and donepezil (Draper, 2011).
Vascular Dementia	Vascular dementia is the second most common form of dementia worldwide (Draper, 2011) and incorporates all forms of dementia caused by vascular-related brain injury. Characteristics can include: Forgetfulness Aphasia, agnosia or apraxia Significant impairments in daily functioning compared to previous levels Struggling to plan and reason (Jefferson *et al.*, 2011).	To diagnose vascular dementia, there needs to be evidence of stroke within the brain; this will present itself in the form of narrowing and degeneration within the brain tissue, along with cerebrovascular disease (a disease within the blood vessels in the	As there are so many risk factors for developing vascular dementia, the main intervention if to maintain a healthy lifestyle and use pharmaceutical interventions when possible (Budson and Kowall, 2011). Preventing further damage to the brain is often

		brain) (Jefferson *et al.*, 2011).	encouraged with the patient being prescribed medication to reduce further strokes; for example, high blood pressure or diabetes medication (Alzheimer's Society, 2018).
Mixed Dementia	This is the diagnosis given when the patient is presenting with more than one form of dementia, the most common is Alzheimer's mixed with vascular dementia, accounting for approximately 25% of all dementia diagnoses (Draper, 2011). The symptoms of mixed dementia will depend on which forms of dementia the person has (Alzheimer's Society, 2018).	The presence of mixed dementia within the organic structure of the brain will depend on the types of dementia within the patient; for the most common mixed dementia (Alzheimer's with vascular), the patient's brain will show amyloid plaques and neurofibrillary tangles (Alzheimer's disease) and narrowing and degeneration within the brain tissue, along with cerebrovascular disease (vascular dementia) (National Institute on Aging, 2017).	There are no approved drugs to treat mixed dementia but if the patient is presenting with a probable Alzheimer's mix, the doctor may decide to prescribe Alzheimer's disease medication (Alzheimer's Society, 2018).
Frontotemporal Dementia	Approximately 5% of dementia diagnoses	Frontotemporal dementia affects	There are no treatments or

	worldwide are frontotemporal dementia (Draper, 2011). Signs of frontotemporal dementia include: Behavioural and personality changes Language problems Problems with mental abilities Memory problems Movement difficulties (US Department of Health and Human Services, 2019).	the front and sides of the brain (frontal and temporal lobes) (NHS, 2020). Frontotemporal dementia is caused by neurones within the frontal and temporal lobes of the brain dying, which results in the brain shrinking (atrophy) (US Department of Health and Human Services, 2019).	cures for frontotemporal dementia, but medication may be prescribed to control the symptoms (NHS, 2020). For problems with language and movement, the patient may be invited to attend speech therapy or physiotherapy (NHS, 2020).
Primary Progressive Aphasia	Primary progressive aphasia (PPA) is a form of frontotemporal dementia (Memory and Aging Centre, 2017) characterised by difficulties with: Reading Writing Processing information Semantic knowledge Pronouncing the sounds of words correctly (Nickels and Croot, 2015)	PPA is caused by two different things; firstly, it can be caused by an Alzheimer's disease pathology or frontotemporal lobe degeneration (Nickels and Croot, 2015).	There is no treatment for PPA, only treatments to alleviate the symptoms. Pharmaceutical treatments to help with the behavioural disturbances and depression may be prescribed to a patient with PPA or speech therapy may be recommended (Léger and Johnson, 2007).
Posterior Cortical Atrophy *Also known as Benson's Syndrome*	Posterior Cortical Atrophy is a rare form of dementia that generally accompanies Alzheimer's disease (Tenovuo *et al*., 2008) which causes complex, visual disturbances which causes difficulty reading,	Not all patients with posterior cortical atrophy show atrophy in clinical images, but those who do, generally have atrophy in	There is no treatment for posterior cortical atrophy, therefore a doctor may prescribe the

	recognising faces or objects, occasionally hallucinations, difficulty in visual targeting and tracking movements (Sacks, 2012).	their parietal, occipital and occipitotemporal cortices (Crutch *et al.*, 2012).	patient with physical, occupational or cognitive therapies to help regain or retain the skills that are affected by their posterior cortical atrophy (Borruat, 2013).
*Please note, there are over 200 different subtypes of dementia (DementiaUK, 2018). This table only highlights the diagnoses received by participants in this study.			

D: Database search terms and number of hits

Database search engine	**Key search terms**	**Limiters applied** (/ - no limiters placed)	**Results**
Medline and Cinahl	Dementia	/	199,460
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/	317,117- **amended search**
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/ full text English 65+	62,845 19,278- **amended search**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ full text English 65+	276 63 – **13 articles saved for further reading**
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ full text English 65+	26,126 11,321- **amended search**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ full text English 65+	20 7 – **1 article saved for further reading**
PubMed	Dementia	/	211,344
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ full text available 65+ English	377,469 126,296- **amended search**

	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/ full text available 65+ English	3,494 1,066- **amended search**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ full text available 65+ English humans	2,644 58- **10 articles saved for further reading**
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ full text available 65+ English humans	312,947 13,653- **amended search strategy**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ full text available 65+ English humans	312,938 13,651
	Amended to: Dementia **AND** life story work	/ full text available 65+ English humans	57 19- **2 saved for further reading**
ProQuest	Dementia	/	1,112,185
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ full text available 65+ English	4,169,828 170,516- **amended search**
	Dementia OR Alzheimer’s disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/ full text available 65+ English	5,060,427 4,306,228- **amended search**

	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ Older people Dementia Caregivers	14,777 2,874- **14 saved for further reading**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ Older people Dementia Caregivers	467,780 114,350- **amended search**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ Older people Dementia Caregivers	310,921 70, 296- **amended search**
	Amended to: Dementia **AND** life story work	/ Older people Dementia Caregivers	7,008 2,015- **9 saved for further reading**
Science Direct	Dementia	/	210,292
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ Research articles	830,153 469,337- **search amended**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ Research articles	13, 963 7,482- **12 saved for further reading**
	Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ Research articles	1,104,906 621,639- **amended search**
	Amended to: Dementia **AND** life story work	/ Research articles	5,208 2,255- **3 saved for**

			further reading
Embase	Dementia	/	396,710
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ Articles Aged Very aged	182,106 39,950- **search amended**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/ Articles Aged Very aged	2,417 240- **amended search**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ Articles Aged Very aged	2,362 159- **3 saved for further reading**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ Articles Aged Very aged	149,450 13,558- **search amended**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ Articles Aged Very aged	149,450 13,558- **search amended**
	Amended to: Dementia **AND** life story work	/	54- **2 saved for further reading**
PsycInfo	Dementia	/	78,512
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ 65+ Full text Peer reviewed	172,180 59,958- **amended search**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR	/ 65+	179,099

	cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	Full text Peer reviewed	142,049- **search amended**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ 65+ Full text Journal article	8,244 448- **8 saved for further reading**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ 65+ Full text Journal article	118, 395 55,883- **search amended**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ 65+ Full text Journal article	27,223 4,858- **8 saved for further reading**
ASSIA	Dementia	/	20,349
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ Old people Aged Humans Dementia English	51,001 126- **search amended**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/ Old people Aged Humans Dementia English	52,852 126- **1 saved for further reading**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ Old people Aged Humans Dementia English	999,981 1
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular	/	104,143

	dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	Old people Aged Humans Dementia English	126- **1 saved for further reading**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ Old people Aged Humans Dementia English	68,464 50 **-2 saved for further reading**
PsycArticles	Dementia	/	6,799
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/ 65+ Full text	35,340 5,456- **amended search**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/ 65+ Full text	36,156 5,500- **amended search**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/ 65+ Full text	1,807 246- **0 saved for further reading**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ 65+ Full text	64,955 7,574- **amended search**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/ 65+ Full text	43,950 4,409- **5 saved for further reading**

Cochrane	Dementia	/	194- **0 saved for further reading**
SIGLE	Dementia	/	762
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body	/	1815- **amended search**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** narratives OR storytelling OR digital storytelling	/	1922- **amended search**
	Amended to: Dementia **AND** narratives OR storytelling OR digital storytelling	/	116- **5 saved for further reading**
	Dementia OR Alzheimer's disease OR mixed dementia OR vascular dementia OR memory loss OR cognitive impairment OR frontotemporal OR Lewy Body **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/	4585- **amended search**
	Amended to: Dementia **AND** life story work OR reminiscence OR autobiography OR life history OR memoir OR biography	/	2793- **amended search**
	Amended to: Dementia **AND** life story work	/	2- **2 saved for further reading**

E: Papers excluded from literature review (with reasons)

Author(s)	**Year**	**Reason for Exclusion**
Benbow and Kingston	2016	Concerned about risks within a care home, not dementia or life with dementia
Cahill and Diaz-Poncer	2011	Said participants had cognitive impairment- did not specify that any had dementia
Elliot, Gessert and Peden-McAlpine	2009	Said participants had cognitive impairment- did not specify that any had dementia
George	2011	Exploring the benefits of people with dementia visiting a nursery group- not relevant to this study
Macquarrie	2005	Inclusion criteria were people with Alzheimer's disease over 50- possible that the experiences are all from participants under 65 (does not meet the inclusion criteria for this study).
Philipson, Jones and Magee	2013	Narrative synthesis- used to identify further studies.
Siverova and Buzgova	2014	Said participants had cognitive impairment- did not specify that any had dementia
Ward-Griffin *et al*.	2012	Explored care home resources not life with dementia
Zimmermann	2011	An analysis of autobiographical texts written by people under 65 years of age with dementia
Behuniak	2011	A review of the Alzheimer's disease literature- used to identify further literature
Chatterji	1998	No mention of the participants' age.
Flanagan	2018	Participants were pastors who explained how they keep people with dementia within their religious community
Yap *et al*.	2008	Examined the effectiveness of the translated version of a questionnaire
Neubert, Konig and Brettschneider	2018	A study protocol, no findings yet
Piau *et al*.	2014	A study about technological assistance
Reynolds	2015	A study about the benefits of joining a choir in later life

Riley *et al*.	2013	A study to develop a quantitative measure on continuity of spousal relationships when one spouse has dementia.
Volandes	2010	Assessing the use of a decision support tool. Participants were likely to develop dementia in the future- did not have dementia at the time of the study
Hepburn *et al*.	1997	The study reflected solely on the process of conducting a family story workshop- not applicable to this study.
Ingersoll-Dayton *et al*.	2013	Preliminary findings- they were not relevant to this study.
Kostov *et al.*	2017	A study exploring patient and carers experiences of junior doctors
O'Shea *et al*.	2011	Findings not reported in this article
Rhynas *et al*.	2018	Participants were older people not specifically people with dementia
Richters *et al*.	2017	A protocol for a study, no findings.
Beard, Knauss and Moyer	2009	50% of the participants with dementia were under 65 years of age (early onset dementia).
Blackstock *et al*.	2006	Vague participant demographics. Participants were aged 40 to 90. No specification on the age of the participants with dementia.
Kave *et al.*	2007	Case study- participant was 61
Ryan, Bannister and Anas	2009	A review of several books written by people with dementia
Tilki *et al.*	2010	A governmental policy review specific to Irish people with dementia living in England
Robinson *et al.*	2012	Exploring the issues faced by carers accessing respite services
Temple-Jones	2012	Focusses on spiritual care professionals’ jobs. Not applicable to this study
Buse and Twigg	2016	Exploring the stories of people with dementia through dress
Kelly	2010	Does not specify the ages of the participants with dementia - cannot be sure that they were 65+

Hulko *et al.*	2010	An exploration of indigenous communities, dementia and elders.
Rodriquez	2013	Early onset dementia- does not meet the inclusion criteria for this study
Robinson, Giorgi and Ekman	2012	The participant was too young at the beginning of the 3 year longitudinal study to meet the inclusion criteria
Capstick and Clegg	2013	Collecting narratives from war veterans so their stories are not lost with the memory loss
Lynch *et al.*	2016	Participants were 40+ and had Down Syndrome alongside their dementia
Jakobsen and Sorlie	2016	An exploration of difficult situations faced by care providers in nursing homes
Gregory	2014	Promoting personhood in dementia through an art exhibition
Hall and Sikes	2017	Participants were children with a parent who had dementia. Oldest participant was 24. Does not specify the ages of the parent with dementia. Does not meet inclusion criteria.
McGolgan, Valentine and Downs	2000	Professionals discussing Iris Murdoch's life with dementia until her death.
Huang *et al.*	2009	Examining different methods of promoting interactivity, social participation, cognitive function improvement in those with dementia, and their effectiveness in reducing symptoms of depression following group treatment.
Yassuda *et al.*	2009	Explored the effectiveness of personalised reminiscence photograph videos (videos that contain a series of photographs personal to each participant) and TV shows to investigate which encouraged most engagement from the participant.
Kuosa, Elstad and Normann	2015	Family members' reflection on their loved one with dementia's

		lack of engagement in meaningful activities within nursing homes.
Gridley, Birks and Parker	2020	Identified 9 steps for good practice when using life story work as a reminiscence tool for people with dementia.

F: Literature review extraction table

Author	**Year**	**Aims**	**Method**	**Participants**	**Results/Findings**	**Critique**
Nordtug *et al*.	2018	To explore how people with dementia frame their former working lived through narrative	Interviews	12 people with dementia	Those who had come to terms with their illness had positive feelings about their past. Some were grieving their loss regardless of former success.	All participants were recruited from central Norway. Rural areas may have had different narratives to share.
Heggestad and Slattebo	2015	To explore what individuals with dementia do by themselves to maintain or promote their dignity of identity when living in a nursing home	Case studies, observation and interviews.	15 residents with dementia	People with dementia in nursing homes use narratives and life stories to manage the chaos associated with living in a care home and to find safety.	Case studies may not provide information that is generalisable to the wider population; however, the use of case studies can provide explanations for the experiences within the person's personal context.
Karlsson *et al.*	2014	To explore how people with Alzheimer's disease present their life story.	Life story narrative interviews.	9 people with Alzheimer's disease.	Contentment, connectedness, self-reliance and personal growth.	Pre-defined interview questions may have led to important information being left out.

Hedman *et al.*	2012	To describe how people with Alzheimer's disease express their sense of self	Interviews. Swedish population.	12 people with Alzheimer's disease.	Participants expressed their sense of self as not changing much, only their personal attitudes had altered since living with Alzheimer's disease. However, they feared that their social self would undergo scrutiny as their disease progressed.	All the participants were highly educated and articulated their experiences well. A different population may have explained their experiences differently.
Barca *et al.*	2011	To study quality of life among dementia patients in institutions	Quantitative. Scores on quality of life in later stage dementia, the self- maintenance scale, mini mental state examination and clinical dementia rating.	156 patients with dementia, over 60	Quality of life is diminished among dementia patients in institutions and this correlated with a diagnosis of depression, worse cognitive functioning and poor performance in daily activities.	Quality of life scoring was completed by a research nurse on behalf of the person with dementia; the nurse may not have recorded the correct scoring to reflect the person’s experiences.
Aminzadeh *et al.*	2009	Exploring the meaning and experiences of people with dementia	Canada. Qualitative interviews. Strauss and Corbin (1998) analysis.	16 community living people with dementia, two months prior to	Relocation to a residential home (a) symbolized the end of an era and a long established way of life, (b) signalled the	Findings from a small sample may not be generalisable to wider populations but provide insight

		relocating to residential care		relocating to residential care	inevitable downward trajectory of old age, (c) meant living a more protected dependent structured lifestyle in a place that is associated with hospitality and rest and (d) presented a life course challenge that could be dealt with by drawing on one's sense of identity as a survivor.	into the personal experiences.
Russell and Timmons	2009	Listening to the stories of older people with dementia to gain insight into their understandings of themselves	Unstructured interviews.	5 people with dementia from a nursing home	The stories told by participants will vary greatly. Some will repeat some of the more influential narratives from their lives while others will cover a much broader area of topics. This demonstrated that people with dementia need to be treated an individual despite collective similarities.	The way the stories were narratives made them unique. Making generalisations from the data will be difficult.
Ryan *et al.*	2009	To explore how authors with dementia express their social identities	9 published memoirs	Analysis of published memoirs of authors with dementia	Authors with dementia project their new identities in a positive light.	"helpers" aided the person with dementia to write their memoirs; the "helpers" may

						have interpreted the person's story differently when writing it down.
Surr	2005	To examine the relevance of a socio-biographical theory of self to people with dementia living in residential care	Unstructured interviews. Transcribed.	14 people with dementia	Relationships with family, other residents and care home staff was important to participants to maintain their sense of self.	Whilst the researcher's intention was to allow the participants to take their interview where they wanted, Surr acknowledges that she altered the direction of some of the interviews.
Hellström, Eriksson and Sandberg	2015	To describe how older women with dementia express the importance of their homes and their chores in everyday life	Interviewed (their home, their dementia illness, everyday life, their relationship with their husbands, dignity and autonomy) on 5 occasions over a 5-year period.	7 women with dementia	Three patterns were identified in the women's narratives: keeping the self through polarised division of labour, keeping the self through the home and keeping the self through negotiations of responsibilities. The home and home-chores are essential to expressing who you are.	This study only explored the experiences of women with dementia; the research team suggested that the husband's experiences should be explored in further research to gain full insight into the experiences.

Svanström and Sundler	2015	To explore living alone with dementia and having care needs.	Field notes and recorded conversations.	6 people with dementia	The person with dementia who lives alone will begin to live a vague existence where it becomes impossible for them to survive without outside help.	For some participants, they struggled to find a topic for conversation with the research team. The research team had to, therefore, choose the topic for conversation. The participants may have wanted to discuss something in particular but felt obliged to talk about the topic chosen by the researcher.
Sterin	2002	To explore how she lives her everyday life with dementia	A personal essay	1 person with Alzheimer's disease	Explores the issues of living with dementia. The way that friends responded to the lady's diagnosis varied in 3 ways; some became smothering, others began to ignore her, and the rest dismissed her diagnosis.	Whilst case studies cannot be generalised, they provide in depth information about a person's unique experiences which can pave the way for future research.

Chen and Lin	2019	To explore the experiences of elderly patients in Taiwan	Interviews	12 elderly people with dementia	Themes identified were; stress caused by inability to remember, counteracting memory loss, worry about being a burden to family members, cherishing the current situation and adopting a dispassionate view about life and death	The average age of the participants in this study was much higher than the average life span for people in Taiwan. The participants' experiences are not typical for people living in Taiwan.
Lethin, *et al.*	2020	To identify the factors associated with caregiver burden	Interviews over a 3-month period that were analysed with a multivariate regression.	1223 caregivers from 8 different European countries	Caregiver burden is positively correlated with hours of time spent caregiving. Additionally, feelings of burden was negatively correlated with psychological wellbeing.	This study collected data from several different countries and explored many risk factors; this enhances the generalizability.
Oliveira, Sousa and Aubeeluck	2020	To explore what older family carers of people with dementia believe would improve their quality of life	Open ended questionnaire	150 unpaid caregivers	The family members believed that more time to have life outside caregiving, financial support and a carer friendly health and social care system would improve their quality of life whilst caregiving for a loved one with dementia.	The anonymous questionnaire data did not allow the researchers to follow up with additional questions to explore key themes.

Polenick *et al.*	2020	To explore the strategies used by family caregivers to manage their loved one's behaviour	Focus groups	26 family caregivers of older people with dementia	6 main methods for managing life with dementia were: Slowing down the pace of the daily routines, modifying the environment, engaging in activities, using humour, taking care of themselves and having social support.	All caregivers in this study were highly educated. Research has shown that lower educated people have different ways of coping with dementia caregiving.
Cronfalk, Norberg and Ternestedt	2018	To explore the experience of people with dementia moving into residential homes	Interviews	10 family members	The care home environment was important to feeling accepted. Four further categories were identified; living in limbo, coming to peace, keeping old habits and relationships, and thoughts about impending death.	The family members' perceptions of the care home were influenced by the length of time that their loved one had been living in the care home. Those who had lived there for 2 years, had significantly different experiences to those who were new.
Hellström *et al.*	2017	Explores how caregiving husbands	Interviews on five occasions over 5-6 years.	7 men cohabiting with	Three main themes were accumulated; me and it, me despite it,	Due to the aims of this study, the participants were

		describe their roles over time		their wives in Sweden	and it is me. These themes describe how the husband's views of themselves changed over the progression of the disease.	narrative their experiences through the “lens” of caregiving being their priority. Their “real” lives may not reflect the narratives they told.
Johansson *et al.*	2014	This qualitative study aimed to illuminate former family caregivers’ experiences of aspects that facilitate and hinder the process of relinquishing the care of a person with dementia to a nursing home.	Narrative interviews	10 former family caregivers	An overall theme showed that family caregivers were remaining connected to the person with dementia despite the separation of living in a care home. Family caregivers found meaning in the new situation as they felt that they could remain connected to their loved one.	Whilst this study only had 10 participants, they collected rich data from a variety of participants over a period. The research team done their utmost to make the data credible, generalisable and trustworthy.
Hennings *et al.*	2013	To explore the caregiving experiences of spouse carers of people with advanced dementia living	Longitudinal study. Three interviews and diary accounts.	10 spousal caregivers	These participants felt they were living in two worlds. The care home setting and the world of wider society. Feelings of guilt associated with	The longitudinal nature of this study, and the length of the narratives, highlight the complexities of

		in nursing homes			care home placement was also identified.	caring for someone with dementia in a nursing home over a 3 year period.
Palmer	2013	To explore the experiences of family members admitting their spouse or parent into long term care	Interviews	15 family caregivers	Supporting the personhood of the person with dementia was central to all decision making.	Only close family caregivers participated in this study. Those who are not close to the person with dementia may have different experiences.
Hutchings *et al.*	2011	To explore the experiences of family members of people with dementia who are relocating from an institution to supported living	Semi-structured interviews	10 family members	Six themes emerged; ongoing communication, relief and contentment, meaningful activities, enhanced environment, improved functioning and engaged staff.	The participants were self-selecting and came from a small town in Canada. These findings may not be applicable to people living in larger areas.
Mullin *et al.*	2011	To explore the experiences of spouses of people with dementia in long term care	Semi-structured interviews.	10 spouses of people with dementia	Four themes; Identity: ‘til death do us part, making sense of the change, relationship with care providers: visiting as surveillance and relationship with the future.	Despite their loved one living in residential care, all the participants were heavily involved in their care. The experiences of

						those who are not do involved in their loved one’s care would be drastically different.
Spigelmyer *et al.*	2018	To identify a general meaning of family caregivers lived experiences	Interviews	8 family caregivers	Five essential constituents were identified; self-questioning of abilities, signal for increased future caregiving responsibilities, changed perceptions of personal self, unexpected emotional responses and seeing a changed person.	The findings from this study are specific to the participants. They are not a general description of the phenomenon.
Andrews *et al.*	2017	To understand what family members of people with dementia know about the disease	Semi-structured interviews	10 family members	Majority of family members did not recognise dementia as being terminal. They had lay understandings of dementia. Little access to formal information. Family members did not ask care staff questions to further their knowledge either.	The findings from this study are very context specific; the participants were purposely recruited from a small organisation.

Elnasseh *et al.*	2016	To examine the link between family dynamics and personal strengths in the caregivers of people with dementia	Quantitative. A series of questionnaires/scales.	105 caregivers from Argentina	Strong family dynamics was associated with greater levels of caregiver resilience	The self-reporting nature of this study could have led to respondent bias.
Jayalath, Ashaye and Kvavilashvili	2016	To compare carers written accounts in a diary to their oral recollections	Comparing written diaries to oral accounts over 8 days	78 caregivers	The diary highlighted more problems than the oral accounts of the caregivers. Problems tended to be behavioural or cognitive.	This study is one of few to encourage the use of written diaries as a data collection method for caregivers. The written diaries provided more in-depth information than oral accounts and provides implications for further research.
Tuomola *et al.*	2016	To explore the lived experiences of caregivers and its impact on their sense of self	Interviews	6 Chinese spousal caregivers	Four themes were identified: impact of caregiving, acceptance of destiny, taking control and view of self.	Whilst all participants were able to participate in data collection through the English language, the research team feel that some may have

						provided more information if they had been able to participate in their native tongue (Mandarin).
England	2015	To explore caregivers' perception of their loved ones, caregiving motivations and family obligations.	Case study analysis	One family living with dementia	Cultural obligations play a part in the family taking on the caregiving role	This is a case study with specific information to the participant that may not be applicable for other people.
Stokes, Combes and Stoke	2014	To understand how caregiving partners understand and make sense of diagnosis information	Semi structured interviews	10 spouses of people with dementia	Lack of information, societal understanding and persistent stigma, personal understanding and implications for adjustment, and lack of partnership working	All participants in this study had accessed additional support to live with dementia. They had a lot more knowledge about living with dementia than others may have.
Kjallman-alm, Norberg and Hellzen	2013	To explore the experiences of adult children of people with dementia	Narrative interviews.	20 adult children of people with dementia	Adult children of people with dementia need more information and support.	All participants within this study were recruited through a dementia support

				attending a support group		group; their experiences are not the same as those who do not attend any support groups.
Uei, Sung and Yang	2013	To explore caregiver self-efficacy and burden of managing behavioural problems	Quantitative. Scales.	162 people with dementia and 162 family caregivers in Taiwan	Caregiver burden was significantly correlated with gender, frequency of challenging behaviours, level of education, relationship, hours of care and caregiver self-efficacy.	This sample was from a small out-patients department in Taiwan. These findings cannot be generalised to other areas.
Shim, Barroso and Davis	2012	To explore the differences in experiences of family caregivers of people with dementia	Interviews. Longitudinal.	21 spousal caregivers	Three groups were identified, positive, negative and ambivalent.	This study was comprised of a secondary analysis on data from a previous study. The responses were limited, and no further questions could be asked.
Hayes *et al.*	2009	To understand how the spousal caregivers of people with dementia perceive the	In depth interviews and observations.	28 spousal caregivers	Women were more likely to note how changes in their spouse had changed their identity within their marriage.	Discussing intimate relationships with spouses of someone with dementia can be a sensitive subject.

		changes in identity and intimate relations with their spouse.			Male participants spoke more openly about a diminished sexual relationship. Diminished intimacy was reported but spousal feelings would remain until their loved one died.	It is likely that the caregivers withheld some information from the research team.
Hibberd *et al.*	2009	To capture the meaning and context of how carers adapt and develop their relationship throughout their caring role	Photographs were taken by participants using a disposable camera with supporting written narratives provided on six photographs that participants selected to best represent their caring role and relationship. These photographs and supporting text were then shared with other participants in a focus group.	9 carers in south east England	Through the data collection process, participants were helped to sort and group the data into narrative themes. The group identified four types of caring relationships, recognising, transforming, stabilising and moving on.	The themes are specific to the 9 participants from this study and cannot be generalised. Participants from a different area or culture may have differing views.
Hasselkus and Murray	2007	Understand the daily occupations of caregivers for people with dementia and	Qualitative telephone interviews focused on the experiences of family members. Analysed using phenomenology.	33 caregivers	Everyday occupation was the fabric of well-being for the participants. The caregivers rated their	Telephone interviews do not allow the researchers to respond to non-verbal cues within

		their perceived well being			well-being in terms of their loved one's state.	the person's narrative. This may have limited the data collection process.
Gottlieb and Gignac	1997	Identify the coping efforts of caregivers of people with dementia	Interviews. The first was in relation to behavioural or cognitive symptoms of dementia that they found most upsetting. The second was about an activity that they have had to give up. And how they coped with both.	51 caregivers	Positive framing, acceptance and avoidance/escaping were the main ways the caregiver coped.	The participants were specifically asked how they coped with only 2 domains of living with dementia. The coping mechanisms used for other elements of life with dementia may be different.
Strommen *et al.*	2020	To identify challenges to obtaining care for an older person with dementia living in rural areas	Used existing data sets.	306 family caregivers	Five themes emerged to explain the challenges experienced when trying to obtain care. Financial burden, insufficient care available, lack ok knowledge of the care services that are available, difficulty navigating the services and challenges related to the environment.	This study involved participants from the same culture. Different cultures residing within rural communities may have different experiences.

Clarke and Bailey	2016	To explore the everyday experiences of living with dementia within rural and semi-urban communities	57 diaries, 69 interviews with families living with dementia and 6 interviews with service providers	13 families living with dementia and service providers	Key themes were others knowing and responding, socially withdrawing and feeling excluded, sustaining and changing activities, belonging and estrangement from place, engaging services and support.	15 GP practices were tasked with finding participants for this study. The GPs may have selectively included/excluded people.
Zhan	2004	To examine the experiences of Chinese American caregivers	Individual interviews	4 family caregivers	Stigma in the Chinese community about Alzheimer's disease, a lack of knowledge, lack of culturally specific services, difficulty with English and negative interactions with care providers.	Small sample- all were educated within the USA. Those who were not educated within the USA education system may have different values and beliefs.
Hinton and Levkoff	1999	To identify differences in the views of dementia between several cultures within Boston	Interviews	14 family members of people with dementia from the below cultures; African American, Irish American, Chinese American and Latino.	African American and Irish American participants viewed dementia as a disease that deteriorates the person's mind. Latino families they described dementia in terms of loss, loneliness and a family's responsibility.	A difficult report to read. Not clearly written. Highlights the differences that may occur within the same district across cultures.

					Chinese American participants did not recognise dementia as a disease and thought that the symptoms of dementia were a natural part of old age.	
Keyes *et al.*	2016	To explore peer support for people with dementia	Interviews	101 people with dementia and 82 staff/stakeholder	Peer support had positive emotional and social effects. The quality of support was better from peers than from staff.	Participants were recruited through one support group; those who attend different support groups may have different experiences.
Koskenniemi, Leino-Kilpi and Suhonen	2015	Describe the manifestation of respect in the care of older patients in long-term care settings from the perspective of older people with dementia and their next of kin	Conducted in Finland. Open ended interviews to ask participants to describe how respect was present within the care home. Interviews took place separately.	40 people with dementia and 20 family members	Theme was respect in a patient-nurse relationship. Falling under two categories; the doing of the nurse and the being of the nurse.	The research team did not return their themes/findings to the participants for validation. This would have added to the credibility of the findings.
Gorska *et al.*	2013	To understand the lived experience of	Individual semi-structured narrative interviews	12 people with dementia and	Participants were generally happy with the services they	The participants averaged 84 years old. It is likely that

		people with dementia regarding their service-related needs		19 unpaid carers	received, however, a number of unmet needs were identified. Post diagnosis support and non-pharmacological interventions to support identity and social engagement were needed.	they have other medical complaints that the research team did not identify. The participants may have gotten confused between their dementia needs and their other medical needs.
Karnieli-Miller	2012	To identify the expectations and experiences of memory clinic patients and their companions	Israel memory clinics. In-depth, post-encounter interviews.	10 people with dementia and 17 companions	Companions had clear cut expectations whereas the patients did not understand the nature of the visit. Dissatisfaction was caused by a lack of information, poor communications and lack of tailored follow up processes.	The time gap (2 weeks) between attending the clinic and being interviewed may have skewed the person's memory of attending the clinic.
Hernandez *et al.*	2019	To explore the sense of "couple-hood" among married couples when one has dementia	Through life review intervention	19 couples where one person has dementia	Maintaining the things that they do together or alone aids the couple maintain their sense of "couple-hood". Discussing their lives in terms of "we" also highlights their sense of	All participants in this study had a strong relationship with their spouse and they were financially well off. Further research needs to explore

					togetherness. Acknowledging their shared history highlights historical instances where the couple has coped with adversity.	the experiences of those from different backgrounds.
Swall *et al.*	2019	To describe the marital relationship when one person has dementia	Open conversations that were video recorded	15 couples whereby one has dementia	Married couples expressed a strengthened sense of togetherness despite the challenged faced when one partner has dementia.	The use of video recordings to collect the data resulted in some participants acting differently in front of the camera. Some forgot that it was there while others were self-conscious.
Hellström and Torres	2013	To explore what couples living with dementia want to know and tell about living with dementia	Qualitative interviews	20 people with dementia and 20 spouses	Themes were; want to know and tell (no reservations), want to know and tell (some reservations), want to know but do not want to tell, want to know but do not know if want to tell and cannot decide either way.	This study sheds light on the processes of sharing information within married couples when one has dementia. This has implications for further researchers regarding the settings of

						interviews; should the couples be interviewed together or not.
Black *et al*	2012	To explore quality of life in community residing persons with dementia	Quantitative. Quality of life Alzheimer's disease scale and caregiver-rated quality of life Alzheimer's disease and Alzheimer's disease related quality of life scales.	254 people with dementia and their caregivers participated in the study	People with dementia quality of life was linked with participant race, unmet needs, depression and medication. Caregiver quality of life was linked with caregiver burden, depression self-rated health, participant function and depression.	All participants within this study were community dwelling (living in their own homes in the community). Had the participants been from supported living or nursing homes, the findings may have been different.
Robertson	2010	To compare the differing views on aging with dementia	PhD Thesis- Interviews	6 people with dementia and 10 family members	People with dementia noted how it was a part of life and lived an ordinary life, dealing with the cognitive impairments as they arrived.	The narrative nature of this study sometimes resulted in participants sharing rehearsed thoughts and ideas. This made it difficult for the researcher to conduct a narrative analysis properly.

Daniels, Lamson and Hodgson	2007	To examine the life experiences of an elderly couple living with dementia	A case study. Three interviews, two months apart.	1 married couple, in their mid-80s	Main themes in the couple's stories were; perspective and preparation for future changes, family influence and social support, life evaluation and experiences with Alzheimer's disease.	All data is specific to one couple during a two-month period. Had the study included more participants or spanned over a longer duration, the findings would be more generalisable.
Steeman *et al.*	2007	To explore elderly peoples' experiences of living with early stage dementia	Conducted in Holland. Longitudinal over 1.5 years. Loosely structured interviews.	20 elderly people diagnosed with probable dementia and their family members	Positive stories of living with dementia were deeply analysed and it was concluded that the positive accounts being reported were the person trying to remain someone of value.	The research team allowed their personal bias to lead the data- which they confess within the discussion on this paper. Had the research team been more varied, this may not have happened.
Phinney	2002	To examine how awareness of dementia symptoms fluctuate over time and circumstance, forcing the	In depth interviews and observations.	9 people with Alzheimer's disease and their family caregivers.	Experiencing symptoms in any of these ways (salient, vague, inconspicuous, forgotten or entirely absent) can lead to difficulty in articulating an illness narrative or	Whilst this was a small-scale study, it highlighted the importance of the family member's input when a person with dementia is trying

		breakdown of illness narratives.			comprehend what is happening in their lives.	to narrate their life. The family members help the person with dementia maintain their sense of personhood by “filling in the gaps”.

G: Steering committee members

Name	Organisation	Membership Dates
Alex Walker	University of South Wales	October 2017-present
Dr Anne Fothergill	University of South Wales	October 2017-present
Dr Nicky Genders	University of South Wales	October 2017-October 2019
Prof Joyce Kenkre	University of South Wales	October 2017-October 2018
Karen Healey	Hafod Care Association	October 2017- May 2018
Angela Griffiths	Hafod Care Association	November 2017-February 2018
Geraint Morgan	Hafod Care Association	February 2018 -present
June Clark	Hafod Care Association	February 2018-October 2018
Dr Rachel Iredale	University of South Wales	October 2018-present
Amanda Whent	Aneurin Bevan University Health Board	October 2018-present
Robert Richards	Cwm Taf Morgannwg University Health Board	October 2018-present
Dr Philip Tyson	University of South Wales	February 2020-present

H: Ethics process

Date	**Procedure to obtaining ethical approval**
1st December 2017	Submitted high risk application to USW Faculty Ethics Committee.
21st December 2017	Received feedback from meeting – minor amendments. USW Faculty Ethics Committee's Chair would take Chair's action would be taken once the amendments were made.
8th January 2018	Made the amendments in line with the feedback received and resubmitted for Chair's action.
8th January 2018	USW Faculty Ethics Committee Chair wanted further amendments.
2nd February 2018	Resubmitted the documents with further amendments to the Chair.
13th February 2018	Received ethical approval from USW Faculty Ethics Committee to recruit participants from residential care homes (ref. 2018AWAF1201).
12th February 2019	Submitted IRAS form to USW Faculty Ethics Committee for approval to begin recruiting through memory clinics instead of residential care homes.
13th March 2019	Received feedback from USW Faculty Ethics Committee. Amendments needed to be addresses and resubmitted to committee.
19th March 2019	Addressed the amendments needed and resubmitted to USW Faculty Ethics Committee.
5th April 2019	Received feedback from. USW Faculty Ethics Committee. Needed to make amendments.
9th May 2019	Made the required amendments and resubmitted to USW Faculty Ethics Committee.
11th June 2019	Received feedback from USW Faculty Ethics Committee.
24th June 2019	Director of Studies attended a meeting with the Chair of USW Faculty Ethics Committee and the reviewers who were not satisfied with the ethical application. Discussed exactly what the reviewers were concerned about.
8th July 2019	Made amendments to the application in line with the meeting on 24th June 2019 and resubmitted to USW Faculty Ethics Committee.
15th July 2019	Received ethical approval from USW Faculty Ethics Committee (ref. 19AW0201HR).
7th August 2019	IRAS form Submitted.
3rd September 2019	Attended Wales REC 1 meeting.
6th September 2019	Received an unfavourable opinion from Wales REC 1.
16th September 2019	Submitted amended IRAS form submitted.

8th October 2019	Provisional favourable opinion received from Wales REC 1.
17th October 2019	Submitted amended documents to IRAS.
17th October 2019	HRA and HCRW approval issued.(IRAS ID 255686, REC Reference 19/WA/0292).
23rd October 2019	Confirmation of capacity and capability from one health board.
24th October 2019	Had the green light to begin data collection with one heath board.
28th October 2019	Study was confirmed eligible to be on the Health and Care Research Wales Research Directory Portfolio (ref. 43951).
20th November 2019	Letter of Access from other health board. Had the green light to begin data collection within this health board.

I: USW Ethics application

PLEASE READ - Information for applicants

- **This form should be completed for all high risk LSE research studies utilising human participants. A low risk route of approval is available if your study is appropriate for low risk review. Please speak to the Research Governance Officer if you have any doubts.**

- **Research recruitment and data collection must not commence until approval from the Faculty Ethics Sub Group (FESG) has been granted - where approval is required. For the avoidance of doubt, data collection cannot begin until you have received written confirmation of approval from the faculty ethics sub group.**

- **External ethics approval – [Research Ethics Service (RES)] approval will be required when the research study includes:**

(a) Participants who are recruited from the NHS.
(b) Use of NHS patient data, premises, NHS resources, and facilities.

http://www.hra.nhs.uk/about-the-hra/our-committees/res/

- **If your research study will require NHS approval please complete the RES application form, print a copy, and submit it for approval to the Faculty Ethics Sub Group. Use of the RES IRAS form replaces the need to complete this form. Please contact the FESG secretary before you complete any forms.**

https://www.myresearchproject.org.uk/

- **If you are unsure of the required 'approvals' for your proposed research study please contact the NRES query line queries@nres.npsa.nhs.uk.**

The Faculty Ethics Champion is: peter.mccarthy@southwales.ac.uk.
Please contact jonathan.sinfield@southwales.ac.uk, to discuss FLSE submission requirements.

- **Submission must be 10 working days before any scheduled meeting.**
- **It may be necessary to defer review where any meeting is already fully subscribed.**

Please note: If your project requires cover by the university insurance policy, or requires a statement of sponsorship from the university, ethical approval from the FESG must be sought. Evidence of such cover is available from Jonathan.sinfield@southwales.ac.uk .

PART A

N.B. All questions should be addressed (e.g. provide an answer or state why not applicable).

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1. RESEARCH STUDY TITLE: An Exploration of Stories or Narratives of Older Persons Living with Dementia

2. NAME OF PRINCIPAL INVESTIGATOR: Alex Walker

QUALIFICATIONS: MSc Clinical and Abnormal Psychology, BSc Psychology

JOB TITLE: Research Student

EMAIL: alex.walker@southwales.ac.uk

ADDRESS (IF NOT STAFF OF USW):

3. CO-INVESTIGATOR(S):

IF APPLICABLE, NAME OF RESEARCH SUPERVISOR:

Dr Anne Fothergill, Dr Nicky Genders, Prof Joyce Kenkre, [redacted] and [redacted] (Both from [redacted] partner organisation).

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4. IMPERATIVE: Please provide the EFAS number for this project. If there is no EFAS please request a Project Start Form number (available from the Research Governance Officer):

EFAS 20828

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5. i) DOES THIS PROPOSAL REPRESENT PART OF AN EDUCATION/TRAINING PROGRAMME?

(If you answer YES to this question, please complete part ii below)

YES ~~NO~~

ii) IF YES, WHAT QUALIFICATION WILL THIS THE PROJECT LEAD TOWARDS?

MRes

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6. BACKGROUND AND CONTEXT / RATIONALE

(Max 100 words):

There are currently 45,000 people living in Wales with dementia (Living and Dying with Dementia in Wales, 2015). This number is set to drastically rise within the coming years (Alzheimer's UK, 2017) which means the care and support provided for people living with dementia must be the best available. No two people with dementia will have identical needs (Welsh Government, 2017). Listening to the experiences of those affected by dementia will help care providers ensure that the services they deliver are specific to the individual.

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7. AIMS AND OBJECTIVE(S) OF THE RESEARCH STUDY:

Research Question: What is it like to live with dementia?
Aims and Objectives:

1. To explore and understand the lived experiences of people with dementia
2. To understand the experiences of family members of people with dementia
3. To identify areas where support services are effective or insufficient
4. To write a 25,000 word MRes final thesis

Outcomes:

1. To demonstrate that people with dementia can be reliable participants in research
2. To replace conventional paper care plans with electronic, personal videos
3. To improve the care and services provided by [redacted] for people with dementia
4. To suggest the implementation of support services for the family members of a person with dementia

The collection and analysis of the stories or narratives provided by the participants will meet the aims and objectives of this project and will answer the research question.

This study is giving people with dementia the opportunity to tell their stories or narratives of living with the condition and explore the experiences of their family members in order to understand life with dementia from both perspectives. The research team are aiming to collect stories from six people with dementia and six family members, all of whom live within Torfaen and Caerphilly. These two sites were chosen in accordance with the convergence areas (West Wales and The Valleys) for the KESS funding that this project received.

The findings of this project will be used to write a 25,000 word MRes final thesis which will explain what life is like when living with dementia, to educate others about living with dementia, to improve the care services and dementia care models within [redacted]. This project also has the potential to encourage the use of video care plans in place of conventional paper care plans and to encourage future researchers to incorporate people with dementia in their projects.

8. STATEMENT OF STUDY DESIGN (E.g. RCT, Crossover, Cohort studies, Case control, Action research, etc. Max 700 words)

Describe the study design, methodology. Discuss why it has been chosen. Please include information pertaining to the timetable / phases of the research study, and where any data collection (interviewing, surveying, etc.) will take place. Please include timescale.

This research project is taking a phenomenological approach whereby it aims to explore the unique experiences of those living with dementia. This study is interested in how the different participants interpret living with the same disease (dementia).

This study will be conducted within [redacted] facilities in Caerphilly and Torfaen's residential homes and Torfaen's domiciliary service. The residential homes taking part in this project have quiet staff training rooms which they are willing to allow the research team to book for data collection. As the participants in this project have dementia, and most will live in residential homes, it is impractical (due to anxiety, upset, insurance etc) to take them to an unfamiliar location for data collection.

This project is qualitative in design as stories or narratives from people living with dementia and their family members will be collected. Random selection will be used to decide which older people living with dementia will take part in the study.

Inclusion criteria for people living with dementia:

1) Have received a diagnosis of dementia
2) Are aware of their diagnosis
3) Are over 65 years of age
4) Receive care from [redacted]
5) Live within Caerphilly and Torfaen.

Family member participation will be self-selecting providing they are related to an older person with dementia who match the inclusion criteria.

A lot of information is included in the information sheets and consent form; therefore, the managers will go through the documents with the participants and make sure they understand fully before they give informed consent. Informed consent will be obtained by the managers as well as they are independent of the research team.

A steering committee has been implemented which includes University of South Wales staff and [redacted] [redacted] staff. This steering committee will advise on the direction of the project.

Interview prompt lists has been created by the research team after conducting a literature review and contain key life events that most people over 65 with a dementia diagnosis and their family members would have experienced[redacted] requested some questions be incorporated which specifically ask about the participants experiences and opinions of the services they provide. The interview prompts contain tentative themes for the participants to base their narratives around if they need prompting. As the participants are telling their stories, they may naturally go in an alternative direction and discuss alternative topics that are of importance to them. The research student will not interrupt the narratives; the participants are free to disclose whatever they like. There is one list for people with dementia and a different list for the family members. The stories or narratives will be recorded using a video recording. The participants will be made aware of the video recording methodology right from the beginning of the project. Where possible, stories will first be collected from the family members as they may provide useful information regarding dates/locations/events which the researcher could use to prompt the person with dementia.

The research team consider video recordings as vitally important in story works research with people who have dementia as it adds to the uniqueness of their stories and tailors it specifically to the person providing the narrative. Video recordings of people telling stories has been found to engage the imagination of the audience more effectively than words on a page (Mitchell, 2006). Video life stories have been proved effective communication tools for educating others about aging, in particular, illnesses that affect mainly the elderly (Mitchell, 2006). [redacted] already have a “this is me” document in place- a one page of A4 document which says their name, preferred name, date of birth, where they lived prior to residential care, some hobbies, likes and dislikes. These documents are vague, kept within the person’s care plan in the office, rarely accessed by staff members and never accessed by family members or friends. Video recordings will provide a lot more in depth details about the person’s life. Every [redacted] resident has a TV in their room; a DVD would allow them and their families/friends to view the stories whenever they like. The video recordings may also act as a keepsafe for many participant’s families long after that person has passed away.

The recordings will be analysed using a narrative analysis whereby they will be transcribed, put into chronological order, returned to the participant for editing then analysed for recurring themes and quotes of particular interest (for example, quotes around relationship change since diagnosis, or quotes about care etc). No in-depth interpretive analysis will be done on the stories.

After the videos have been transcribed, the research team will view the videos and transcripts to ensure they contain no information that could cause upset, is offensive or has the potential to ruin relationships. Anything with the potential to cause negative emotions will be removed as this project has no intention to harm anyone. The transcripts and video recordings will then be taken back to the participants and the researcher will go through the information with the participant to decide what needs to be edited out or altered for inaccuracy.

This project is being conducted "with" older people who have dementia, not "on" older people with dementia. Therefore, they will been included in the story editing process from the very beginning. The final stories will be coproduced between the persons living with dementia, the family members, the [redacted] staff and the research team.

After themes and quotes of interest have been identified, the research student will use the information to write a 25,000 word Master's Degree final thesis. The findings will also be used to educate others about living with dementia through academic journals and, alongside the video recordings, at conferences. The results of this study will also help [redacted] develop their dementia care models and improve the services they provide.

Thompson (2011) notes how life story works can be highly beneficial for people with dementia, strengthening their relationship with family members, care staff and friends, along with improving person-centred care by providing the care staff with a greater understanding of the person they are caring for.

Copies of the final video recordings will be copied onto a DVD for the participant to keep for their own records. Benbow and Kingston (2016) explain how the spouse of one of their life work participants got in touch after the project finished to ask for a copy of her husband's recording as her husband had passed away and the video would allow her to listen to his voice. The videos recorded in this project will not only provide educational outputs (MRes, journals and conferences) but may also be keepsakes for the participants and their loved ones.

The participants will be free to withdraw their video from the project at any time; however, the research team are expecting that they will not withdraw their stories or videos after they have had the chance to edit the video and approve the final version. The research team will have some "back up" participants who also meet the inclusion criteria who could be approached to participate should someone withdraw before the end of data analysis. The use of the stories for the final MRes thesis will be emphasised and that the data will be destroyed by the University after 5 years.

[redacted] has requested copies of the videos at the end of the project to use for marketing purposes (for use on websites, leaflets, newsletters and internal training). Consent for this will be attained via a separate consent form, administered by [redacted] after data collection for the research project has taken place.

Timeframe:

December 2017-Ethics

January 2018- Explaining the project to potential participants and gaining informed consent

February and March 2018- Data collection

April 2018- Data transcription and editing

May and June 2018- Narrative analysis

July 2018- Write up results

August 2018- Final literature search and thesis write up

September 2018- Dissemination at USW, [redacted] and an international conference (e.g Alzheimer's Society or Royal College of Nursing International Network for Psychiatric Nursing Conference).

9. MATERIALS AND METHODS

i. What procedures/interventions will be carried out as part of the research study?
ii. What resources/facilities will be used during the research study?
iii. Where will the study take place? (If external, please include a letter of support that conveys agreement from the external venue)

[redacted] staff will identity potential participants for this study and assign them a number; these numbers will be placed into a bowl for the research team to randomly select the participants. The person corresponding to the chosen number will be approached by their line manager (Caerphilly residential home residents will be approached by [redacted], Torfaen residential home will be approached by [redacted] and Torfaen domiciliary will be approached [redacted]). These managers will explain the project, give them a formal invitation to participate, ask if they would be interested in taking part, and give them an information sheet to read and make a decision. Two days later, the managers will approach the older person with dementia again, ask if they would still be interested in taking part and answer any questions. The potential participant will then be approached by the researcher to explain the project once more, answer any more questions and gain informed consent. The participants will receive a copy of the interview prompts prior to the data collection so that they can prepare answers.

[redacted] managers will also approach the family members of the person living with dementia to make them aware of the project. If they are interested in taking part, they will be given an information sheet and the contact details of the research team.

This research study has two information sheets: one for the family members and an adapted version written in a “dementia friendly” manner. Similarly, the consent form has been designed specifically for people with dementia to easily understand and follow.

A convenient date and time will be arranged to begin data collection. For some participants, they will have several opportunities to share their stories if they do not feel they can provide the information in one sitting. Data collection will take place within the [redacted] residential homes and domiciliary care in Caerphilly and Torfaen. “Process consent” will be used for the project whereby participants will be asked on every meeting with the researcher if they still wish to participate in the project.

Participants will be video recorded whilst giving some demographic information about themselves and telling their stories. The researcher will speak as little as possible to allow the participant to fully disclose everything they want to share about their experiences. At the end of the data collection, the participant will be thanked for their time, and for sharing their stories. The use of their story will also be reiterated so that they feel they have contributed to the project greatly. After the researcher has ensured the participant is in good spirits, they will provide the participant with a debrief sheet reiterating the purpose of the study, that they are free to withdraw their data at any time, what their stories will be used for and the contact information of the research team. For some participants, they will have several opportunities to share their stories if they do not feel they can provide the information in one sitting. As with the information sheet, the debrief sheet is also formatted slightly differently for the people with dementia.

The videos will be transcribed and taken back to the participant where the researcher and the participant will work together to edit the stories. The edited versions will then be analysed using a narrative analysis. Once the project has been written up, it will be disseminated to [redacted] staff to help them improve their services. At the end of the project a copy of the video recordings will be put onto DVD for the participants to keep for their own personal records.

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10. PARTICIPANTS

Discuss the number of participants required, from where the participants will be recruited, and the exclusion and inclusion criteria. Please include power calculations where applicable.

For this project, 6 older people living with dementia and 6 family members will be participating. These participants will be recruited through [redacted]. The research team will ask that [redacted] only select people with dementia who have been told their diagnosis.

Inclusion Criteria:
People with dementia must be over 65, receiving care through [redacted] and living within Caerphilly and Torfaen.
Family member participants must be related to, or close friends with, an older person with dementia who is also participating in this project.

Advice has been sought from safeguarding leads within Caerphilly and Torfaen county councils concerning capacity to take part in research. The advice received back from [redacted] (Caerphilly council) was that, as long as the participants are not asked anything which they cannot answer and they are not pushed for answers, there are no further regulations when using them for research. The participants must also consent to any related images, static or video recordings, being used and what they are being used for- all of which has been incorporated into the information and consent sheets.

The older people living with dementia will be identified by the [redacted] staff as having capacity to consent and given a corresponding number that will be used in the random selection process. Six older people with dementia will be randomly selected by the research team to take part.

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11. HAVE NATIONALLY APPROVED / REGULATORY BODY GUIDELINES BEEN FOLLOWED IN PREPARING THIS PROTOCOL?

(E.g. Association of the British Pharmaceutical Industry Guidelines (1983), Royal College of Physicians Guidelines, The Declaration of Helsinki, British Psychological Society guidelines, BERA, etc.). If so, please specify.

Health and Social Care – Good Clinical Practice guidelines have been followed

Health and Social Care- Taking Informed Consent guidelines have been followed

Health and Social care- Taking Informed Consent from Adults Lacking Capacity have been followed

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12. HAVE POTENTIAL PARTICIPANTS BEEN INVOLVED IN, PLEASE INDICATE. IF NO, PLEASE INDICATE WHY.

	YES	NO
THE DESIGN OF THIS STUDY		No KESS project, therefore the project was pre-planned
INFORMED CONSENT DOCUMENTS		No KESS project, therefore the project was pre-planned
DATA COLLECTION TOOLS		No KESS project- pre-planned

13. DATA COLLECTION TOOLS

Have you tested the data collection tool(s) for face validity? Where **more than one tool** is being utilised please fill in the table.

YES ~~NO~~ NA (ALL tools are already validated)

Title of DCT	Validated by you? (Y / N / NA - already validated)
Interview Schedules	Will be piloted in January.

PART B

N.B. All questions should be addressed (e.g. provide an answer or state why not applicable).

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14. POTENTIAL RISKS AND BURDENS

Describe potential risks and burdens for your participants. Include any potential for distress, discomfort, with an explanation of why it is necessary. For any risk stated here please state what will be done to minimise such effects.

As examples; complications during a surgical intervention, the risk of breaching confidentiality, or the causing of upset during a qualitative interview, would be considered as valid risks or burdens. Potential risks and burdens should be conveyed in the study participant information leaflet so that a participant can clearly understand what is involved if they consent to take part.

As the participants in this study will be discussing their experiences of living with dementia, they may become upset. Should this happen, the researcher will ask the participant if they want to terminate the session or have a break. Their choice will be respected.

The research team have no intent to cause distress or harm but are also unable to guess what could cause stress to each individual participant. The methodology for this project allows the participants to disclose what they choose and take their stories in any chosen direction; therefore, they may begin to talk about upsetting topics; for example, end of life circumstances. The research student has over four years' experience of working with palliative clients and is well accustomed to hearing such topics of conversation. However, should the participant show any signs of stress or discomfort, whether that be verbal or non-verbal body cues, the researcher would try to change the course of conversation, pause or terminate the data collection. In the event of data collection being terminated, a member of care staff will be informed as soon as possible.

The family member participant will be provided with the contact details for advice or counselling services should they need it. The participants with dementia in residential homes do not have access to telephones; therefore, they have been instructed to speak to a member of their care team who will contact the desired service on their behalf.

For older people living with dementia, they may become upset/frustrated if they cannot remember certain facts. They will be told throughout that the factual accuracy of their story does not matter; it is the content that is of interest not specific names and dates. The researcher will inform the participant that their stories will be edited before they are analysed, so the specifics can be edited in later. Where possible, the family member will be recorded first so that the researcher may be made aware of certain life events that could be used as prompts for the person with dementia.

A PIA was also completed for this project and is attached.

15. DISCLOSURE OF INFORMATION FROM INTERVIEW/QUESTIONNAIRE

Where research might lead to unexpected disclosure of information by participants that could require notification or other follow up action by the researcher, how will this be handled? This provision should also be explained clearly within the participant information sheet.

Should the participants disclose anything deemed sensitive, the researcher will inform the project supervisor as soon as possible for further advice. If they disclose anything concerning safeguarding, the researcher will have a point of contact within each county who they can disclose any safeguarding concerns to. Should the participant disclose any illegal activity or harm to their self or others, the researcher will share the information with relevant parties. The participants will be made aware, prior to data collection beginning, of the procedure followed by the researcher in the event of sensitive information disclosure.

A PIA was also completed for this project and is attached.

16. POTENTIAL RISKS TO THE RESEARCHER

Describe any potential risks to the safety and wellbeing of the researcher, such as lone working. Describe the measures proposed to address such concerns. Have the procedures been risk assessed in accordance with USW guidance?

When collecting data from people within their own homes, the researcher will adhere to the lone working protocol whereby the research supervisor will be informed in advance of the researcher’s intention to go to a property alone, the researcher will inform the supervisor when they arrive at the property, how long they expect to be, and will inform the supervisor as soon as they have left the property.

As [redacted] are tasked with deciding who could participate in this study, it will be asked that they ensure they do not consider someone who could be a threat to the research student.

The research student has a full DBS certificate and is covered under both the University of South Wales and [redacted] [redacted] insurance.

The research student has over four year's experience of working in care with people who have dementia, therefore, has regularly had to provide palliative care and discuss end of life with clients. Should the research student feel the need for support whilst undertaking this project, the University of South Wales offers a wellbeing counselling service that is accessible to all students.

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17. SCREENING OF IDENTIFIABLE PERSONAL INFORMATION

Give details of the sources (e.g. patient notes) of identifiable personal information that will be used to identify potential participants.

In a clinical context, if the person responsible for identifying a patient as a potential participant is not part of that patient's clinical team, please explain why.

Please remember, where researchers are required to identify potential participants from clinical records, the clinical team should first seek consent from the patient to allow access for the researcher; this is to avoid a breach in confidentiality.

Not Applicable- the research team will not be accessing any clinical records.

---

18. ADVERTISEMENTS

All advertising material intended to recruit research participants must be reviewed by the Faculty ethics sub group. This includes but is not limited to: posters, letters, web pages and radio/TV broadcasts.

Are you intending to use any advertisements? ~~YES~~ **NO**

If yes, please list the documents appended to this application.

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19. APPROACHING PARTICIPANTS

Describe how potential participants will be approached and who will be involved.

In a clinical context, patients should be initially approached by a member of their clinical care team.

Copies of documentation used to approach potential participants should be enclosed with this application, such as a copy of the participant information sheet.

Potential participants will be identified by [redacted] staff in accordance with the inclusion criteria and the advice from the safeguarding leads. Potential participants will be given a number. All numbers will be put into a bowl and randomly selected back out by the research team. This method of selecting participants has been incorporated to prevent any bias occurring from selecting specific participants. Using this method ensures everyone who meets the inclusion criteria has a chance to take part in this research.

The participants corresponding to the chosen numbers will be approached by the [redacted] managers ([redacted]) to provide them with a formal invitation to take part in the project, have the project verbally explained, given an information sheet and allowed to ask any questions. Two days later, the manager will approach the participant again and ask if they would still like to take part. Should they consent, the manager will take formal consent from the person and introduce the research student to agree a date/time to begin data collection.

[redacted] staff will also identify possible family members who may want to take part in the project. They will provide them with information sheets containing the contact details of the research team. Should they wish to take part, they will be asked to please contact the research team or speak to their nearest [redacted] manager who will arrange a date and time to meet.

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20. INFORMED CONSENT

Describe the arrangements for taking consent from research participants prior to their participation in the research study. Describe the time allowed to decide to take part. Please include a copy of a written consent sheet (where used) with this application.

For consent to be ethical and valid in law participants must be 'capable' of giving consent. Please ensure you have adhered to current guidance on the attributes of a capable person and adhered to such guidance in your recruitment strategy.

As this project is working with older people with dementia, the research team has sought out the advice of the local authority safeguarding leads from the 2 counties (Torfaen and Caerphilly) to inform on the council's protocol for people with dementia participating in research. Their guidance stated that there are no safeguarding considerations, providing [redacted] and USW do not ask questions that the residents (or carer) cannot answer (or has limited capacity to) and the answers are not forced. Permission and consent for filming and putting information onto a public platform must also be obtained.

A diagnosis of "dementia" does not mean that someone lacks capacity, it means that their capacity is greater for some tasks than others and that capacity will alter on a day by day, hour by hour, basis (Mental Capacity Act, 2005).

People with early to mid-onset dementia could have the capacity to give informed consent.

As the research team are not familiar with the clients of [redacted], the [redacted] staff, who work with the client's daily, will be the people to assess who does or does not have capacity to consent.

The participants may be approached several times over a period of time to have the project explained to them. Once they have met with the research team, it will be considered that the project has been described to them enough times (at least 3) for them to be able to give informed consent.

In accordance with the Mental Capacity Act 2005, the participants will not intentionally be harmed during this project, nor will they feel burdened to take part. Most participants for narrative data collection find the experience therapeutic (Gonzales, 2015). The project is exploring the lives of people with dementia, therefore, it cannot use participants who have not experienced life with dementia.

For the family members, informed consent will be gained after they have been provided with a written information sheet and a verbal explanation of the study. Once all of their questions have been satisfactorily answered, informed consent will be obtained.

For both sets of participants, process consent will take place whereby the researcher will check that they still want to partake in the research at every meeting.

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21. INFORMED CONSENT TOOLS

Please confirm the information sheet and consent form have been considered as appropriate for the target audience?

YES ~~NOT APPLICABLE (state why below)~~

Please note, the information sheets and debrief sheets do not follow the traditional format for such documents. Since they are being used for people with dementia, they were created following guidelines from the Dementia Engagement and Empowerment Project regarding "dementia-friendly" documents (DEEP, 2013). The information is either bold, underlined or placed into boxes; this makes it easier to locate information they find useful, makes some sentences stand out from others and prevents the person with dementia from feeling overwhelmed by the amount of information being presented to them.

Similarly, as the family members may also be elderly and may have a visual impairment, a similar lay out have been used for them too.

The data protection officer from [redacted]) requested a copy of the consent form. Upon inspection, she suggested that the clauses be specific and minimal. She also required the participants to be provided with several different methods of contacting the research team, all of which need to be incorporated in the consent form to meet [redacted] regulations. All of her advice was carried out to her satisfaction.

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22. DATA ANALYSIS / STATISTICS

Please describe the arrangements for analysing your data (qualitative and quantitative). Where appropriate discuss what data/statistical analysis will be completed. Where used, please remember to discuss sample size and how the sample size was decided upon.

The sample will consist of 6 people with dementia and 6 family members as this project is only a yearlong and the information being collected is thorough. Therefore, it was felt that 12 stories were suitable for a yearlong project.

Data will be analysed using a narrative analysis technique (Nykvist, Larsson and Lyckhage, 2013).

The video recordings will be transcribed.

These transcripts and DVDs will then be edited by the research team to remove any information that may cause upset, be sensitive or offensive towards another, or that may harm relationships before the participant edits the information.

The transcripts and DVDs will then be taken back to the participants to edit.

The edited transcripts will be analysed in terms of recurring themes and statements of interest.

NVivo will be used to conduct the analysis.

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23. DATA CUSTODIAN

Please identify the person who is responsible for overall data security.

Alex Walker and Dr Anne Fothergill

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24. DATA MANAGEMENT

Please describe the location and arrangements for data storage. Describe where/how your data will be securely stored during, and after the research study has completed.

Are the data being collected regulated by the Data Protection Act?

YES ~~NO~~

Video recordings and electronic data will be stored on a password protected computer. Hard copies of data, such as consent forms and printed transcripts, will be stored in a lockable drawer. Both the drawer and the computer hard drive are located within an electronically locked office which requires an approved I.D card to unlock.

The data will be kept for 5 years then destroyed. Alex will keep the information until her studentship comes to an end, at which time, Anne will be responsible for it and also responsible for its destruction.

The participants will be provided with their own copies of the DVDs that is theirs to keep. What they choose to do with them is totally up to them.

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25. CONFIDENTIALITY OF DATA

Describe the provision for ensuring that the confidentiality of personal data is preserved, such as a strategy for anonymity.

To ensure potential participants are not identifiable, their names and corresponding numbers will only be accessible to one member of [redacted].

Once the participants have been identified and agree to participate in the study when asked by a [redacted] manager, they will become known to the research team and therefore cannot remain confidential any longer.

The research team will not discuss the participant with anyone outside of the project, unless for reasons relating to safeguarding or disclosure of sensitive information.

Sensitive information will be edited out the transcripts/DVDs. Similarly, participants will be requested to affirm their stories before they are disseminated.

26. PAYMENT TO RESEARCH PARTICIPANTS
Please note, participants should not be paid for taking risks. Payment should not be set to a level that would unduly influence potential participants. Information pertaining to participant payment should be included on the Participant Information Sheet.

Will participants be paid? ~~YES~~ **NO**

If yes, please give details.

Although the participants will not be paid, they will be given copies of their video narratives on DVD.

27. PAYMENT TO RESEARCHER
Describe any payment that the research team is receiving as part of carrying out this research study. Researcher payment should be recorded in the participant information sheet.

KESS funded project.

28. CONFLICT OF INTEREST
Describe any conflict of interest that anyone in the research team might have.

[redacted]- Partner within the project but is also the Director of Nursing- Quality and Development within [redacted].

[redacted]- Partner within the project but also the Training and Quality Lead within [redacted].

Both [redacted] and [redacted] are part of the steering committee and will aid in decision making about methodology and design, but they will not have anything to do with participant selection.

29. ENSURING ANONYMITY OF IDENTIFIABLE DATA IN PUBLICATIONS

Describe the provision for ensuring anonymity in any publication or publically available output produced from this research study.

Due to the nature of this study, participant information will not be anonymised. The videos of them telling their stories will be used by the research team for conferences, academic publications, to inform the dementia models in [redacted] and in the final thesis for the project. As the data will contain visually identifiable details about the person, they cannot be anonymised.

Should the participant also consent to it, their video may be used by [redacted] for marketing purposes or internal training.

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30. SCIENTIFIC SCRUTINY AND RESOURCING

Has this research study been peer reviewed?
YES (internal USW) **YES (external)** ~~NO~~

If YES, please provide information about the review, including the reviewing body and date of review/approval.

Bangor University and the University of South Wales - KESS Project

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31. INSURANCE INDEMNITY
i. Does this research study require indemnity/insurance cover from the University of South Wales?

YES ~~NO~~

ii. Will the research take place on University of South Wales' premises?

~~YES~~ **NO**

If NO, give details of any offsite locations:

Data will be collected in the partner organisation, [redacted] within Caerphilly and Torfaen residential homes and Torfaen domiciliary services.

iii. DOES THE RESEARCH UTILISE ANY OF THE FOLLOWING (PLEASE INDICATE ALL THAT APPLY):

Investigating or participating in methods of contraception? NO
Assisting with or altering the process of conception? NO
The use of drugs? NO

The use of surgery? (other than biopsy) NO
Genetic engineering? NO
Participants under 5 years of age? (other than activities above) NO
Participants known to be pregnant? (other than activities above) NO
Pharmaceutical product/appliance designed or manufactured by host institution? NO
Work outside of United Kingdom? NO

- At the time of signing this application, I consider it to be complete and accurate

- I will notify the faculty ethics sub group immediately if I subsequently consider the application requires any correction or qualification, or if there is any revision to the proposal.

- I understand that I may be invited to discuss my proposal with the faculty ethics sub group.

SIGNATURE OF INVESTIGATOR .... A. Walker ....

SIGNATURE OF SUPERVISOR …… A Fothergill ……………………………..

(MSc Students)

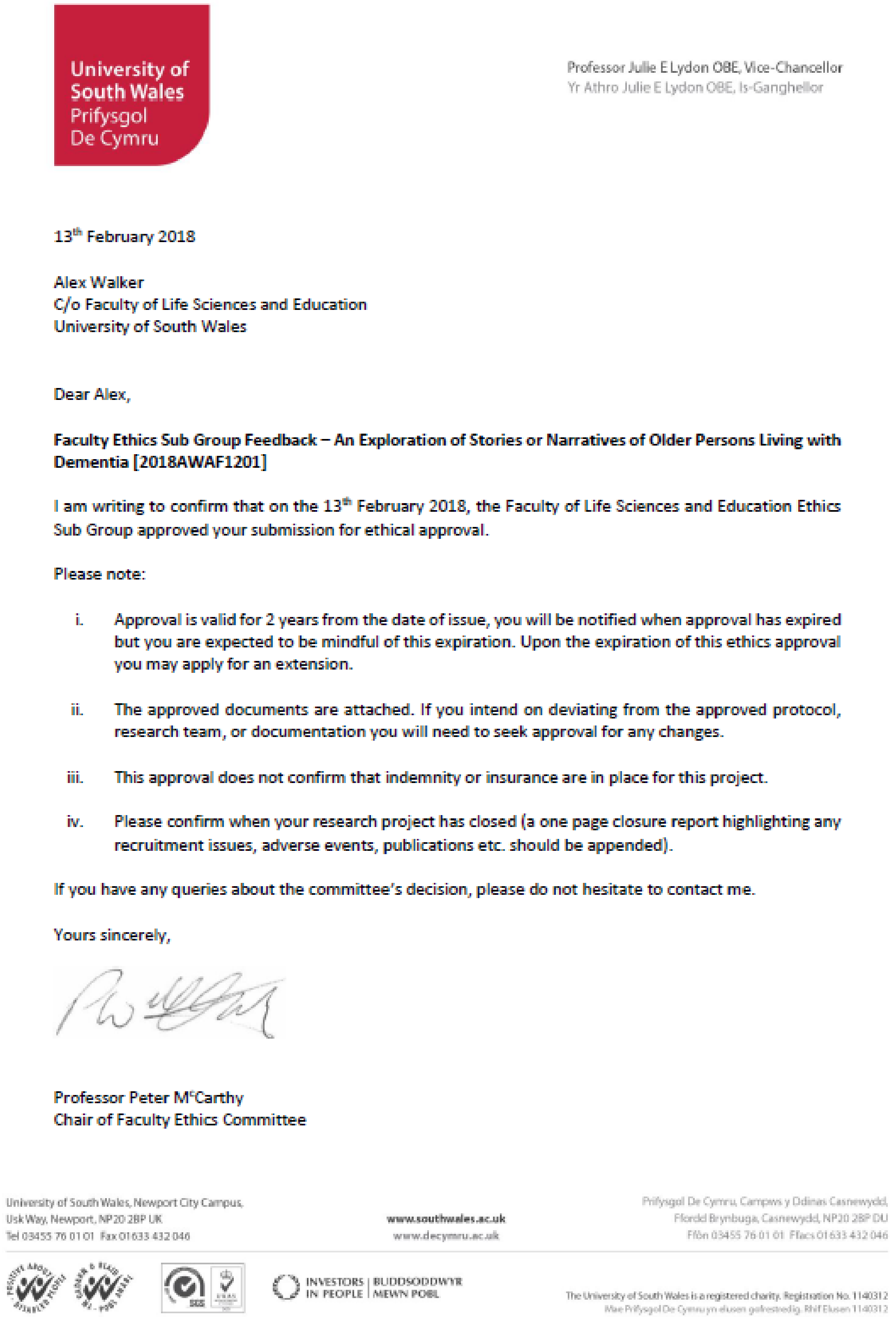
DATE OF SUBMISSION .... 05.01.2018 ....

SIGNATURE OF APPROVAL ……P McCarthy……………………………………………...

(Chair/Secretary – FESG)

DATE OF APPROVAL ....13.02.2018..

J: 1st USW ethical approval certificate



University of
South Wales
Prifysgol
De Cymru

Professor Julie E Lydon OBE, Vice-Chancellor
Yr Athro Julie E Lydon OBE, Is-Ganghellor

13th February 2018

Alex Walker
C/o Faculty of Life Sciences and Education
University of South Wales

Dear Alex,

Faculty Ethics Sub Group Feedback – An Exploration of Stories or Narratives of Older Persons Living with Dementia [2018AWAF1201]

I am writing to confirm that on the 13th February 2018, the Faculty of Life Sciences and Education Ethics Sub Group approved your submission for ethical approval.

Please note:

i. Approval is valid for 2 years from the date of issue, you will be notified when approval has expired but you are expected to be mindful of this expiration. Upon the expiration of this ethics approval you may apply for an extension.

ii. The approved documents are attached. If you intend on deviating from the approved protocol, research team, or documentation you will need to seek approval for any changes.

iii. This approval does not confirm that indemnity or insurance are in place for this project.

iv. Please confirm when your research project has closed (a one page closure report highlighting any recruitment issues, adverse events, publications etc. should be appended).

If you have any queries about the committee's decision, please do not hesitate to contact me.

Yours sincerely,

Professor Peter McCarthy
Chair of Faculty Ethics Committee

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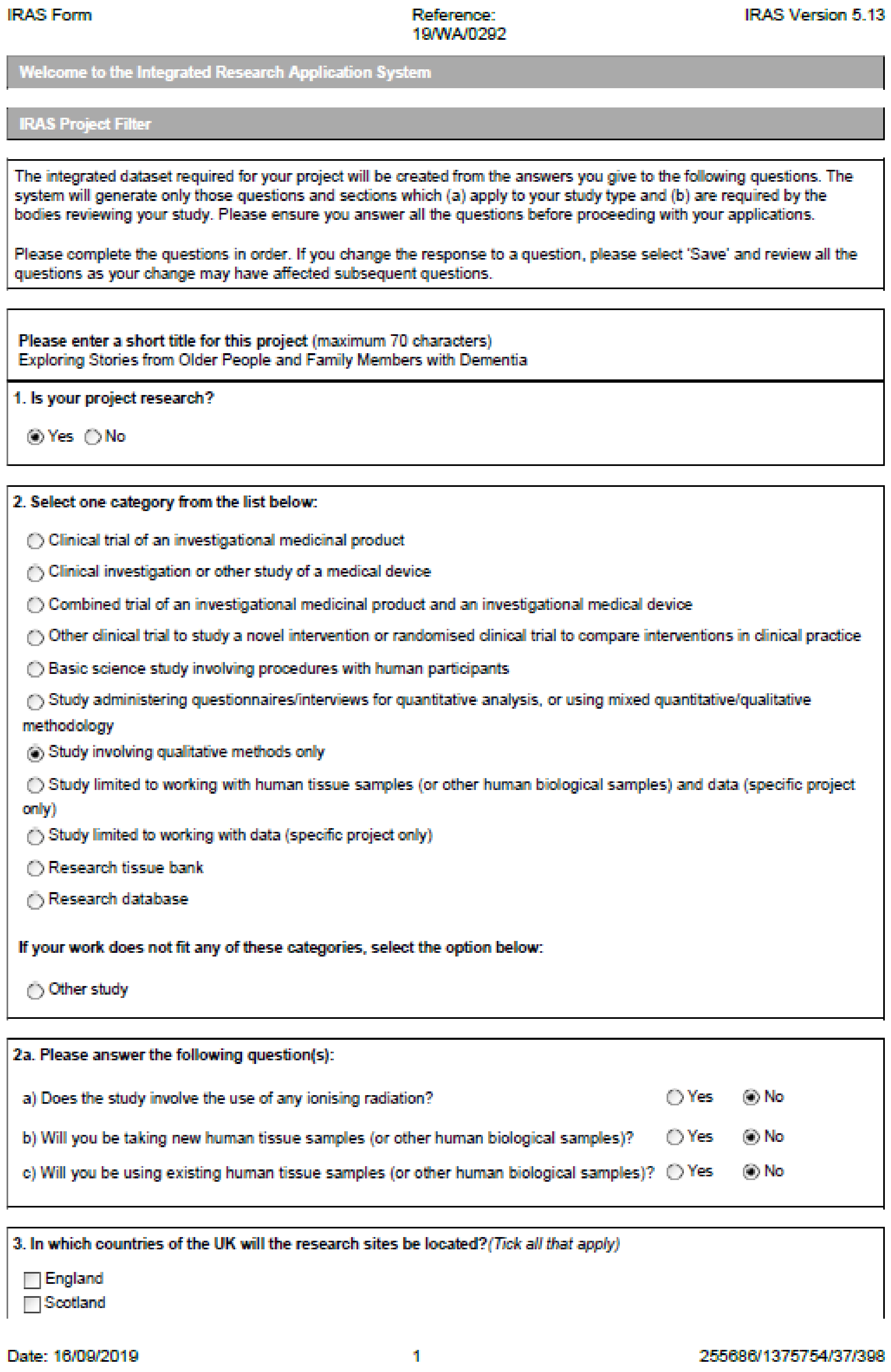
K: IRAS form



Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Exploring Stories from Older People and Family Members with Dementia

1. Is your project research?

● Yes ○ No

2. Select one category from the list below:

- ○ Clinical trial of an investigational medicinal product
- ○ Clinical investigation or other study of a medical device
- ○ Combined trial of an investigational medicinal product and an investigational medical device
- ○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ○ Basic science study involving procedures with human participants
- ○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ● Study involving qualitative methods only
- ○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ○ Study limited to working with data (specific project only)
- ○ Research tissue bank
- ○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	○ Yes	● No
b) Will you be taking new human tissue samples (or other human biological samples)?	○ Yes	● No
c) Will you be using existing human tissue samples (or other human biological samples)?	○ Yes	● No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

☐ England
☐ Scotland

☑ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England
○ Scotland
● Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which applications do you require?

☑ IRAS Form
☐ Confidentiality Advisory Group (CAG)
☐ Her Majesty's Prison and Probation Service (HMPPS)

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

○ Yes ● No

5. Will any research sites in this study be NHS organisations?

● Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ● No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ● No

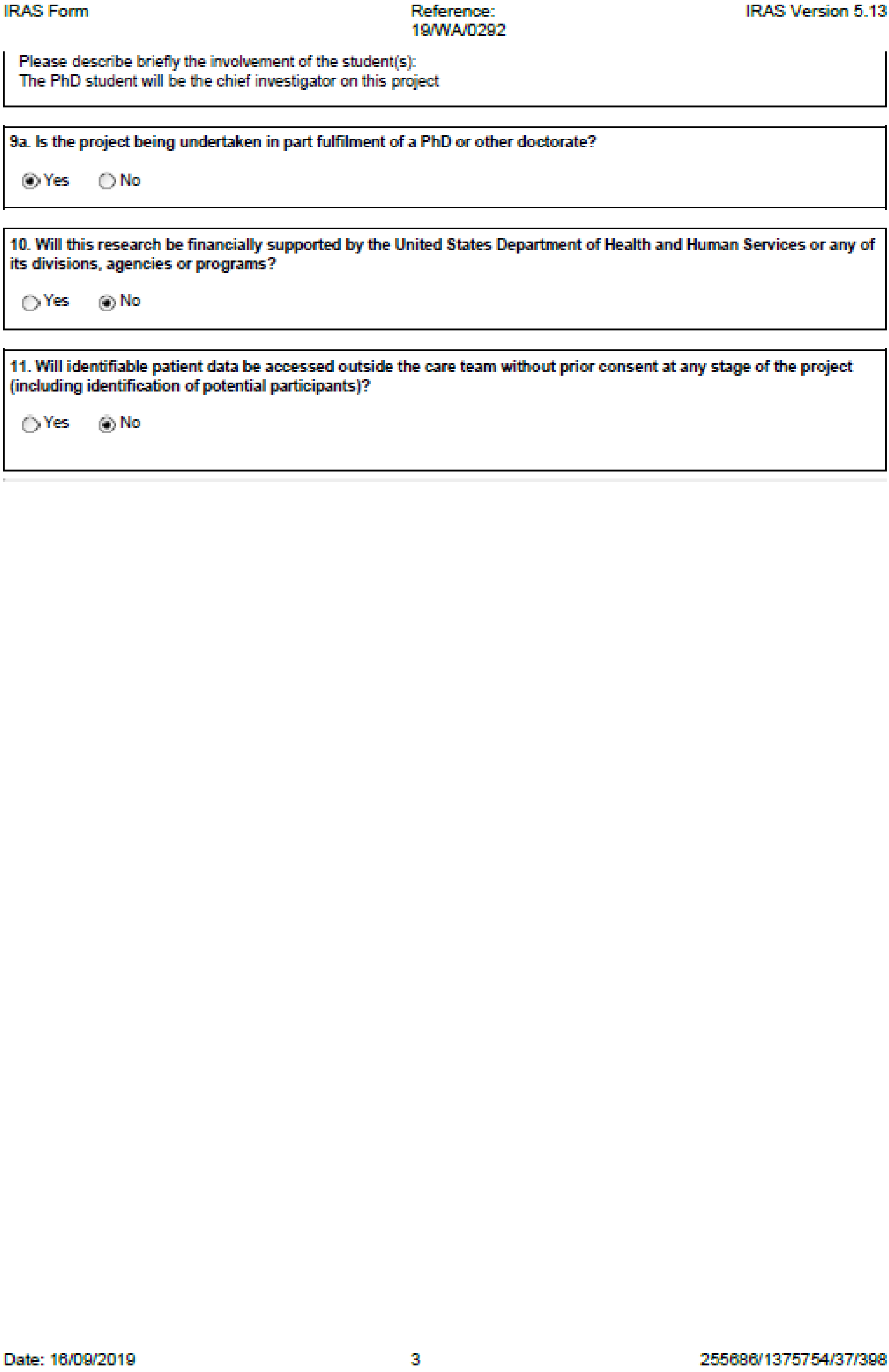
Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ● No

9. Is the study or any part of it being undertaken as an educational project?

● Yes ○ No



Please describe briefly the involvement of the student(s):
The PhD student will be the chief investigator on this project

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

● Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ● No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ● No

Integrated Research Application System
Application Form for Research involving qualitative methods only

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Exploring Stories from Older People and Family Members with Dementia

Please complete these details after you have booked the REC application for review.

REC Name:
Wales REC 1

REC Reference Number:
19/WA/0292

Submission date:
16/09/2019

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

An Exploration of Stories of Older Persons and Family Members Living with Dementia

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Alex	Walker
Address	AB034 Lower Glyntaff Campus University of South Wales Treforest		
Post Code	CF37 4BE		
E-mail	alex.walker@southwales.ac.uk		
Telephone	07760821292		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
PhD

Name of educational establishment:
University of South Wales

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Anne	Fothergill

Address	AB047 Lower Glyntaff Campus University of South Wales Treforest
Post Code	CF37 4BE
E-mail	anne.fothergill@southwales.ac.uk
Telephone	
Fax	

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Nicky	Genders

Address	AB126 Lower Glyntaff Campus University of South Wales Treforest
Post Code	CF37 4BE
E-mail	nicky.genders@southwales.ac.uk
Telephone	
Fax	

Academic supervisor 3

	Title	Forename/Initials	Surname
	Dr	Rachel	Iredale

Address	AB030 Lower Glyntaff Campus University of South Wales Treforest
Post Code	CF37 4BE
E-mail	rachel.iredale@southwales.ac.uk
Telephone	
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 Miss Alex Walker	☑ Dr Anne Fothergill ☐ Dr Nicky Genders ☐ Dr Rachel Iredale

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

● Student
○ Academic supervisor
○ Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname Miss Alex Walker
Post	PhD Student
Qualifications	MSc Abnormal and Clinical Psychology BSc Psychology A Level Psychology A Level Sociology A Level History 12 GCSE's
ORCID ID	
Employer	University of South Wales
Work Address	AB047 Lower Glyntaff Campus University of South Wales Treforest
Post Code	CF37 4BE
Work E-mail	alex.walker@southwales.ac.uk
* Personal E-mail	allywalker1994@yahoo.co.uk
Work Telephone	07760821292
* Personal Telephone/Mobile	[redacted]
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname Dr Anne Fothergill
Address	AB047 Lower Glyntaff Campus University of South Wales Treforest
Post Code	CF37 4BD
E-mail	anne.fothergill@southwales.ac.uk
Telephone	01443483017
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	2017AWAF1201
Sponsor's/protocol number:	1
Protocol Version:	4
Protocol Date:	10/09/2019
Funder's reference number (enter the reference number or state not applicable):	KESS 21363
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

● Yes ○ No

Please give brief details and reference numbers.
Began as a year long MRes with [redacted] which got upgraded to PhD with [redacted] [redacted] KESS Ref Number 20828.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

The main aim of this research project is to explore and understand what it is like to live with dementia from the perspective of both the older person with dementia and their family members.
The proposed outcomes of this study are to improve awareness of life with dementia and suggest ways to improve the care/support offered to people affected by dementia.
For more in depth results, digital life stories will be used to explore the experiences of those affected by dementia.
This study is exploring life with dementia from the perspective of both the older person with dementia and a family member. This is a two year long study and aims to recruit 15 people with dementia and 15 family members from the older person's services within [redacted] and [redacted] It is important to acknowledge the "person behind the dementia" in order to fully understand their experiences of living with the disease; therefore, the participants with dementia will be asked to explain their life experiences from childhood, through to the present day and their hopes for the future, discussing dementia onset, dementia diagnosis, life with dementia, identity changes and relationship changes. The family members will be asked to describe their relationship with the person with dementia prior to dementia onset and explain if/how this relationship has changed, additionally, they will be asked to explain their experiences of dementia onset signs, the diagnosis process and services/support they have experienced.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Full Informed Consent- Some participants in this study will have a diagnosis of dementia. To ensure they are able to give full informed consent, the research team are requesting that possible participants are (1) aware of their diagnosis and able to discuss it and (2) have the capacity to consent for themselves. In regard to 2, the research team are asking memory clinic nurses from the older persons services within both HBs to nominate service users they feel meet the inclusion criteria and are able to discuss life with dementia. The research team recognise that capacity can fluctuate for people with dementia; therefore, the research student will assess the participant's capacity for giving full informed consent when they meet (to obtain written consent, data collection and video editing).

Upset- It is likely that some of the participants in this study will become upset while narrating their experiences of life with dementia or considering end of life planning. In the event of this, the research student will gain the participant's consent to pause or cease recording. The participants will additionally be given the option to pause or recording at any time they like. The research student has four years experience of working with people with dementia and family members through these emotional times and is, therefore, capable of dealing with such situations. Nevertheless, the participants will be provided with the contact details for the lead nurse of their corresponding memory clinic should they want to seek further support. Alternatively, the research student will ask permission from the participant to contact the nurse on the participant's behalf. This will be the participant's preference.

Disclosure of sensitive information- It is commonly noted that people with dementia can disclose information they have kept suppressed for many years. If the participant should disclose any sensitive information or information likely to cause upset to others, the participants will be given the opportunity to edit their stories before they are analysed to ensure the stories only contain the information they want included. If the research student feels that some data should not be included as it contains potentially upsetting information about a family member/friend, the research student can remove it. "Sensitive information" includes, but is not limited to, criminal activity, physical, psychological, sexual or financial abuse. Information likely to cause upset to others may include family affairs, family disagreements etc.
In addition to the information above, the participants will be given the option to conduct data collection and video editing alone (with the research student) or with their family member present for prompting support.

Disclosure of illegal or dangerous information- should the participate disclose any illegal activity or activities that risk the health and well-being of themselves or others, the research student will have to tell the relevant people. The participants will be made aware of this on the consent and information sheets.

In Accordance with TREAD guidance, (The Research Ethics Application Database), if the participant discloses any information that could put someone at risk (emotionally or physically), it must be omitted from the data. Therefore, the research student will retain the right to remove anything deemed upsetting/ inappropriate or derogative about any other person/organisation/service.
The participants are made aware of this on the information sheets.

Confidentiality- The participant's videos will be used to defend the PhD thesis during examination. The videos will only be shown to the examiners on the day of the VIVA examination within the University of South Wales. The videos will be stored on a password protected external hard drive and will be shown to the examiners on a University desktop machine. The use of video recordings to defend the PhD thesis make it impossible to conceal the participant faces from the two examiners. For all written outputs from this study, direct quotations from the participants will be used with all identifiable information contained with the quotes being anonymised.

Frustration- People with dementia can become frustrated when they cannot remember facts/names/dates or formulate what they're trying to say. Participants will be reassured to take their time. If they become particularly stuck, the research student will come back to the particular question. To try and aid with facts relating to their life, the research student will try and gain some factual information about the participant prior to data collection so that prompts can be used. Similarly, personal photographs may also be used to prompt responses.

Capacity of participants- People with dementia will have a fluctuating capacity that can deteriorate very quickly. The nursing staff within the memory clinics will assess the capacity of possible participants prior to approaching them about the study. If the staff feel the person meets the inclusion criteria, they will approach them to explain the study. It is likely that some of the participants can understand the study and wants to participate, but will forget about the study. To overcome this, process consent will be used whereby the participant will have the study explained and verbal consent obtained on every correspondence related to the study (for example, nurse obtaining verbal consent, research student obtaining written consent, data collection and video editing). Dementia can progress rapidly, to accommodate this, the research student aims to complete data collection and editing within a month of the participant initially being approached. The research student will aim to return the transcripts and videos within a week of data collection. Additionally, the research student will assess the participant's capacity on the day of meeting, where the participant's capacity has dropped (as is common in dementia) the research student will arrange an alternative day to visit. The research student will assess ongoing capacity using the principles outlined in the Mental Capacity Act (2005); the participant must be able to understand the information relevant to the study, retain the information, use the information to make their decision on whether to participant/continue participating and can clearly communicate their decision to proceed with data collection.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply:*

☐ Case series/ case note review
☐ Case control
☐ Cohort observation
☐ Controlled trial without randomisation
☐ Cross-sectional study
☐ Database analysis
☐ Epidemiology
☐ Feasibility/ pilot study
☐ Laboratory study
☐ Metanalysis
☑ Qualitative research
☐ Questionnaire, interview or observation study
☐ Randomised controlled trial
☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

Research question: "what is it like to live with dementia?"

Objectives:
(1) to explore and understand the lived experiences of older people with dementia
(2) to explore understand the experiences of family members of older people with dementia

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Dementia is one of the largest health and social care issues (Welsh Government, 2017) with over 22,000 people currently living with a diagnosis in Wales (Alzheimer's Research UK, 2018). The Prime Minister's Challenge on Dementia 2020 Plan (Department of Health, 2016) emphasised that research into curing dementia is essential, but equal effort needs to be placed into improving the care and support offered to people currently living with dementia in both the community and care environments. Additionally, the Prime Minister's Challenge on Dementia 2020 highlights four prime areas that research needs to focus on; research, awareness and social action, risk reduction, health and social care. Three of these are being addressed by this study.
The Older People's Commissioner for Wales (2018) noted that there are very few opportunities for people with dementia and family members to voice their opinions; where the facilities are available to share their viewpoint, they are rarely considered when planning care improvements or service change. The Older People's Commissioner for

Wales (2018) also reported that personal histories, religious beliefs, culture, likes and dislikes and hopes for the future were not recorded within care plans for people with dementia, nor were they made visible for care staff to see.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The memory clinics will be shadowed prior to ethical submission and observations written as notes. These notes may be used for the final thesis write up to inform decisions related to data collection (e.g. recruitment sites, interview prompts).

This is a descriptive phenomenology study aiming to understand the lived experiences of people with dementia and their family members. Phenomenology is a popular methodology for health care research (Edward and Welch, 2011) as it gives researchers the opportunity to explore new topic areas (Polit and Beck, 2014). The exploratory nature of descriptive phenomenology allows a researcher to gain an understanding of the participant's interpretation of the world they live in and the lives they have led without intellectual bias and preconceptions having an influence on the findings (Wirihana et al., 2018).

Life story work is a novel method of collecting data in research which can help the researcher to understand the experiences of people living with dementia in a more personal and creative manner (Benbow and Kingston, 2016). Within Welsh health boards, it is now customary to begin board meetings with a patient's story of their experiences of living with a given disease/illness/disability.

Digital life story work is an established tool within health and social care research (Capstick and Ludwin, 2015) but its use with people who have dementia in negligible. A systematic review conducted by de Jager et al (2017) found no studies that had used digital storytelling as a data collection tool for participants with dementia. The originality of using digital life story work as a data collection tool with participants who have dementia will meet the criteria for a PhD thesis' originality.

The participants for this study will be interviewed in their own homes or within the memory clinic, where ever they feel most comfortable. The research student will adhere to University of South Wales lone worker policy at all times. The participants will be given the option to be video recorded with their family member present or alone. The family member may offer support and prompts when needed but it will be the participant's decision. The participants with dementia will describe their life histories from childhood through to the present day (interview prompts will be used in case the participant needs some guidance on where to take their story next). The participants will be asked to describe their childhood, schooling, marriage, employment, children, retirement, relationship with family and friends (and how this relationship has changed), dementia onset, diagnosis process, life with dementia (including changes in identity and role) and future hopes.
The family members will also be video recorded in their own homes but will be asked to describe their relationship to the person with dementia prior to dementia onset, their experience of the dementia diagnosis process and their experiences of currently living with dementia.

All of the video recording, transcribing and video editing will be done by the research student. The equipment used to do so had already been purchased out of the student's KESS budget and was successfully used in Phase 1 of this PhD (within residential homes). This equipment includes Hama Lavalier Microphone LM-09, Panasonic Video Recorder HC-V770, SanDisk Extreme Pro 64 GB memory card (x2), Hama Tripod, Toshiba 2TB External Hard Drive Videos will be edited on a USW computer using Adobe Premier Pro CC, converted to H.264 format and burnt onto Verbatim DVD-R using DVD Flick.

Based on previous experience of conducting digital life story work from phase 1 of this study, the interviews will last approximately an hour and a half.
The video recordings will be transcribed word for word by the research student. The transcript and the video will be returned to the participants for editing (validate and choose exactly what they want in their story). It is likely that there will be approximately a week between data collection and the stories being returned for editing. Anything deemed sensitive or upsetting that has not been previously removed by the participant will be removed by the research student (e.g. saying that their son is good for nothing. This may be the participant's opinion of their son but it may cause unnecessary upset to the family).
Final videos are likely to be an hour and a half in length.
The participants will be able to request a copy (via the consent form) of their final DVD at the end of the study (1) as they may hold sentimental value and (2) the participant could use them alongside traditional paper based care plans to ensure staff see the person past the dementia.
The videos will be used by the PhD student in defence of her thesis during VIVA examination. This will involve the 2

examiners being present within the university for an hour before the examination, during this hour, they will be shown the videos on a university desktop computer by the research student. This is the only time the videos will be used by the research team. For the written PhD thesis, journal articles and conferences, direct anonymised quotations and notes on non-verbal cues from the participants will be used.

It is estimated that the participant's video editing will be completed within a month of them initially being approached about the study.
It is important to understand the person prior to dementia onset to fully understand their journey with dementia.

The use of video recordings as apposed to traditional voice recordings was deemed necessary by the research team as video recordings allow for a more creative and personal means of illustrating one's life story (Benbow and Kingston, 2016). Video recordings of people telling stories has been found to engage the imagination of the audience (examiners in this case) more effectively than words on a page (Mitchell, 2006). Video life stories have been proved effective communication tools for educating others about aging, in particular, illnesses that affect mainly the elderly (Mitchell, 2006). Digital storytelling gives the participant a sense of ownership over their life experiences and can make them feel proud of the lives they have lived (McKeown et al., 2010). Furthermore, digital storytelling has been proven to: empower participants (Davis, 2005), raise awareness amongst viewing audiences (Larkey and Hill, 2012) and provide multisensory data to aid research (Gubrium and Harper, 2013). De Jager et al (2017) also noted that the studies within their systematic review reported that digital storytelling provided significantly more information than traditional interviews.

Digital storytelling has been used as group workshop for people with dementia by Stenhouse et al. (2013). It was reported that all of the participants engaged with this creative activity and it seemed to benefit their sense of self (Stenhouse et al, 2013). Digital storytelling allowed for self-expression and a sense of achievement (Stenhouse et al., 2013). Furthermore, digital storytelling can provide a deeper knowledge of the experiences of living with dementia (Aadlandsvik, 2008).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☑ Design of the research
☐ Management of the research
☐ Undertaking the research
☐ Analysis of results
☑ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
People with dementia were asked to validate the research documentation to ensure all documents (information sheets, consent forms etc) were appropriate for people with dementia to understand. This included altering some of the terminology and lay out of the forms to ensure people with dementia understood what was being asked of them and what they were consenting to- thus ensuring the inclusion for people with dementia in research.
The participants will also be given the opportunity to edit their transcripts and videos.
The participants will be have to give permission for their videos to be used in defence of the PhD thesis at VIVA examination. The participant will also have to acknowledge that their identities will be anonymised for everything else.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

☐ Blood

☐ Cancer
☐ Cardiovascular
☐ Congenital Disorders
☑ Dementias and Neurodegenerative Diseases
☐ Diabetes
☐ Ear
☐ Eye
☐ Generic Health Relevance
☐ Infection
☐ Inflammatory and Immune System
☐ Injuries and Accidents
☐ Mental Health
☐ Metabolic and Endocrine
☐ Musculoskeletal
☐ Neurological
☐ Oral and Gastrointestinal
☐ Paediatrics
☐ Renal and Urogenital
☐ Reproductive Health and Childbirth
☐ Respiratory
☐ Skin
☐ Stroke

Gender:	Male and female participants
Lower age limit: 65	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

For people with dementia:
1) have a formal dementia diagnosis
2) are aware of their diagnosis
3) able to give full informed consent
4) are 65 years plus*
5) access [redacted] or [redacted] older persons services
6) have been diagnosed for more than six months
7) will consent to being video recorded.

*participants with dementia need to be 65 years or older as 65 is the age where patients within the health boards would be able to access the "older persons services".

For family members:
1) Are related to a person with dementia who receives services from the memory clinics in [redacted] or [redacted]
2) Will consent to being video recorded.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

For people with dementia:
1) have not got a formal diagnosis of dementia
2) are not able to give full informed consent

3) are not aware of their diagnosis
4) do not access [redacted] or [redacted] older persons services
5) will not consent to be video recorded.

For family members:
1) have a diagnosis of dementia
2) are not able to give full informed consent
3) will not consent to be video recorded.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Project and Information sheet discussed	1	N/A	30 minutes	Memory Clinic Lead Nurse ([redacted] or [redacted] Memory Clinic
Obtaining verbal consent to participate via telephone call	1	N/A	30 minutes	Memory Clinic Lead Nurse ([redacted] or [redacted] Memory Clinic
Informed consent taken	1	N/A	20 minutes	Alex Walker Participant's home or Memory Clinic
Data Collection	1	N/A	90 Minutes	Alex Walker Participant's Home or Memory Clinic
Video and transcript editing	1	N/A	90 Minutes	Alex Walker Participant's Home or Memory Clinic
Ongoing seeking of consent to use clips from the videos	1	N/A	10 minutes	Alex Walker or Dr Fothergill

A21. How long do you expect each participant to be in the study in total?

Data collection is likely to be a one off event. Should the participant wish to spread their life story over several sittings, that would be acceptable (especially people with dementia who cannot sit and concentrate for extended periods of time).
Based on previous experience from Phase 1, data collection will take, on average, 90 minutes..
Participants will be required to edit their stories a few days later which could take another 90 minutes.
After this, the participant will no longer be required to participate in the study. Their DVDs will be returned to them upon completion.

Therefore, participants are likely to be in the study for 90 minutes on 2 days (not consecutive). Totalling 3 hours on average; however, their stories will be used for the duration of the PhD. There is likely to be a maximum of a month between the participant initially being approached to participate and their video editing being completed.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Older people may find it difficult to sit in the same position for extended periods of time. Data collection will last approximately 90 minutes. The participant will be able to pause collection at any point or spread data collection over a few days.

People with dementia can become disorientated or distressed when in unfamiliar environments, to reduce this, data collection will take place either within their own homes or within the memory clinic- where ever they feel most comfortable.

The participants may feel distressed when discussing their diagnosis. To try and minimise this, the research team have specified within the inclusion criteria that the participants have had their formal diagnosis for more than six months. This will ensure that participants have had time to come to terms with their diagnosis and living with dementia prior to discussing it with the research student.
If a participant should become distressed, the research student will obtain permission from the participant to contact the lead nurse from their memory clinic for additional support.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

● Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

Discussing life with dementia can be an emotive topic and based on prior experience from Phase 1, family members can become upset when discussing the future. Participants will be made aware that they can pause or stop video recording at any time. If the research student feels that the participant is becoming too upset, the research student will ask permission to pause the recording. Similarly, the participant will be made aware that they can pause or cease recording whenever they want.
If a participant becomes upset, they will be provided with the contact details for the lead nurses within their corresponding memory clinic and advised to telephone. Alternatively, the participant will be given the option for the research student to telephone the lead nurse on their behalf. Permission to do so will be sought from the participant.

As previously discussed, if the participant discloses information deemed sensitive (e.g. abuse), upsetting or embarrassing, they will be given the opportunity to edit it out. If the research student feels that the video still contains something sensitive, upsetting or embarrassing, the research student will remove it. This study has no intention to cause upset to participants or other family members/friends. Anything derogative will also be removed by the research student.

Should the participant disclose any illegal activity or something requiring action, the research student will have to notify the relevant parties. The participants will be made aware and consent to this.

A24. What is the potential for benefit to research participants?

Most participants for narrative data collection find the experience therapeutic (Gonzales, 2015); therefore, participants in this study may find that explaining their experiences to someone independent could have a therapeutic effect. Similarly, based on feedback from Phase 1, family member participants reported to care home managers that they felt a weight had been lifted and talking through their thoughts and feelings was greatly beneficial. For participants with dementia, talking through their life history can illicit positive emotions.

Participants will also be given copies of their edited DVDs to keep if they request them on the consent form. People with dementia may use these alongside care plans for care staff to see the person past the dementia or they may hold sentimental value.

The data collected within this study will be analysed and recommendations will be made to the health boards regarding the support and care offered to people affected by dementia.

A26. What are the potential risks for the researchers themselves? *(if any)*

When collecting data from people within their own homes, the research student will adhere to University of South Wales' lone working protocol whereby the research supervisor (Dr Anne Fothergill) will be informed in advance of the research student's intention to go to a property alone, the research student will inform the supervisor when they arrive at the property, how long they expect to be, and will inform the supervisor as soon as they have left the property.

As NHS staff are tasked with deciding who could participate in this study, it will be asked that they ensure they do not consider someone who could be a threat to the research student.
The research student has a full DBS certificate and is covered under the University of South Wales insurance.
The research student has over four year's experience of working in care with people who have dementia, therefore, has regularly had to provide palliative care and discuss end of life with clients. Should the research student feel the need for support whilst undertaking this project, the University of South Wales offers a wellbeing counselling service that is accessible to all students.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Potential participants will be identified by senior members of staff within the memory clinics; for example, Michelle Dicks (lead nurse for memory clinic in Ysbyty George Thomas) or Angela Jarrett (lead nurse for memory clinic in Ysbyty Tri Chwm) will identify potential participants within her services while they attend follow up clinic.
Michelle will explain the study to the participants and provide them with an invitation, information sheets, consent form and a copy of the interview prompts. At this point, the potential participant will also be required to sign a permission to be contacted form which allows the nurse and research student to telephone a few days later.

The potential participant will be given two days to contemplate participating. The lead nurse will telephone the potential participant to take verbal consent to participate, should they wish to take part.
If the participant agrees to take part, their contact details will be passed on to the research student who will telephone to answer any questions and arrange data collection.

Written consent will be obtained by the research student on the day of data collection. The research student has completed "taking informed consent" training (January 2018).

The senior staff members will be provided with a file that contains instructions for taking consent, consent to be contacted forms, invitations, information documents, blank consent forms and the interview prompts.
Memory clinics are outpatient appointments, the patient may not return to the clinic for another six months; therefore the research nurse will have to telephone the participant to get verbal consent to participate.

All staff within the participating memory clinics are aware of the study as the research student has attended meetings to present the project.

This process has been approved by both [redacted] and [redacted]

If a patient of the memory clinics hears about the study (for example, from a friend whilst sitting in the waiting room, but not from the lead nurse) and wants to participate so telephones the research student, the research student will refer the person back to the lead nurse who will be able to assess suitability based on inclusion criteria.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ● No

Please give details below:
Potential participants will be identified based on their attendance to follow up clinic at the older persons' memory clinic. The staff will assess whether the participant meets the inclusion criteria i.e. being aware of their diagnosis and able to give full informed consent.
As senior nurses, understanding full informed consent is a part of their day to day work role.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

○ Yes ● No

A29. How and by whom will potential participants first be approached?

Potential participants will first be approached by the lead nurse for the memory clinic they attend.

A30-1. Will you obtain informed consent from or on behalf of research participants?

● Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

People with dementia are considered a vulnerable group. To ensure their consent is voluntary and fully informed, they will have the study explained verbally by the lead nurse and on paper (information sheet). They will then be given the opportunity to ask any questions, provided with the study documentation and asked to sign a permission to be contacted form. Potential participants will be given 2 days to consider taking part.
After this, they will be telephoned by the lead nurse and asked if they have any more questions and do they want to partake. If they say yes, the nurse will pass their contact details on to the research student who will telephone the participant to arrange data collection. On the day of data collection, the research student will also obtain written consent from the participant.

As previously mentioned, the participant's capacity to consent will be assessed throughout and process consent will be used. The research student will assess ongoing capacity using the principles outlined in the Mental Capacity Act (2005); the participant must be able to understand the information relevant to the study, retain the information, use the information to make their decision on whether to participant/continue participating and can clearly communicate their decision to proceed with data collection.
If the participant is experiencing a temporarily loss of capacity (i.e. a water infection), the research student will re-arrange for a later date. This loss of capacity will be recorded within the site file.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

● Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

As some of the participants will have dementia, they will be given two days to decide about participating in the study.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

All of the participants will receive verbal and written information about the study.
The documentation for people with dementia has been altered, in accordance with the Dementia Enablement and Engagement Project (2017) and has been validated by people with dementia to ensure maximum understanding from people with dementia.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

All of the research documents will be available in welsh upon request.

The research student does not speak fluent Welsh. If a participant requests data collection be conducted in Welsh, the research team will request a nurse from within the health board be present at data collection to translate what is said between research student and participant. All efforts will be made to include a participant requesting data collection in Welsh.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

● The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Unfortunately, dementia is a progressive disease that can, in some cases, cause rapid deterioration.

If a participant is able to give informed consent at the time of data collection and able to edit their digital story, their narrative will remain in the study until PhD completion.

The research student will assess fluctuating capacity at every meeting with the participant. If the participant has a temporary loss of capacity (caused by an infection, tiredness, time of day, etc), the research student will rearrange data collection. The research student will assess ongoing capacity using the principles outlined in the Mental Capacity Act (2005); the participant must be able to understand the information relevant to the study, retain the information, use the information to make their decision on whether to participant/continue participating and can clearly communicate their decision to proceed with data collection.

Where possible, the research student will aim to conduct data collection within the participants "golden hour" where their capacity is at its highest for the day.

The research student will aim to complete all study related tasks (written informed consent, data collection and digital story editing) with the participant within a month of the participant initially being approached by the lead nurse within the memory clinic.

If a participant loses capacity after data collection, it reinforces the importance of the video recordings to show the "person behind the dementia".

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team

☐ Access to social care records by those outside the direct social care team

☐ Electronic transfer by magnetic or optical media, email or computer networks

☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers

☑ Publication of direct quotations from respondents

☑ Publication of data that might allow identification of individuals

☑ Use of audio/visual recording devices

☑ Storage of personal data on any of the following:

  ☑ Manual files (includes paper or film)

  ☐ NHS computers

  ☐ Social Care Service computers

  ☐ Home or other personal computers

  ☑ University computers

  ☐ Private company computers

  ☐ Laptop computers

Further details:
Participants in this study will be video recorded. The research team consider video recordings as vitally important in digital story work research with people who have dementia as it adds to the uniqueness of their stories and tailors it specifically to the person providing the narrative. Digital life stories has been found to engage the imagination of the listener more effectively than words on a page (Mitchell, 2006).

Participants will be required to consent to their videos being used in defence of the research student's final PhD examination whereby only the two appointed examiners will be shown the videos, on university property.
Written versions of the participant's stories will be anonymised with all identifiable information being removed within the appendices of the final PhD thesis.
When reporting the findings from this study within the PhD thesis, journal articles and conferences, direct quotations from the participant's stories will be used. Again, these will be anonymised with all identifiable information being removed.

As previously mentioned, allowing the participants to edit their digital stories will give them a sense of pride and ownership (McKeown et al., 2010). The participants will be able to withdraw their stories from the study at any time.

The videos and transcripts will be stored on a password protected computer within the University of South Wales. This computer is situated within an office that has an electronically locked door, only accessible to those with an authorised ID card. The transcripts will be printed off and returned to the participants for editing; once returned to the research student, these edited transcripts will be stored in a lockable drawer within the office described above to which only the research student has a key. After the PhD thesis has been written, any paper copies of the transcripts will be destroyed.

A37. Please describe the physical security arrangements for storage of personal data during the study?

All personal data will be stored within the University of South Wales. The research student has an office with an electronically locking door that only authorised personnel have access to. All electronic files will be stored on a password protected computer. All physical files (e.g. transcripts and consent forms) will be stored within locked drawers that only the research student has a key to.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Possible participants will not be known to the research team until they give verbal consent to the lead nurse from the memory clinic after two days of considering participation in the study.
After this verbal consent has been obtained, the participant will become known to the research student.
After data collection, this participant will become known to the whole research team.
As previously mentioned, the participants video will only be shown to the two appointed PhD examiners in defence of the research student's PhD thesis. For all written outputs (i.e. the written PhD thesis, journal articles and conferences), direct quotations will be used. Any identifiable information within these quotes will be anonymised. Pseudo names will

be used throughout.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Participant's personal data will be known to the research student who will anonymise identifiable information and use pseudo names within the PhD thesis, journal articles and conferences. Where direct quotations are being used, the research student will anonymise any identifiable information within these.

The participant's video will be used, in defence of the thesis, at PhD VIVA examination where only the 2 appointed examiners will view the videos, on university property with the research student present.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

Data will be analysed by Alex Walker (Research student) in her lockable office at University of South Wales.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Miss	Alex	Walker
Post	Research Student		
Qualifications	PhD Student MSc Clinical and Abnormal Psychology BSc Psychology		
Work Address	AB034 Lower Glyntaff Campus University of South Wales Treforest		
Post Code	CF37 4BE		
Work Email	alex.walker@southwales.ac.uk		
Work Telephone	07760821292		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ● 6 – 12 months
- ○ 12 months – 3 years
- ○ Over 3 years

A44. For how long will you store research data generated by the study?

Years: 5
Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say* *where data will be stored, who will have access and the arrangements to ensure security.*

Research data will be stored by the Director of Studies (Dr Anne Fothergill) once the study has ended as the research student may no longer be at University of South Wales upon completion of the PhD.
Dr Fothergill will be the only person with access to the data. All electronic data will be stored on a password protected computer. Paper based data will be kept in a locked drawer within a locked office to which only Dr Fothergill has a key.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

● Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
At the end of the study, participants will be given a copy of their edited digital life stories on DVD.
The DVDs could also hold sentimental value for the participant's family (Benbow and Kingston, 2016)

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ● No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ● No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ● No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

● Yes ○ No

Please give details, or justify if not registering the research.
This study will be on the Health and Care Research Wales Clinical Research Portfolio.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals

☑ Internal report

☑ Conference presentation

☑ Publication on website

☐ Other publication

☐ Submission to regulatory authorities

☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☑ Other (please specify)

This study will be written up as a PhD thesis for the student to obtain their qualification.
Results will be disseminated through academic journals, conferences and a report for both participating health boards.

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Identifiable personal data will not be used when publishing the results of this study. All identifiable personal data will be anonymised by the research student.

A53. Will you inform participants of the results?

● Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be provided with contact information on the information sheets to request a copy of the results of the study should they wish.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☑ Independent external review

☑ Review within a company

☐ Review within a multi−centre research group

☑ Review within the Chief Investigator's institution or host organisation

☑ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
This is a KESS 2 project which has been reviewed and approved by the supervision team, University of South Wales graduate research office, Bangor University, KESS 2, [redacted] and has recently been reviewed by an external examiner from Bradford University for transfer viva purposes.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in* *total? If there is more than one group, please give further details below.*

Total UK sample size:	30
Total international sample size (including UK):	
Total in European Economic Area:	

Further details:
An estimated 15 people with dementia and 15 family members will be recruited for this study

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Based on the uptake from the initial year long study whereby 7 participants were recruited through residential homes, it was felt that 30 was a suitable goal for recruiting via memory clinics where participants would not be so far advanced with their dementia. As this is a life story work study, there will be a wealth of information to be analysed within the remaining two years of this PhD. Therefore, it was decided that 30 would be a reasonable recruitment goal.
This figure was approved by USW, [redacted] and [redacted]

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

This is a qualitative, descriptive phenomenology study therefore, an appropriate descriptive phenomenology analysis will be chosen. As it is still early days, it is estimated that the analysis type will be Colaizzi's (1979) descriptive phenomenology framework. This consists of 6 steps:

1. Reading and rereading the descriptions of the phenomenon
2. Extracting statements of significance
3. Formulating meanings
4. Identify themes
5. Describe the phenomenon
6. Refine the description of the phenomenon

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Mr	[redacted]	[redacted]

Post	Clinical Advisor (Senior Nurse Older Persons Services)
Qualifications	Bachelor of Nursing Mental Health MSc Module Independent Prescribing
Employer	[redacted]
Work Address	[redacted] [redacted]
Post Code	[redacted]
Telephone	
Fax	
Mobile	
Work Email	[redacted]

	Title	Forename/Initials	Surname
	Mrs	[redacted]	[redacted]

Post	Clinical Advisor (Lead Nurse Dementia)
Qualifications	RCM (Mental Health Nurse), Diploma in Community Practice, MSc in Professional Practice (Mental Health)
Employer	[redacted]
Work Address	[redacted] [redacted]
Post Code	[redacted]
Telephone	
Fax	
Mobile	
Work Email	[redacted]

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
○ NHS or HSC care organisation
● Academic
○ Pharmaceutical industry
○ Medical device industry
○ Local Authority
○ Other social care provider (including voluntary sector or private organisation)
○ Other

If Other, please specify:

Commercial status: Non-Commercial

Contact person

Name of organisation	University of South Wales
Given name	Louise
Family name	Bright
Address	Research and Business Engagement Department
Town/city	Treforest
Post code	CF37 1DL
Country	UNITED KINGDOM
Telephone	01443482011
Fax	
E-mail	louise.bright@southwales.ac.uk

A65. Has external funding for the research been secured?

Please tick at least one check box.

☑ Funding secured from one or more funders

☐ External funding application to one or more funders in progress

☐ No application for external funding will be made

What type of research project is this?

○ Standalone project

○ Project that is part of a programme grant

○ Project that is part of a Centre grant

● Project that is part of a fellowship/ personal award/ research training award

○ Other

Other – please state:

Please give details of funding applications.

Organisation	Knowledge Economy Skills Scholarship (KESS)
Address	University of South Wales 8 Forest Grove Treforest
Post Code	CF37 1DL
Telephone	
Fax	
Mobile	
Email	kess@southwales.ac.uk

Funding Application Status: ● Secured ○ In progress

Amount:

Duration
Years: 2
Months:

If applicable, please specify the programme/ funding stream:

What is the funding stream/ programme for this research project?
European Social Fund via the Welsh Government

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes ● No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ● No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Prof	J[redacted]	[redacted]

Organisation Director of Research and Development
Address Research and Development Department
[redacted]
[redacted]
Post Code [redacted]
Work Email [redacted]
Telephone [redacted]
Fax [redacted]
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/04/2019
Planned end date: 31/07/2020
Total duration:
Years: 1 Months: 3 Days: 31

A71-1. Is this study?

○ Single centre
● Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?
○ Yes ● No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☐ NHS organisations in England
☑ NHS organisations in Wales 2

☐ NHS organisations in Scotland
☐ HSC organisations in Northern Ireland
☐ GP practices in England
☐ GP practices in Wales
☐ GP practices in Scotland
☐ GP practices in Northern Ireland
☐ Joint health and social care agencies (eg community mental health teams)
☐ Local authorities
☐ Phase 1 trial units
☐ Prison establishments
☐ Probation areas
☐ Independent (private or voluntary sector) organisations
☐ Educational establishments
☐ Independent research units
☐ Other (give details)

Total UK sites in study: 2

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

○ Yes ● No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

This study will meet USW protocols for evaluating quality of work produced.
Research is approved and monitored by USW FRPC. Student progress is monitored and reports are completed 4 monthly (KESS) and 6 monthly (USW GRO).
Weekly supervisions with the Director of Studies. Meetings with the supervision team are monthly. The steering committee will meet two-monthly throughout the study to monitor and discuss progress. All meeting notes are available to view on request.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:** in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

University of South Wales indemnity scheme will cover the study.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

The University of South Wales insurance policy will provide the cover for this study

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ● No ○ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For further information please refer to guidance.*

Investigator identifier	Research site		Investigator Name	
IN1	● NHS/HSC Site ○ Non-NHS/HSC Site			
			Forename	[redacted]
			Middle name	[redacted]
			Family name	[redacted]
			Email	[redacted]
	Organisation name	[redacted]	Qualification (MD...)	Bachelor of nursing mental health 2007 Msc module independent prescribing 2012
	Address	[redacted]	Country	UNITED KINGDOM
	Post Code	[redacted]		
	Country	WALES		
IN2	● NHS/HSC Site ○ Non-NHS/HSC Site			
			Forename	[redacted]
			Middle name	
			Family name	[redacted]
			Email	[redacted]
	Organisation name	[redacted]	Qualification (MD...)	Diploma in Community Practice, MSc in Professional Practice (Mental Health)
	Address	[redacted]	Country	UNITED KINGDOM
	Post Code	[redacted]		
	Country	WALES		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to fulfil the responsibilities of the chief investigator for this study as set out in the UK Policy Framework for Health and Social Care Research.
3. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
4. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
5. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
6. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
7. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
8. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
9. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 2018.
10. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.
11. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 2018.
12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the Health Research Authority (HRA) together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after the issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

HRA would like to include a contact point with the published summary of the study for those wishing to seek further *information. We would be grateful if you would indicate one of the contact points below.*

● Chief Investigator
○ Sponsor
○ Study co-ordinator
○ Student
○ Other – please give details
○ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Alex Walker on 16/10/2019 19:18.

Job Title/Post:	PhD student
Organisation:	University of South Wales
Email:	alex.walker@southwales.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The responsibilities of sponsors set out in the UK Policy Framework for Health and Social Care Research will be fulfilled in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Dr Louise Bright on 17/10/2019 08:46.

Job Title/Post:	Director, Research and Busienss Engagement
Organisation:	USW
Email:	louise.bright@southwales.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the UK Policy Framework for Health and Social Care Research.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Rachel Iredale on 17/10/2019 09:32.

Job Title/Post:	Associate Professor
Organisation:	USW
Email:	Rachel.Iredale@southwales.ac.uk

Academic supervisor 2

This section was signed electronically by dr Nicky Genders on 17/10/2019 11:10.

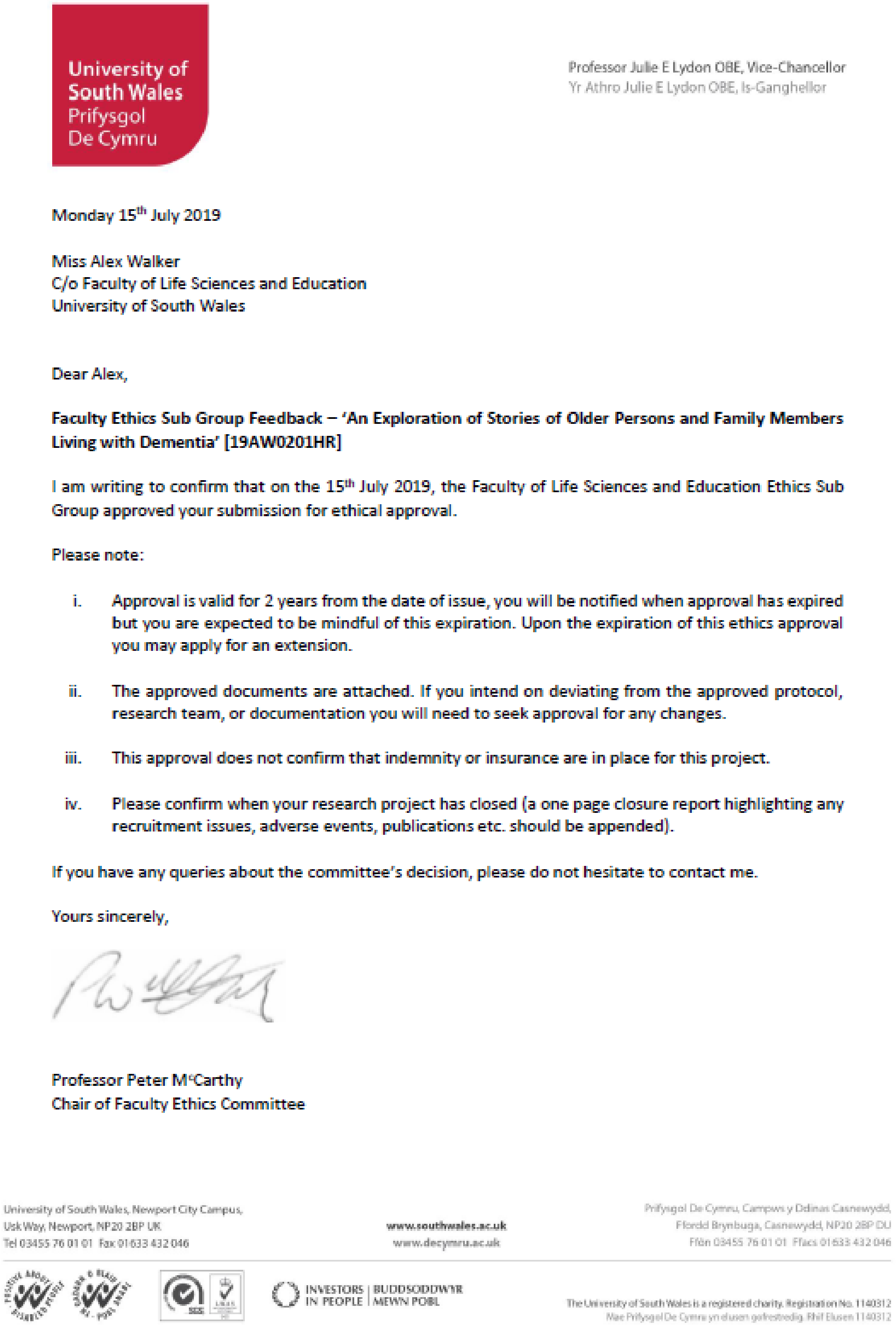
Job Title/Post:	Head of School/Supervisor
Organisation:	University of south wales
Email:	nicky.genders@southwales.ac.uk

Academic supervisor 3

This section was signed electronically by Dr Anne Fothergill on 17/10/2019 07:40.

Job Title/Post:	Principal Lecturer
Organisation:	University of South Wales
Email:	

L: 2nd USW ethical approval certificate



University of South Wales
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De Cymru

Professor Julie E Lydon OBE, Vice-Chancellor
Yr Athro Julie E Lydon OBE, Is-Ganghellor

Monday 15th July 2019

Miss Alex Walker
C/o Faculty of Life Sciences and Education
University of South Wales

Dear Alex,

Faculty Ethics Sub Group Feedback – 'An Exploration of Stories of Older Persons and Family Members Living with Dementia' [19AW0201HR]

I am writing to confirm that on the 15th July 2019, the Faculty of Life Sciences and Education Ethics Sub Group approved your submission for ethical approval.

Please note:

i. Approval is valid for 2 years from the date of issue, you will be notified when approval has expired but you are expected to be mindful of this expiration. Upon the expiration of this ethics approval you may apply for an extension.

ii. The approved documents are attached. If you intend on deviating from the approved protocol, research team, or documentation you will need to seek approval for any changes.

iii. This approval does not confirm that indemnity or insurance are in place for this project.

iv. Please confirm when your research project has closed (a one page closure report highlighting any recruitment issues, adverse events, publications etc. should be appended).

If you have any queries about the committee's decision, please do not hesitate to contact me.

Yours sincerely,

Professor Peter McCarthy
Chair of Faculty Ethics Committee

University of South Wales, Newport City Campus,
Usk Way, Newport, NP20 2BP UK
Tel 03455 76 01 01 Fax 01633 432 046

www.southwales.ac.uk
www.decymru.ac.uk

Prifysgol De Cymru, Campws y Ddinas Casnewydd,
Ffordd Brynbuga, Casnewydd, NP20 2BP DU
Ffôn 03455 76 01 01 Ffacs 01633 432 046

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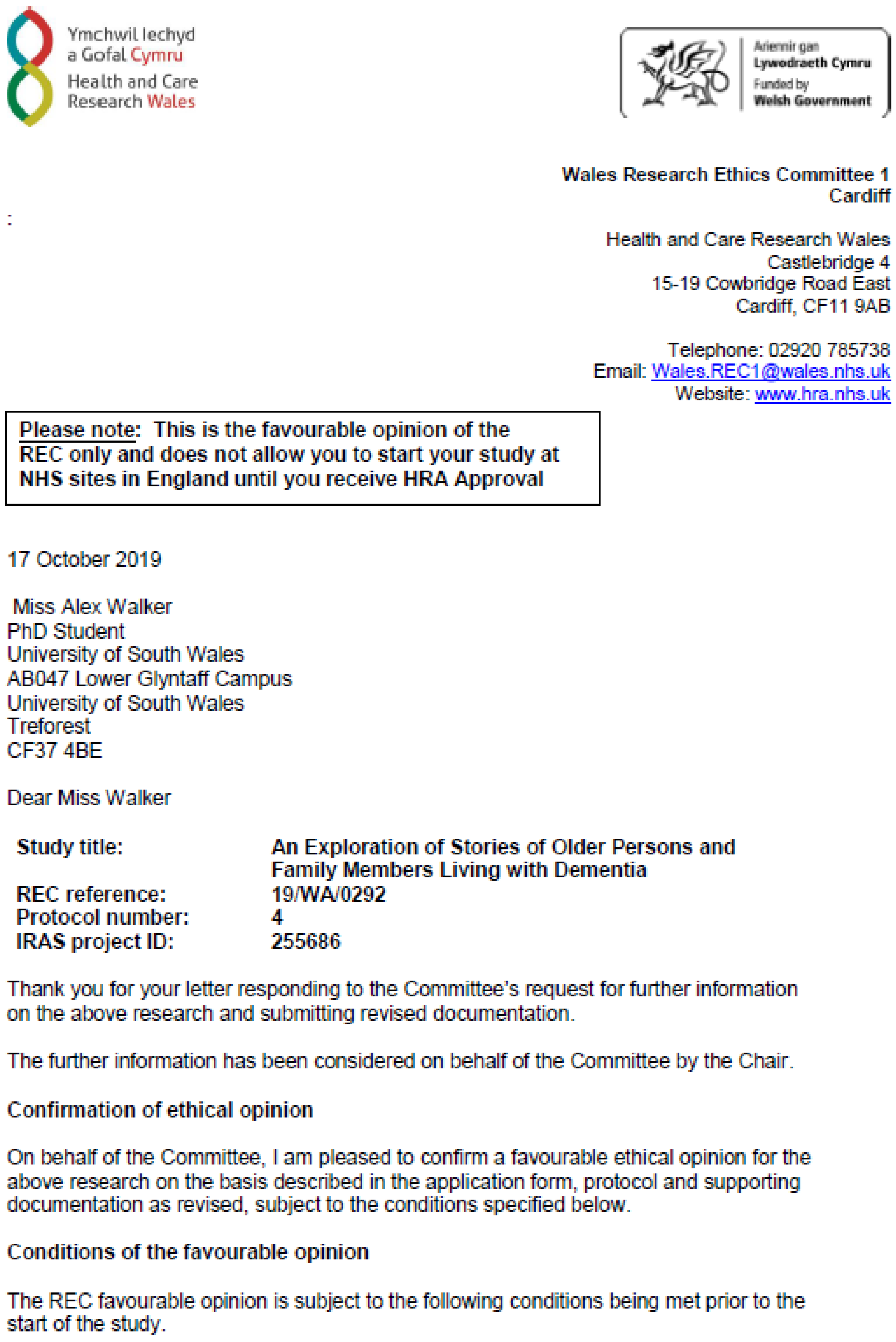
Mae Prifysgol De Cymru yn elusen gofrestredig. Rhif Elusen 1140312

M: Favourable opinion letter from REC



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Ariennir gan Llywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 1
Cardiff

Health and Care Research Wales
Castlebridge 4
15-19 Cowbridge Road East
Cardiff, CF11 9AB

Telephone: 02920 785738
Email: Wales.REC1@wales.nhs.uk
Website: www.hra.nhs.uk

:

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

17 October 2019

Miss Alex Walker
PhD Student
University of South Wales
AB047 Lower Glyntaff Campus
University of South Wales
Treforest
CF37 4BE

Dear Miss Walker

Study title:	**An Exploration of Stories of Older Persons and Family Members Living with Dementia**
REC reference:	**19/WA/0292**
Protocol number:	**4**
IRAS project ID:	**255686**

Thank you for your letter responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports

- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Covering letter]	n/a	Undated
Covering letter on headed paper [Covering letter]	n/a	12 September 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [USW Indemnity Insurance]	1	16 July 2019
Interview schedules or topic guides for participants [Person with Dementia Interview Prompt]	1	08 January 2019
Interview schedules or topic guides for participants [Family Member Interview Prompts]	1	08 January 2019
IRAS Application Form [IRAS_Form_17102019]	n/a	17 October 2019
IRAS Checklist XML [Checklist_16092019]	n/a	16 September 2019
IRAS Checklist XML [Checklist_17102019]	n/a	17 October 2019
Letter from funder [Letter from Funder]	n/a	14 August 2018
Letter from sponsor [USW Sponsor Letter]	n/a	04 December 2018
Letters of invitation to participant [Person with Dementia Invitation]	2	19 March 2019
Letters of invitation to participant [Invitation for Family Member]	2	19 March 2019
Other [Good Clinical Practice Certificate_A Walker]	1	24 November 2017
Other [Valid Informed Consent in Research Certificate_ A Walker]	1	11 January 2018
Other [Person with Dementia debrief sheet]	3	10 September 2019
Other [Family member Debfrief sheet]	3	10 September 2019
Other [Permission to be contacted form]	2	19 March 2019
Other [Informed Consent with Adults Lacking Capacity Certificate_A Walker]	1	07 December 2017
Other [GCP refresher certificate_A Walker]	n/a	23 August 2019
Other [MRes_PhDS Project Conversion Proposal Form]	n/a	25 July 2018
Other [Dr Gender's CV]	n/a	01 July 2019
Other [Dr Iredale CV]	n/a	01 July 2019
Other [REC 1 unfavourable opinion letter]	n/a	06 September 2019
Other [Confirmation of CI]	n/a	16 October 2019
Other [REC1 feedback and responses]	1	14 October 2019

Other [KESS MRes-PhD Project Conversion Proposal Form]	n/a	23 November 2018
Participant consent form [Person with dementia consent form]	7	15 October 2019
Participant consent form [Family member consent form]	7	15 October 2019
Participant information sheet (PIS) [Person with dementia information sheet]	7	15 October 2019
Participant information sheet (PIS) [Family member information sheet]	7	15 October 2019
Research protocol or project proposal [Protocol]	4	10 September 2019
Summary CV for Chief Investigator (CI) [Research Student & CI CV]	n/a	01 July 2019
Summary CV for supervisor (student research) [Dr Fothergill CV]	n/a	01 July 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/WA/0292	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

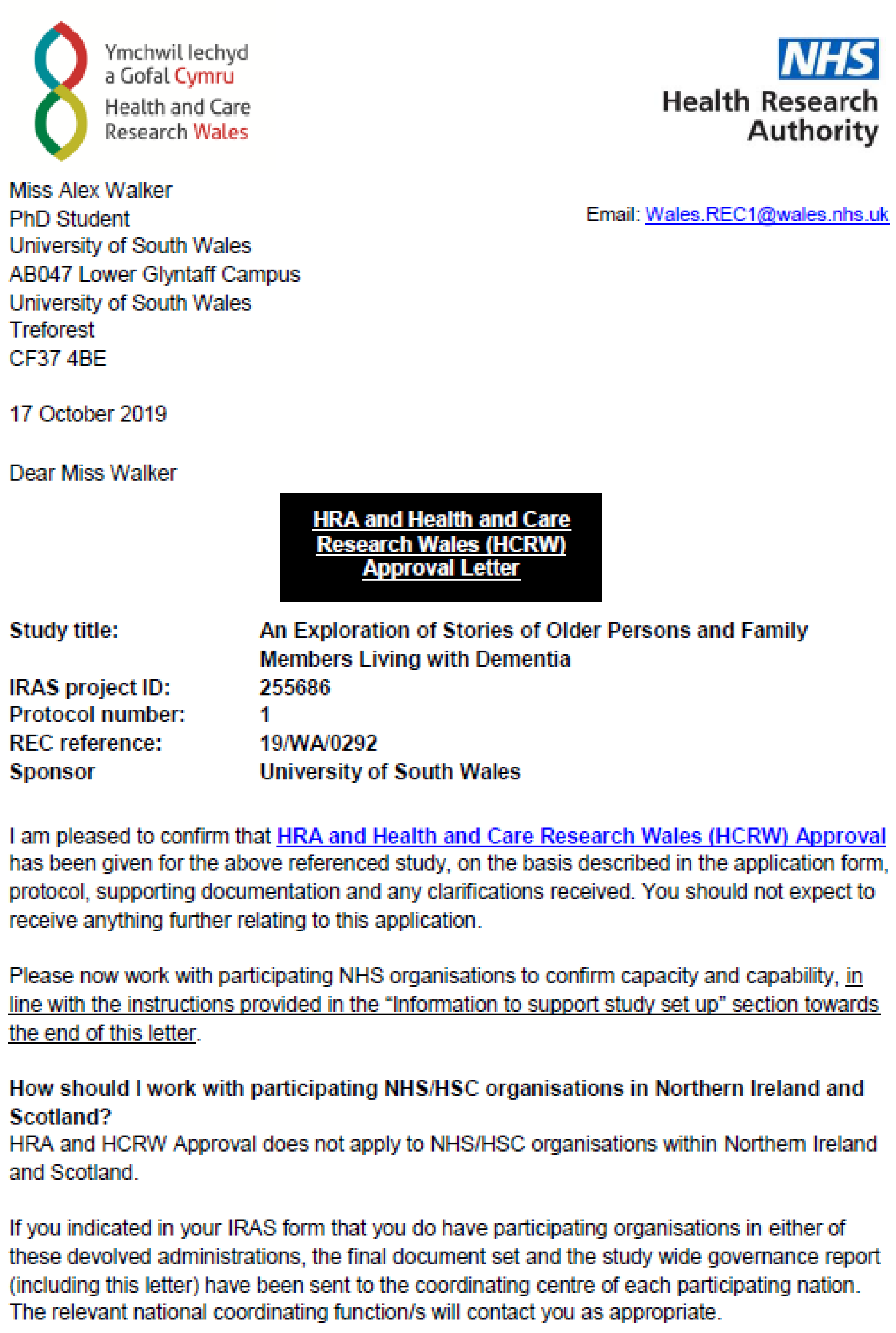
Yours sincerely

Carl Phillips
pp
Dr Kathrine J Craig
Chair

Email:Wales.REC1@wales.nhs.uk

Copy to: Dr Anne Fothergill

N: Approval letter from HRA and HCRW



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Alex Walker
PhD Student
University of South Wales
AB047 Lower Glyntaff Campus
University of South Wales
Treforest
CF37 4BE

Email: Wales.REC1@wales.nhs.uk

17 October 2019

Dear Miss Walker

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **An Exploration of Stories of Older Persons and Family Members Living with Dementia**
IRAS project ID: **255686**
Protocol number: **1**
REC reference: **19/WA/0292**
Sponsor **University of South Wales**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **255686**. Please quote this on all correspondence.

Yours sincerely,

Carl Phillips

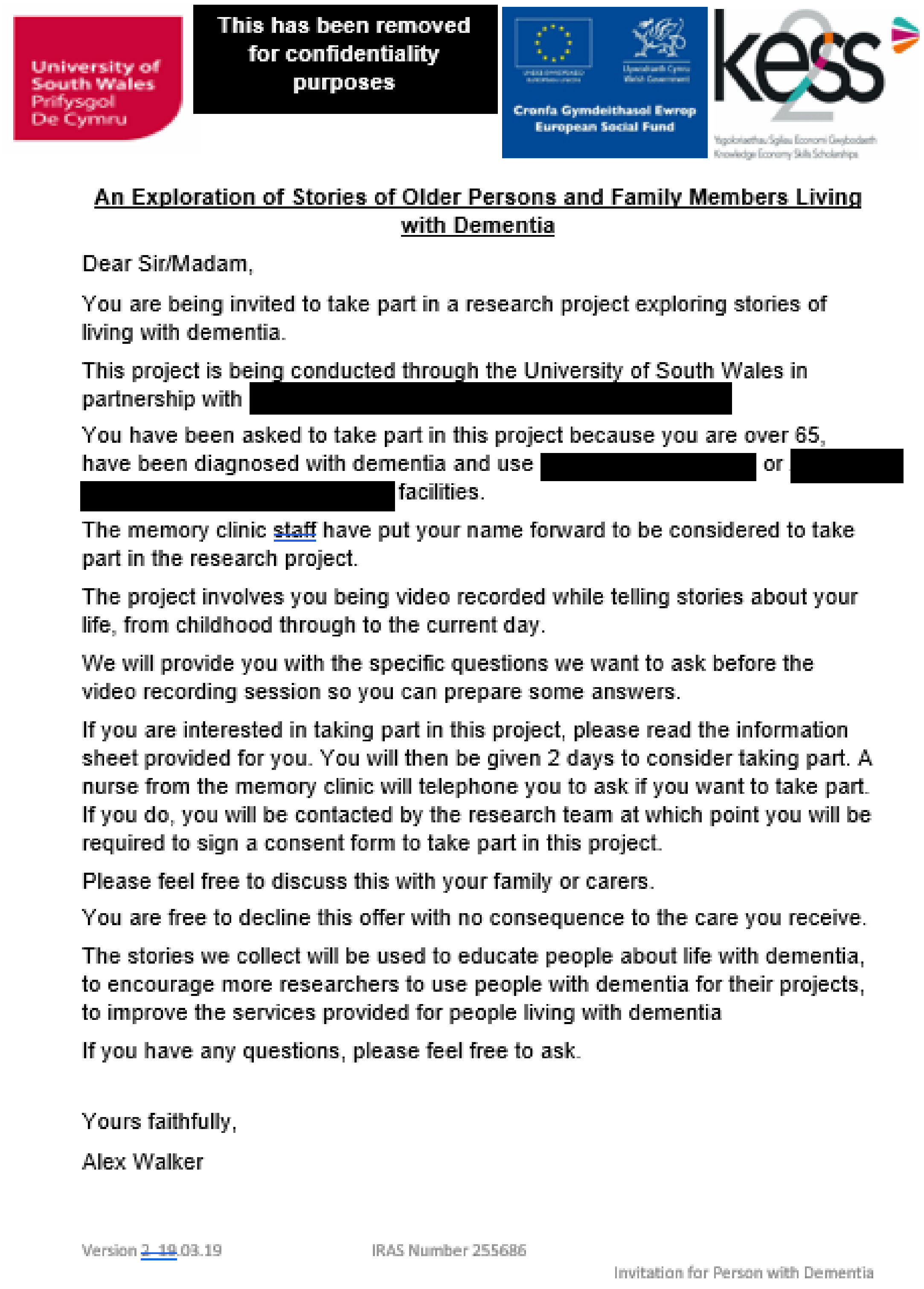
Carl Phillips
Approvals Specialist

Email: Wales.REC1@wales.nhs.uk

Copy to: *Dr Anne Fothergill*

O: Participant with dementia information pack

O.1 Invitation



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Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

An Exploration of Stories of Older Persons and Family Members Living with Dementia

Dear Sir/Madam,

You are being invited to take part in a research project exploring stories of living with dementia.

This project is being conducted through the University of South Wales in partnership with [redacted]

You have been asked to take part in this project because you are over 65, have been diagnosed with dementia and use [redacted] or [redacted] [redacted] facilities.

The memory clinic staff have put your name forward to be considered to take part in the research project.

The project involves you being video recorded while telling stories about your life, from childhood through to the current day.

We will provide you with the specific questions we want to ask before the video recording session so you can prepare some answers.

If you are interested in taking part in this project, please read the information sheet provided for you. You will then be given 2 days to consider taking part. A nurse from the memory clinic will telephone you to ask if you want to take part. If you do, you will be contacted by the research team at which point you will be required to sign a consent form to take part in this project.

Please feel free to discuss this with your family or carers.

You are free to decline this offer with no consequence to the care you receive.

The stories we collect will be used to educate people about life with dementia, to encourage more researchers to use people with dementia for their projects, to improve the services provided for people living with dementia

If you have any questions, please feel free to ask.

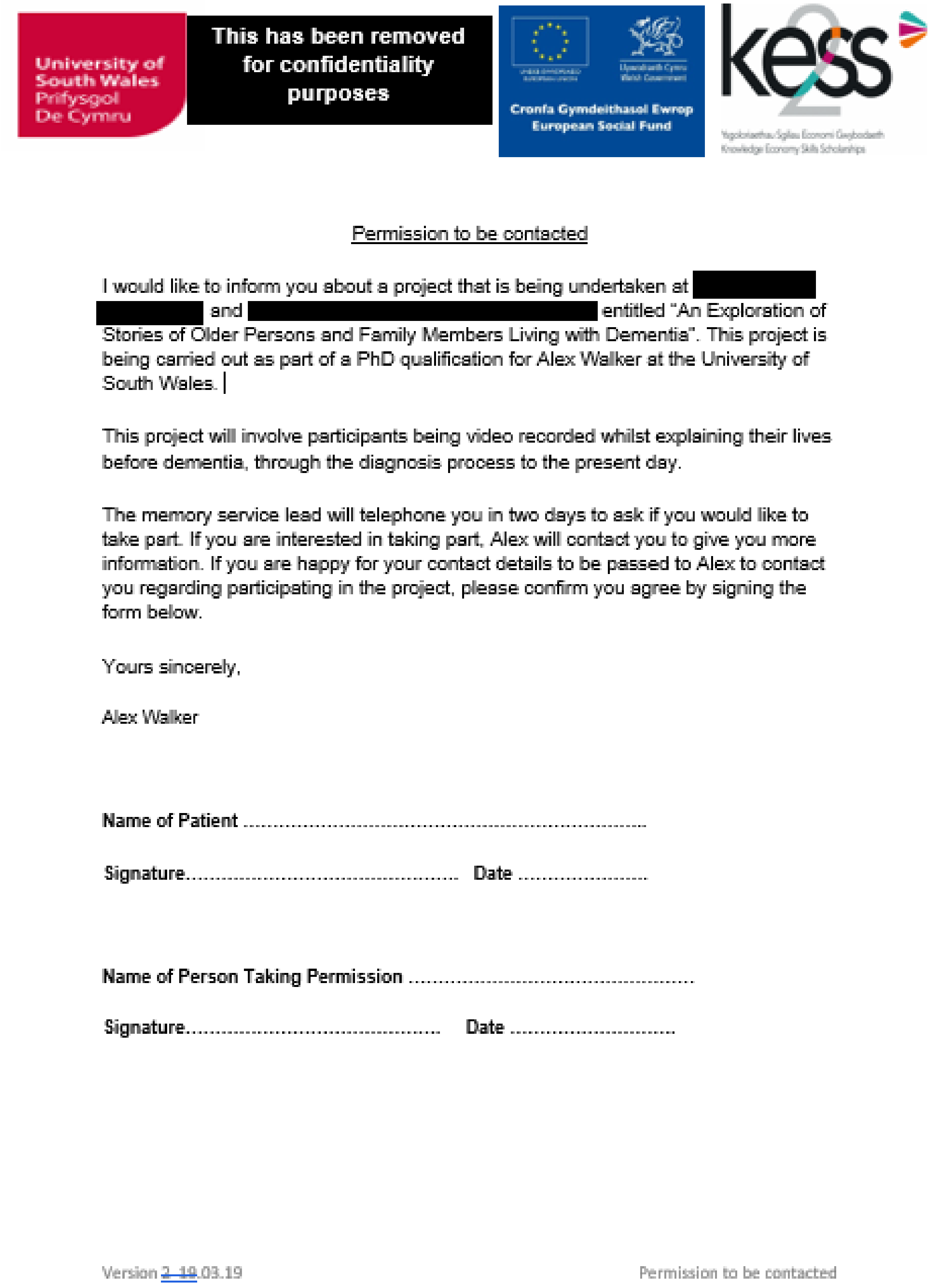
Yours faithfully,

Alex Walker

Version 2 19.03.19 IRAS Number 255686

Invitation for Person with Dementia

O.2 Permission to be contacted



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Knowledge Economy Skills Scholarships

Permission to be contacted

I would like to inform you about a project that is being undertaken at [redacted] [redacted] and [redacted] entitled "An Exploration of Stories of Older Persons and Family Members Living with Dementia". This project is being carried out as part of a PhD qualification for Alex Walker at the University of South Wales.

This project will involve participants being video recorded whilst explaining their lives before dementia, through the diagnosis process to the present day.

The memory service lead will telephone you in two days to ask if you would like to take part. If you are interested in taking part, Alex will contact you to give you more information. If you are happy for your contact details to be passed to Alex to contact you regarding participating in the project, please confirm you agree by signing the form below.

Yours sincerely,

Alex Walker

Name of Patient ……………………………………………………………………

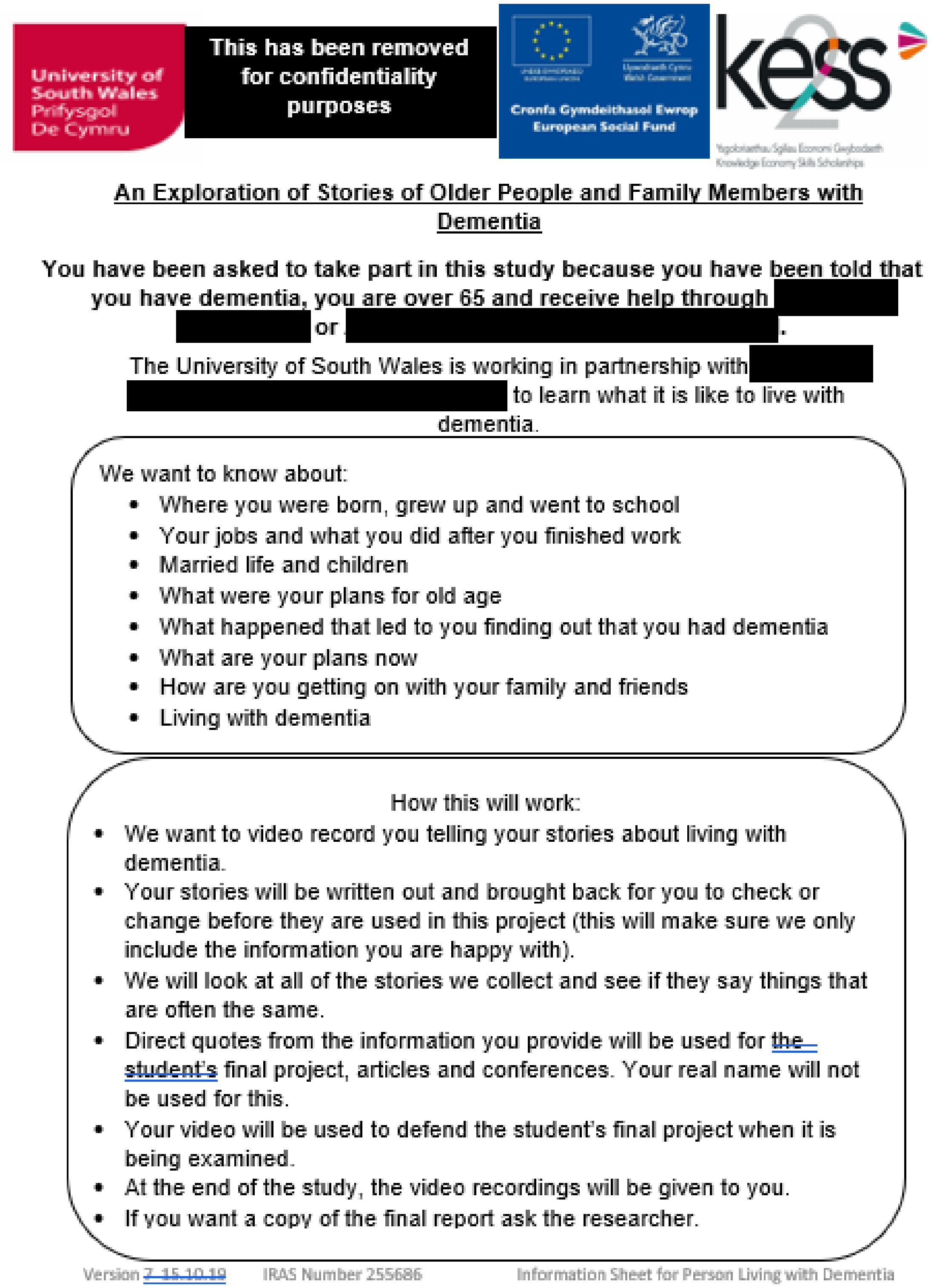
Signature…………………………………………… **Date** ……………………

Name of Person Taking Permission ……………………………………………

Signature………………………………………… **Date** ………………………

Version ~~2 19~~.03.19 Permission to be contacted

O.3 Information



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kess 2

Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

An Exploration of Stories of Older People and Family Members with Dementia

You have been asked to take part in this study because you have been told that you have dementia, you are over 65 and receive help through [redacted] or [redacted].

The University of South Wales is working in partnership with [redacted] to learn what it is like to live with dementia.

We want to know about:

- Where you were born, grew up and went to school
- Your jobs and what you did after you finished work
- Married life and children
- What were your plans for old age
- What happened that led to you finding out that you had dementia
- What are your plans now
- How are you getting on with your family and friends
- Living with dementia

How this will work:

- We want to video record you telling your stories about living with dementia.
- Your stories will be written out and brought back for you to check or change before they are used in this project (this will make sure we only include the information you are happy with).
- We will look at all of the stories we collect and see if they say things that are often the same.
- Direct quotes from the information you provide will be used for the student's final project, articles and conferences. Your real name will not be used for this.
- Your video will be used to defend the student's final project when it is being examined.
- At the end of the study, the video recordings will be given to you.
- If you want a copy of the final report ask the researcher.

Version ~~7 15.10.19~~ IRAS Number 255686 Information Sheet for Person Living with Dementia

We want to collect stories from 15 older people living with dementia and 15 family members. You can take part in this study without your family member also participating.

The stories you tell us will be used to:

- Help other people to know about living with dementia
- Let people know the services and help people need to live well with dementia
- Improve the help given by the hospitals

Direct anonymised quotes from the information you provide will be used to write a PhD final thesis, in academic journals and conferences.

You are free to leave this project at any time. If you leave before the end, this will not affect the care you get and there will be no more questions. If you withdraw from the study, all your data and video held by the research team will be deleted. If you withdraw after your video is edited, your edited video will be returned to you. If your video has not yet been edited, your raw video will be returned to you due to time constraints on the research student.

If you get upset when telling your story, you can stop the session or take a break. Special help will be there if you need it.

If you say something offensive about another person, the research student will have to remove it from your story.

Your anonymised data will be kept by the University for 5 years, on a safe computer or in a locked drawer. Only the research team will be able to see it.

An additional copy of your video will be stored by the research team for up to 12 months after the PhD is completed.

The University will copyright your video as the University has intellectual property rights to products made during this PhD. This will protect your video from being used by other people who do not have permission to do so.

Please note:

Because of the way this work is set up, your video will be shown to the examiners for the student's final project, but your real name will not be used.

If you tell us things that break the law or suggest you or others might be hurt, the person you tell has to tell others who must know about it.

This study received favourable ethical approval from University of South Wales (15th July 2019) and Wales Research Ethics Committee 1 (17th October 2019).

For more information, please ask Alex (research student) on 077608 21292.

To complain about the study, please contact

Jonathan Sinfield (Research Governance at the University)

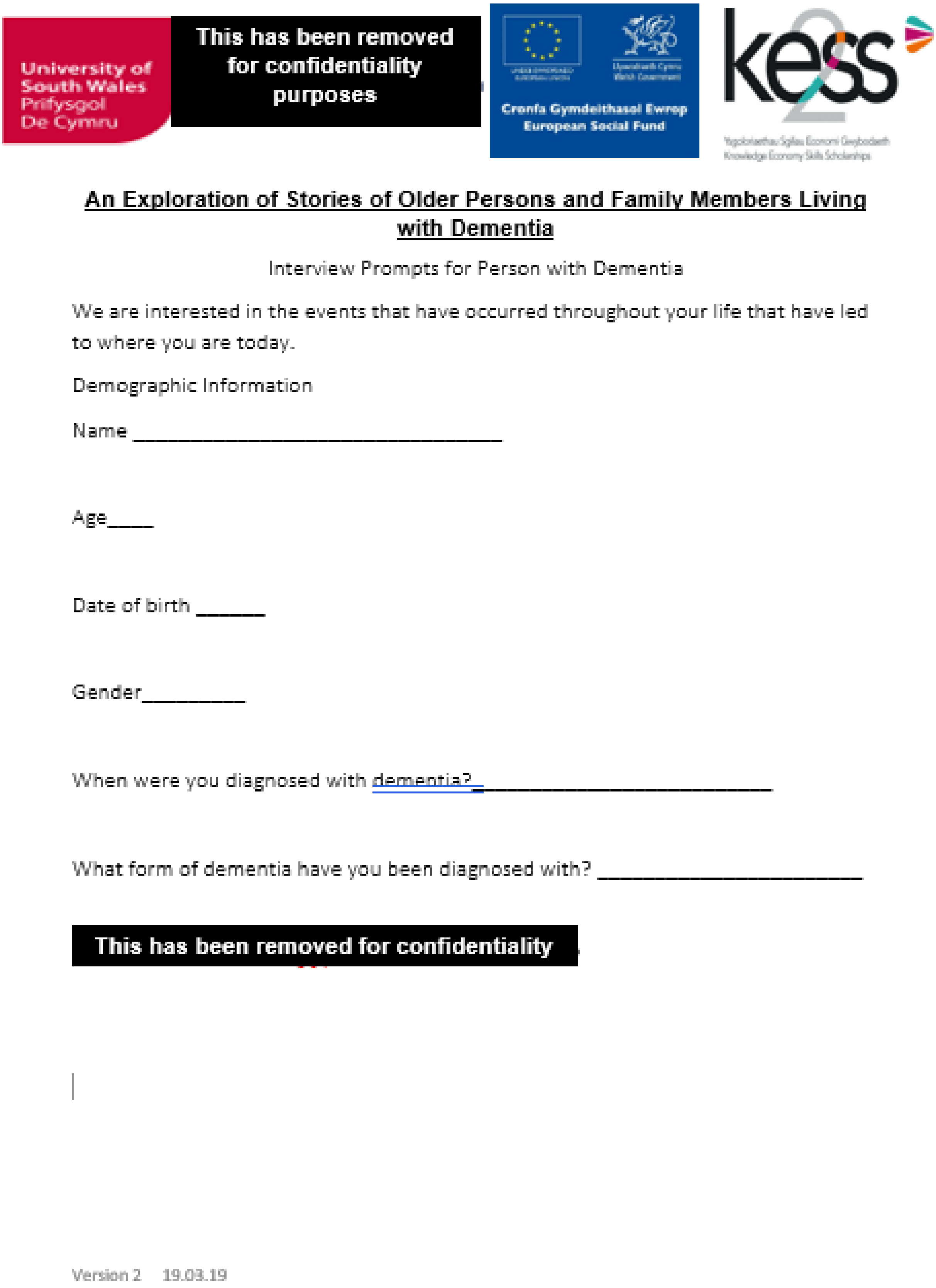
Telephone 01443 484518

Email jonathan.sinfield@southwales.ac.uk

This project is being conducted as part of a PhD qualification funded by University of South Wales, [redacted] and KESS. Knowledge Economy Skills Scholarships (KESS) is a pan-Wales higher level skills initiative led by Bangor University on behalf of the higher education sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys.

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code name instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. You can find out more about how your information is used by asking one of the research team.

O.4 Interview prompts



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European Social Fund

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Knowledge Economy Skills Scholarships

An Exploration of Stories of Older Persons and Family Members Living with Dementia

Interview Prompts for Person with Dementia

We are interested in the events that have occurred throughout your life that have led to where you are today.

Demographic Information

Name ____________________________________

Age____

Date of birth ______

Gender__________

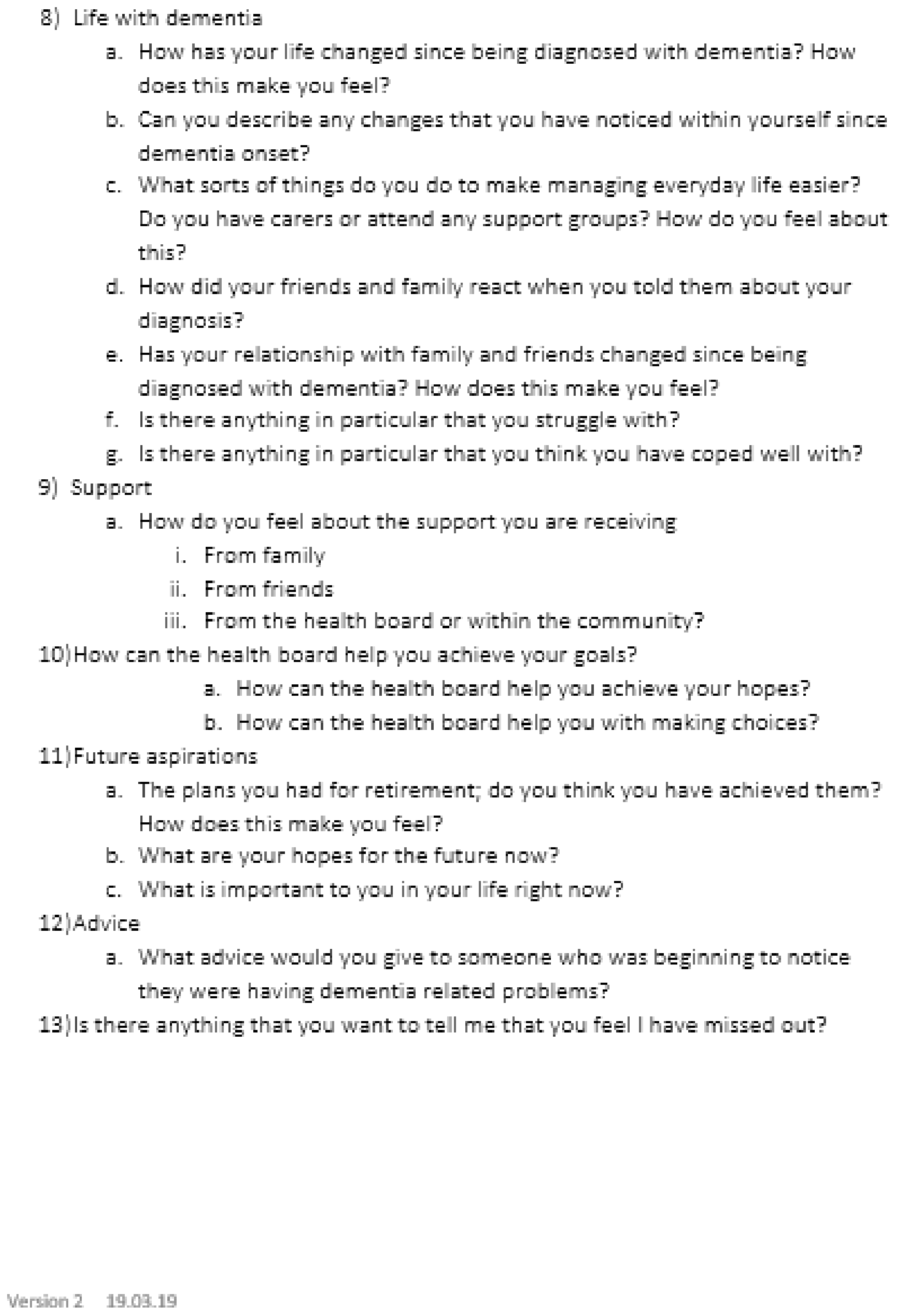
When were you diagnosed with dementia? ____________________________

What form of dementia have you been diagnosed with? __________________________

This has been removed for confidentiality

Version 2 19.03.19

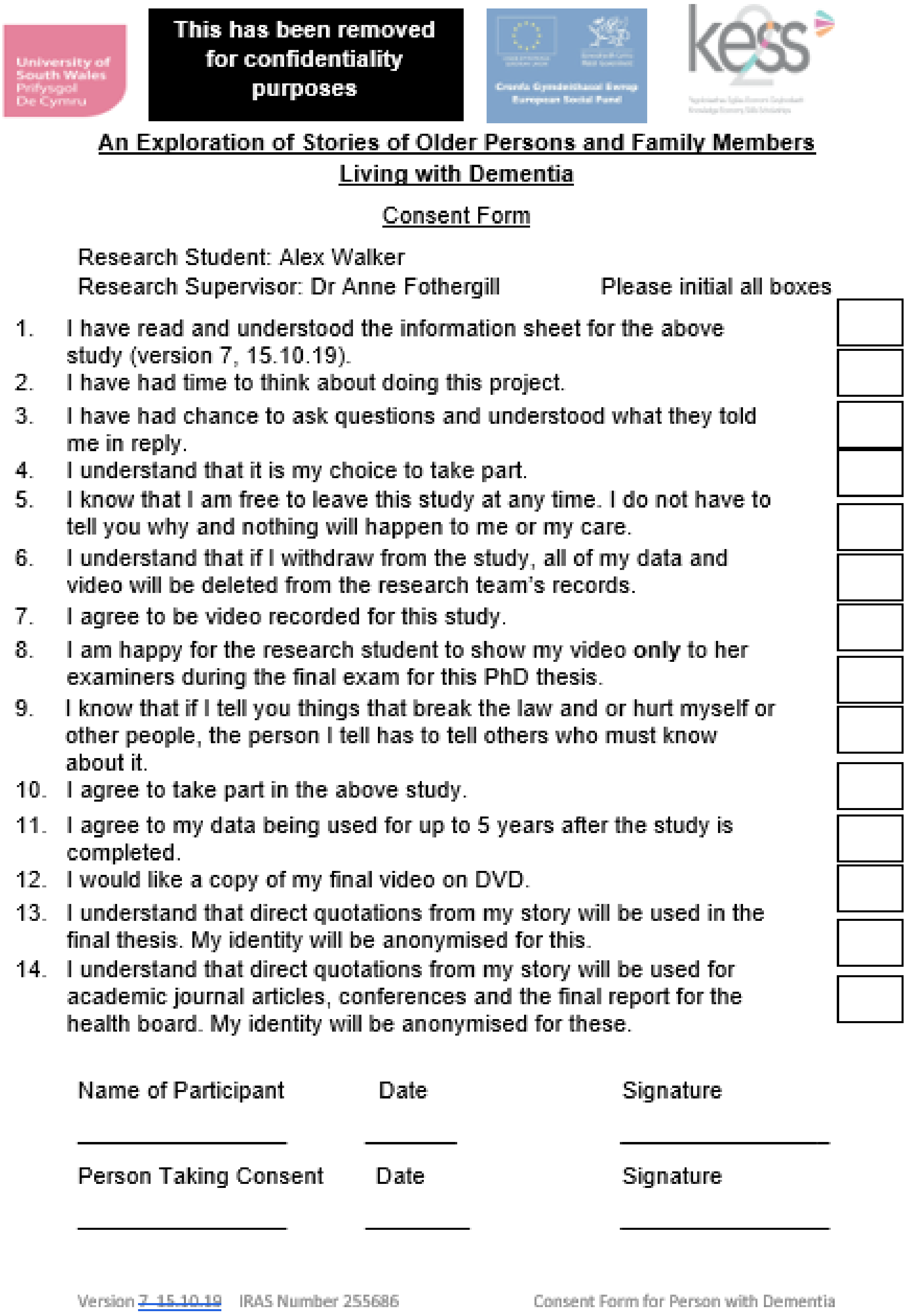
1) Can you tell me a little about your childhood?
    a. Where you were born?
    b. Siblings?
    c. Where you went to school?
    d. What age did you leave school?
    e. Where did you grow up and what was it like?
2) Where have you work throughout your life?
3) Marriage
    a. Where and when did you meet your spouse?
    b. Where/when did you get married?
    c. How long have you been married?
4) Children
    a. Did you have any children?
    b. Were they boys or girls?
    c. How long after getting married did you have children?
5) Retirement
    a. Where were you working before you retired?
    b. How old were you?
    c. Did you retire at the same time as your spouse?
    d. What did you plan to do after retiring?
    e. Hopes for the future
6) Grandchildren
    a. Do you have grandchildren?
    b. How many?
    c. Do you see them often?
7) Start of dementia
    a. When did you start noticing you were having dementia related difficulties?
    b. What sorts of things were you doing that began to raise concerns
        i. For yourself?
        ii. For family/friends?
    c. How did you feel about going to the doctor about it?
    d. How did you feel about being diagnosed with dementia?
    e. How did you find the diagnosis process?
    f. Was there anything of note happening at the time of dementia onset?



8) Life with dementia
    a. How has your life changed since being diagnosed with dementia? How does this make you feel?
    b. Can you describe any changes that you have noticed within yourself since dementia onset?
    c. What sorts of things do you do to make managing everyday life easier? Do you have carers or attend any support groups? How do you feel about this?
    d. How did your friends and family react when you told them about your diagnosis?
    e. Has your relationship with family and friends changed since being diagnosed with dementia? How does this make you feel?
    f. Is there anything in particular that you struggle with?
    g. Is there anything in particular that you think you have coped well with?
9) Support
    a. How do you feel about the support you are receiving
        i. From family
        ii. From friends
        iii. From the health board or within the community?
10) How can the health board help you achieve your goals?
        a. How can the health board help you achieve your hopes?
        b. How can the health board help you with making choices?
11) Future aspirations
    a. The plans you had for retirement; do you think you have achieved them? How does this make you feel?
    b. What are your hopes for the future now?
    c. What is important to you in your life right now?
12) Advice
    a. What advice would you give to someone who was beginning to notice they were having dementia related problems?
13) Is there anything that you want to tell me that you feel I have missed out?

Version 2 19.03.19

O.5 Consent form



University of South Wales
Prifysgol De Cymru

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An Exploration of Stories of Older Persons and Family Members Living with Dementia

Consent Form

Research Student: Alex Walker
Research Supervisor: Dr Anne Fothergill

Please initial all boxes

1. I have read and understood the information sheet for the above study (version 7, 15.10.19). ☐
2. I have had time to think about doing this project. ☐
3. I have had chance to ask questions and understood what they told me in reply. ☐
4. I understand that it is my choice to take part. ☐
5. I know that I am free to leave this study at any time. I do not have to tell you why and nothing will happen to me or my care. ☐
6. I understand that if I withdraw from the study, all of my data and video will be deleted from the research team's records. ☐
7. I agree to be video recorded for this study. ☐
8. I am happy for the research student to show my video only to her examiners during the final exam for this PhD thesis. ☐
9. I know that if I tell you things that break the law and or hurt myself or other people, the person I tell has to tell others who must know about it. ☐
10. I agree to take part in the above study. ☐
11. I agree to my data being used for up to 5 years after the study is completed. ☐
12. I would like a copy of my final video on DVD. ☐
13. I understand that direct quotations from my story will be used in the final thesis. My identity will be anonymised for this. ☐
14. I understand that direct quotations from my story will be used for academic journal articles, conferences and the final report for the health board. My identity will be anonymised for these. ☐

Name of Participant	Date	Signature
____________________	________	____________________
Person Taking Consent	Date	Signature
____________________	________	____________________

Version 7 15.10.19   IRAS Number 255686   Consent Form for Person with Dementia

If you want to leave this study, tell:

By phone

Alex Walker on 07760821292

By email

Alex Walker Research Student alex.walker@southwales.ac.uk

or

Anne Fothergill Director of Studies anne.fothergill@southwales.ac.uk

By post to

Alex Walker
AB034
Glyntaff Campus
University of South Wales
Pontypridd
CF37 4BE

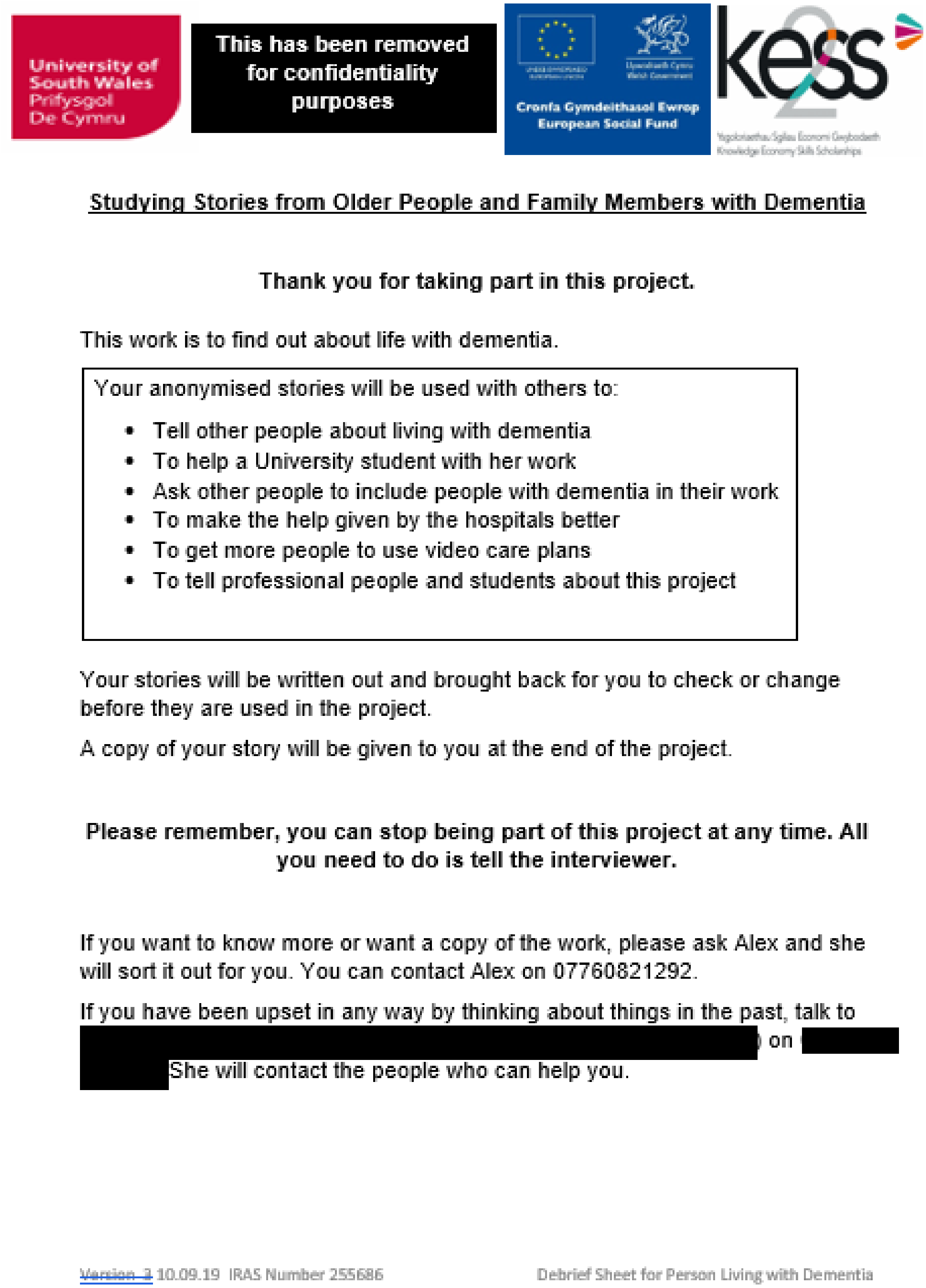
To complain about the project, please contact:

Jonathan Sinfield

Phone 01443 484 518

Email jonathan.sinfield@southwales.ac.uk

O.6 Debrief sheet



This has been removed for confidentiality purposes

Studying Stories from Older People and Family Members with Dementia

Thank you for taking part in this project.

This work is to find out about life with dementia.

Your anonymised stories will be used with others to:

- Tell other people about living with dementia
- To help a University student with her work
- Ask other people to include people with dementia in their work
- To make the help given by the hospitals better
- To get more people to use video care plans
- To tell professional people and students about this project

Your stories will be written out and brought back for you to check or change before they are used in the project.

A copy of your story will be given to you at the end of the project.

Please remember, you can stop being part of this project at any time. All you need to do is tell the interviewer.

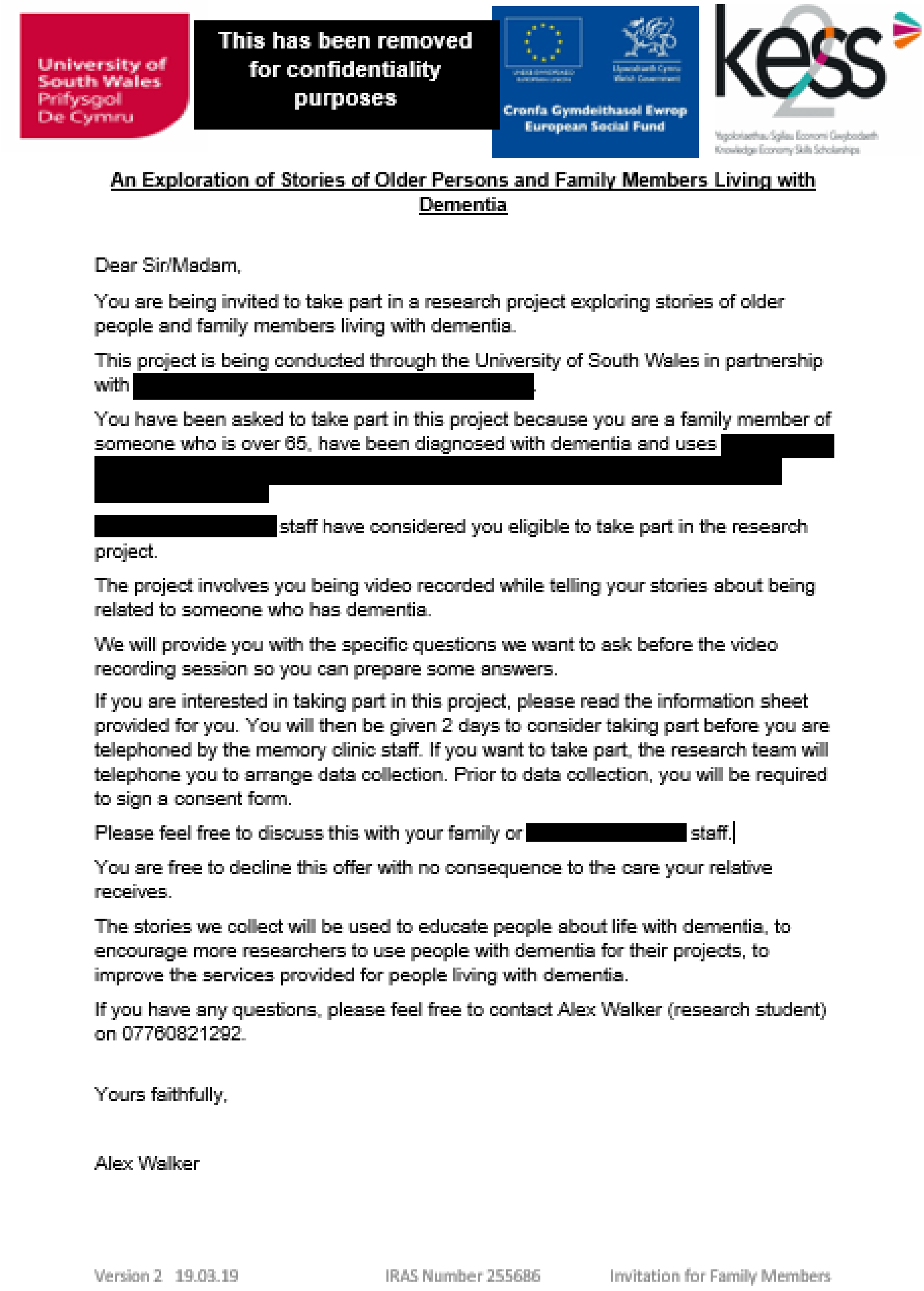
If you want to know more or want a copy of the work, please ask Alex and she will sort it out for you. You can contact Alex on 07760821292.

If you have been upset in any way by thinking about things in the past, talk to [redacted] on [redacted] [redacted] She will contact the people who can help you.

~~Version 3~~ 10.09.19 IRAS Number 255686 Debrief Sheet for Person Living with Dementia

P: Family member information pack

P.1 Invitation



University of South Wales
Prifysgol De Cymru

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Cronfa Gymdeithasol Ewrop
European Social Fund

kess 2

<u>An Exploration of Stories of Older Persons and Family Members Living with Dementia</u>

Dear Sir/Madam,

You are being invited to take part in a research project exploring stories of older people and family members living with dementia.

This project is being conducted through the University of South Wales in partnership with [redacted].

You have been asked to take part in this project because you are a family member of someone who is over 65, have been diagnosed with dementia and uses [redacted]

[redacted] staff have considered you eligible to take part in the research project.

The project involves you being video recorded while telling your stories about being related to someone who has dementia.

We will provide you with the specific questions we want to ask before the video recording session so you can prepare some answers.

If you are interested in taking part in this project, please read the information sheet provided for you. You will then be given 2 days to consider taking part before you are telephoned by the memory clinic staff. If you want to take part, the research team will telephone you to arrange data collection. Prior to data collection, you will be required to sign a consent form.

Please feel free to discuss this with your family or [redacted] staff.

You are free to decline this offer with no consequence to the care your relative receives.

The stories we collect will be used to educate people about life with dementia, to encourage more researchers to use people with dementia for their projects, to improve the services provided for people living with dementia.

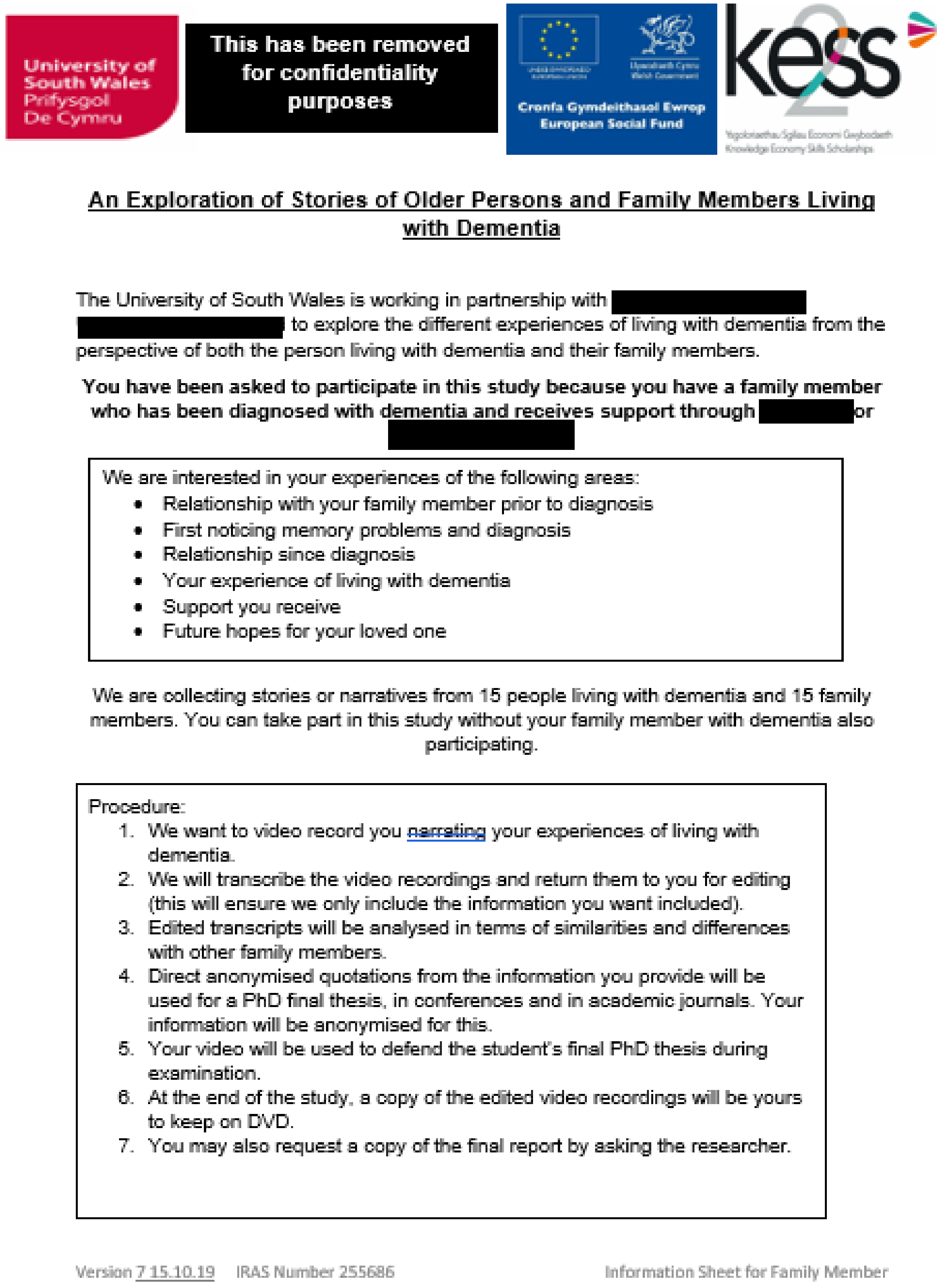
If you have any questions, please feel free to contact Alex Walker (research student) on 07760821292.

Yours faithfully,

Alex Walker

Version 2 19.03.19 IRAS Number 255686 Invitation for Family Members

P.2 Information



University of South Wales
Prifysgol De Cymru

This has been removed for confidentiality purposes

Cronfa Gymdeithasol Ewrop
European Social Fund

kess 2
Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

An Exploration of Stories of Older Persons and Family Members Living with Dementia

The University of South Wales is working in partnership with [redacted] to explore the different experiences of living with dementia from the perspective of both the person living with dementia and their family members.

You have been asked to participate in this study because you have a family member who has been diagnosed with dementia and receives support through [redacted] or [redacted]

We are interested in your experiences of the following areas:

- Relationship with your family member prior to diagnosis
- First noticing memory problems and diagnosis
- Relationship since diagnosis
- Your experience of living with dementia
- Support you receive
- Future hopes for your loved one

We are collecting stories or narratives from 15 people living with dementia and 15 family members. You can take part in this study without your family member with dementia also participating.

Procedure:

1. We want to video record you narrating your experiences of living with dementia.
2. We will transcribe the video recordings and return them to you for editing (this will ensure we only include the information you want included).
3. Edited transcripts will be analysed in terms of similarities and differences with other family members.
4. Direct anonymised quotations from the information you provide will be used for a PhD final thesis, in conferences and in academic journals. Your information will be anonymised for this.
5. Your video will be used to defend the student's final PhD thesis during examination.
6. At the end of the study, a copy of the edited video recordings will be yours to keep on DVD.
7. You may also request a copy of the final report by asking the researcher.

The information you provide will be used to:

- Educate others about living with dementia
- Improve awareness of the services and support people need to live well with dementia
- Write a PhD final thesis, in academic journals and conferences
- Improve the services/care provided for people living with dementia

You are free to withdraw from this project at any time. No questions will be asked and it will not affect the care your family member receives. If you withdraw from the study, all your data and video held by the research team will be deleted. If you withdraw after your video is edited, your edited video will be returned to you. If your video has not yet been edited, your raw video will be returned to you due to time constraints on the research student.

It is completely understandable that you may become upset whilst telling your stories. Should this happen, you are free to terminate the data collection session or take a break.

Please note:

Identifiable information will be anonymised for this study with the exception of your video, which will be shown to the PhD thesis examiners only to defend the student's thesis.

If you disclose any sensitive information (e.g. illegal activity, harm to yourself or others etc) the researcher is legally bound to pass the information along to the relevant bodies.

If you say anything offensive about another person, the research student will have to remove this from your video.

Your anonymised data will be kept by the University for 5 years in a locked drawer or on a password protected computer, only accessible to the research team. Your identifiable data, including a copy of your video, will be stored by the research team for up to 12 months after the PhD is completed.

Your video will be copyright of the University of South Wales as the University has intellectual property rights to all products made during this PhD. This will protect it from unauthorised use or copying.

This study received favourable ethical approval from University of South Wales (15th July 2019) and Wales Research Ethics Committee 1 (17th October 2019).

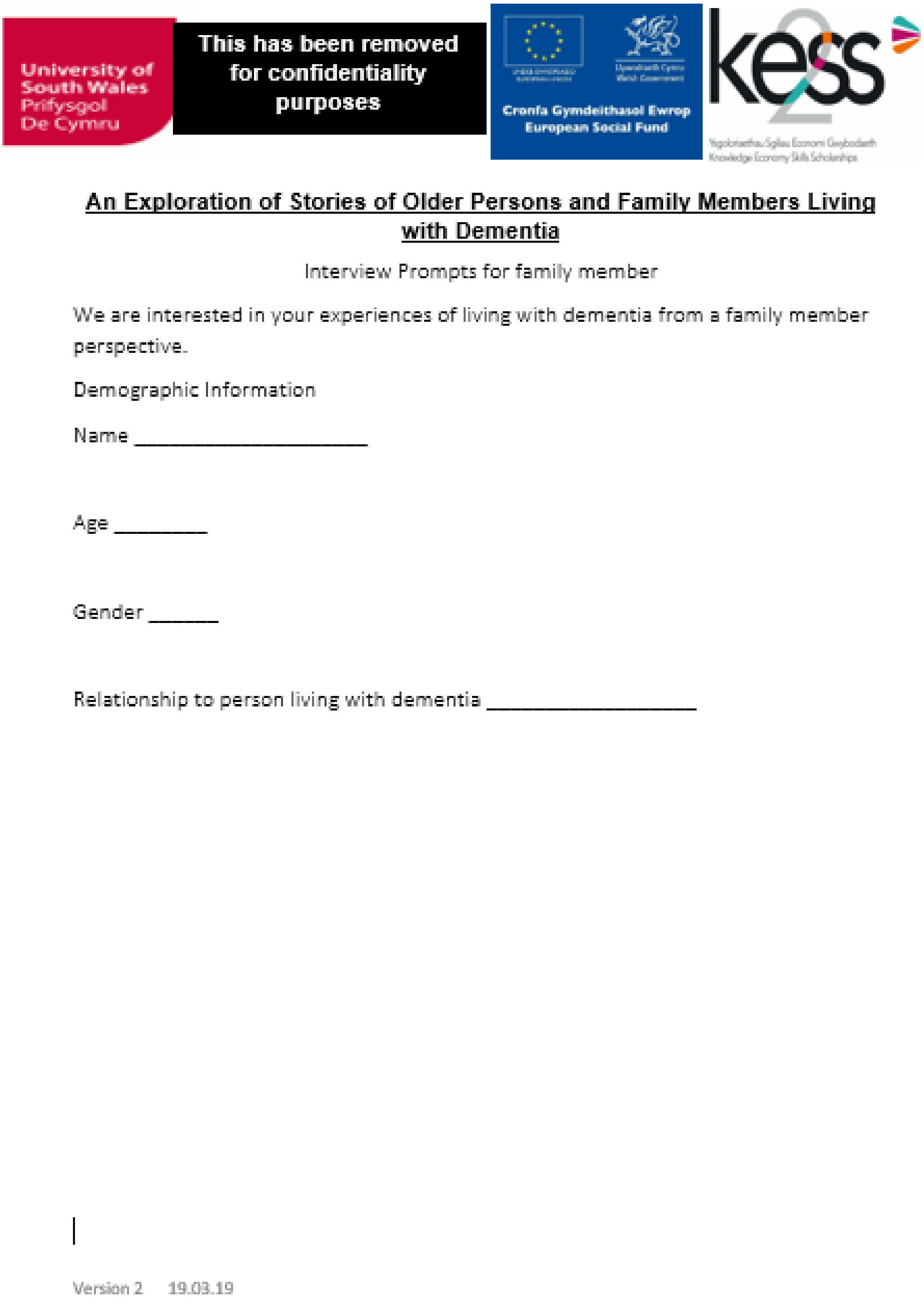
For more information, please contact any of the following:

Alex Walker *Research Student*	07760821292
Dr Anne Fothergill *Director of Studies / Project Manager*	anne.fothergill@southwales.ac.uk
[redacted]	[redacted]
[redacted]	[redacted]
To complain about the project, please contact: Jonathan Sinfield (Research Governance) Phone 01443 484 518 Email jonathan.sinfield@southwales.ac.uk	

This project is being conducted as part of a PhD qualification funded by University of South Wales, [redacted] and KESS. Knowledge Economy Skills Scholarships (KESS) is a pan-Wales higher level skills initiative led by Bangor University on behalf of the higher education sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys.

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code name instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. You can find out more about how your information is used by asking one of the research team.

P.3 Interview prompts



University of South Wales
Prifysgol De Cymru

This has been removed for confidentiality purposes

Cronfa Gymdeithasol Ewrop
European Social Fund

kess 2
Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

An Exploration of Stories of Older Persons and Family Members Living with Dementia

Interview Prompts for family member

We are interested in your experiences of living with dementia from a family member perspective.

Demographic Information

Name ______________________

Age _________

Gender ______

Relationship to person living with dementia ____________________

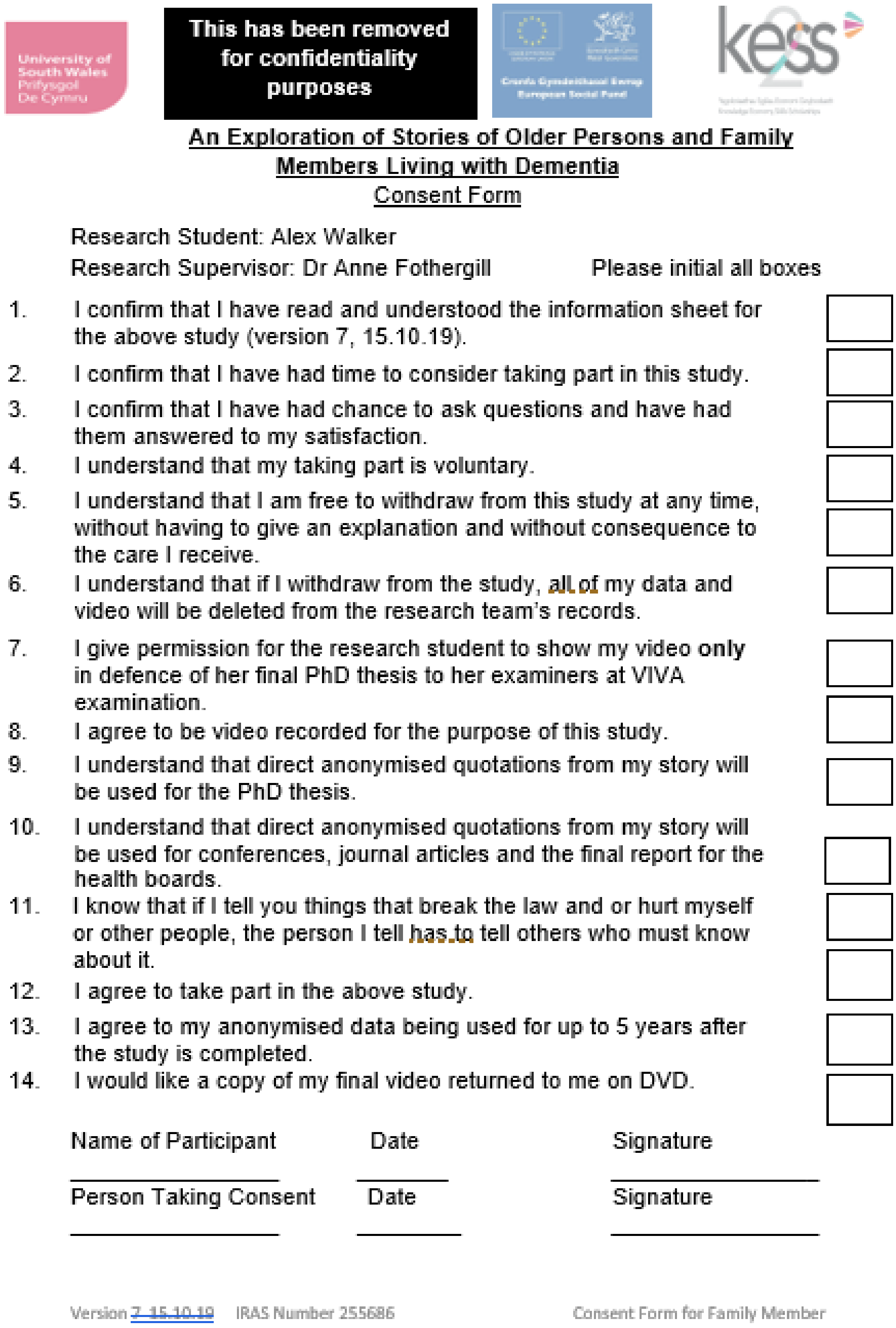
Version 2 19.03.19

1. Can you tell me about your (family member)?
2. Life before dementia
    a. Can you tell me what your relationship was like with your family member (FM) before they began having memory problems?
3. Dementia Beginning
    a. When did you start noticing that they were having dementia related problems?
    b. What sorts of things were they doing that were out of the ordinary?
    c. How did they react to this?
    d. Was there any key event taking place at the time of dementia onset?
4. Diagnosis
    a. How did you find the diagnosis process?
    b. Has your FM's relationship with other family members and friends changed since being diagnosed? How does this make you feel?
    c. Has your relationship with other family members and friends changed since your FM was diagnosed? How does this make you feel?
5. Support
    a. What support was put in place after your FM was diagnosed? How long did it take for this support to begin? How did you feel about this support?
    b. Who provided you with information about dementia and the support available? Was this helpful?
    c. Do you think you were provided with enough information about dementia?
    d. What support do you receive?
    e. How do you feel about the support you receive from
        i. Family
        ii. Friends
        iii. 3rd party services e.g. memory teams, support groups etc.
    f. Is there any support you feel is needed but not offered?
6. Living with dementia
    a. How would you describe your experience of living with dementia? How does this make you feel?
    b. Has your life changed since your FM was diagnosed?
    c. Has your relationship with your FM changed?
    d. As a family, is there anything in particular that you have struggled with?
    e. As a family, is there anything in particular that you have coped well with?

7. Future
    a. What are your hopes for the future of your FM?
8. Advice
    a. If someone were in your situation a few years ago, where they are beginning to notice memory problems or about to go through the diagnosis process; what advice would you give them?
9. Is there anything else you want to tell me that you feel I have missed out?

Version 2 19.03.19

P.4 Consent *form*



This has been removed for confidentiality purposes

An Exploration of Stories of Older Persons and Family Members Living with Dementia

Consent Form

Research Student: Alex Walker

Research Supervisor: Dr Anne Fothergill

Please initial all boxes

1. I confirm that I have read and understood the information sheet for the above study (version 7, 15.10.19). ☐
2. I confirm that I have had time to consider taking part in this study. ☐
3. I confirm that I have had chance to ask questions and have had them answered to my satisfaction. ☐
4. I understand that my taking part is voluntary. ☐
5. I understand that I am free to withdraw from this study at any time, without having to give an explanation and without consequence to the care I receive. ☐
6. I understand that if I withdraw from the study, all of my data and video will be deleted from the research team's records. ☐
7. I give permission for the research student to show my video only in defence of her final PhD thesis to her examiners at VIVA examination. ☐
8. I agree to be video recorded for the purpose of this study. ☐
9. I understand that direct anonymised quotations from my story will be used for the PhD thesis. ☐
10. I understand that direct anonymised quotations from my story will be used for conferences, journal articles and the final report for the health boards. ☐
11. I know that if I tell you things that break the law and or hurt myself or other people, the person I tell has to tell others who must know about it. ☐
12. I agree to take part in the above study. ☐
13. I agree to my anonymised data being used for up to 5 years after the study is completed. ☐
14. I would like a copy of my final video returned to me on DVD. ☐

Name of Participant   Date   Signature

Person Taking Consent   Date   Signature

Version 7 15.10.19   IRAS Number 255686   Consent Form for Family Member

If you want to withdraw from this study, you will need to contact any of the following:

By telephone

Alex Walker	Research Student	07760821292

By email

Alex Walker	Research Student	alex.walker@southwales.ac.uk
Anne Fothergill	Director of Studies	anne.fothergill@southwales.ac.uk

By post to

Alex Walker
AB034
Glyntaff Campus
University of South Wales
Pontypridd
CF37 4BE

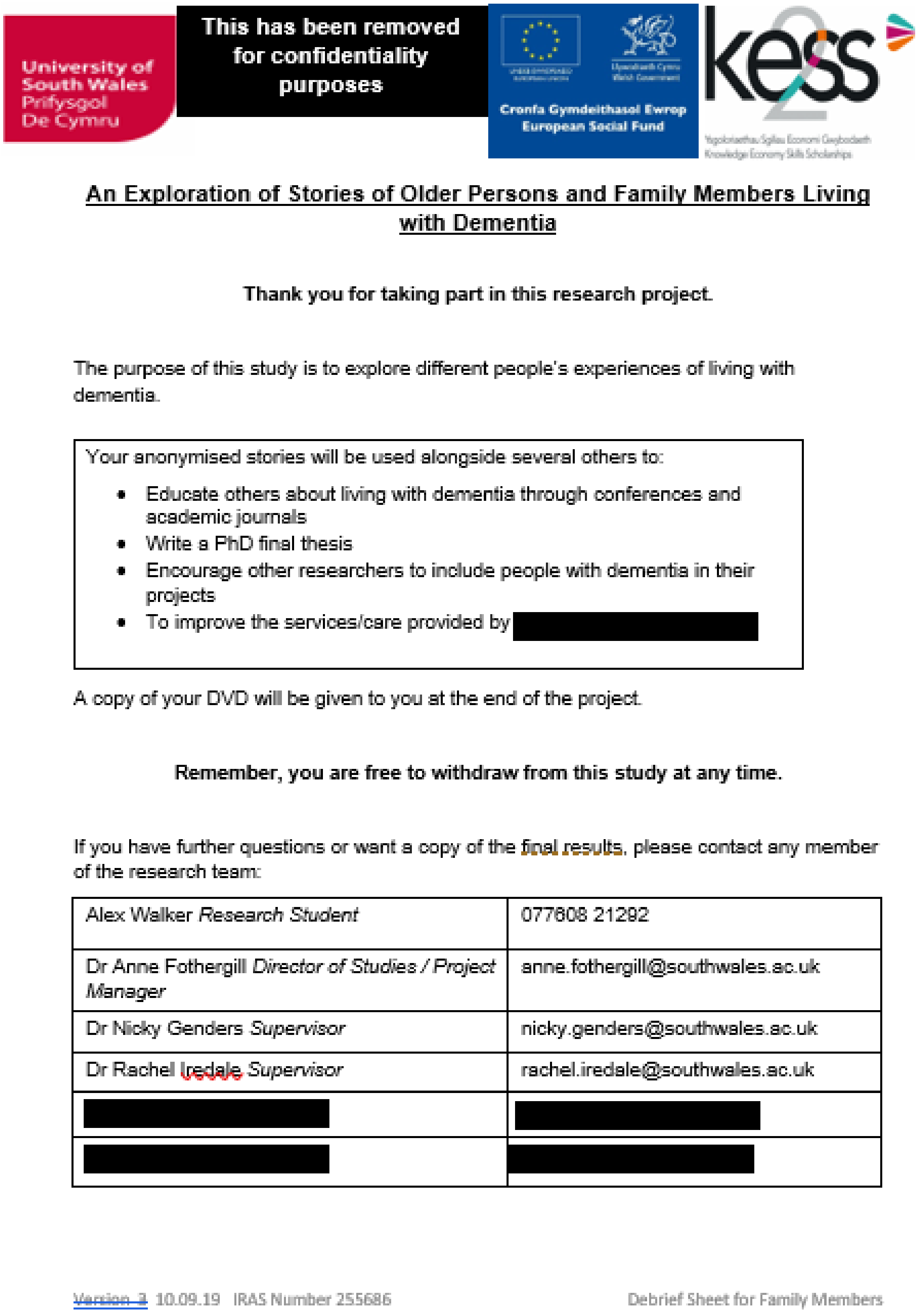
To complain about the project, please contact:

Jonathan Sinfield

Phone 01443 484 518

Email jonathan.sinfield@southwales.ac.uk

P.5 Debrief sheet



University of South Wales
Prifysgol De Cymru

This has been removed for confidentiality purposes

Cronfa Gymdeithasol Ewrop
European Social Fund

kess2
Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

An Exploration of Stories of Older Persons and Family Members Living with Dementia

Thank you for taking part in this research project.

The purpose of this study is to explore different people's experiences of living with dementia.

Your anonymised stories will be used alongside several others to:

- Educate others about living with dementia through conferences and academic journals
- Write a PhD final thesis
- Encourage other researchers to include people with dementia in their projects
- To improve the services/care provided by [redacted]

A copy of your DVD will be given to you at the end of the project.

Remember, you are free to withdraw from this study at any time.

If you have further questions or want a copy of the final results, please contact any member of the research team:

Alex Walker *Research Student*	077608 21292
Dr Anne Fothergill *Director of Studies / Project Manager*	anne.fothergill@southwales.ac.uk
Dr Nicky Genders *Supervisor*	nicky.genders@southwales.ac.uk
Dr Rachel Iredale *Supervisor*	rachel.iredale@southwales.ac.uk
[redacted]	[redacted]
[redacted]	[redacted]

~~Version 3~~ 10.09.19 IRAS Number 255686 Debrief Sheet for Family Members

If you have been at all affected by this research project, require additional support or counselling advice, please contact any of the following:

This has been removed for confidentiality purposes

- Alzheimer's Society
    - Telephone 0300 222 11 22
    - Website www.alzheimers.org.uk
- AgeUK Cymru
    - Telephone 08000 223 444
    - Website www.ageuk.org.uk/cymru/

To complain about the project, please contact:

Jonathan Sinfield

- Phone 01443 484 518
- Email jonathan.sinfield@southwales.ac.uk

Q: Recording equipment used for data collection

The equipment used for this study was:

- Hama Lavalier Microphone LM-09
- Panasonic Video Recorder HC-V770
- SanDisk Extreme Pro 64 GB memory card (x2)
- Hama Tripod
- Toshiba 2TB External Hard Drive

Videos were edited on a USW computer using Adobe Premier Pro CC, converted to H.264 format and burnt onto Verbatim DVD-R using DVD Flick.

R: Training certificates

R.1 Good clinical practice

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

NIHR CRN Workforce Development
Enabling learning and development in the Clinical Research Network

NHS
National Institute for Health Research

Certificate of Attendance

Alex Walker

attended

Introduction to Good Clinical Practice (GCP):

A practical guide to ethical and scientific quality standards in clinical research

on 24th November, 2017

Sessions include:
1. The Value of Clinical Research and the role of NIHR CRN & Health and Care Research Wales
2. Introduction to research and the GCP standards
3.Preparing to deliver your study
4.Identifying and recruiting participants: Eligibility & Informed Consent
5. Data collection and ongoing study delivery
6. Safety reporting and Study closure

Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations and the Department of Health Research Governance Framework for Health and Social Care, as applied to the conduct of Clinical Trials and other studies conducted in the NHS

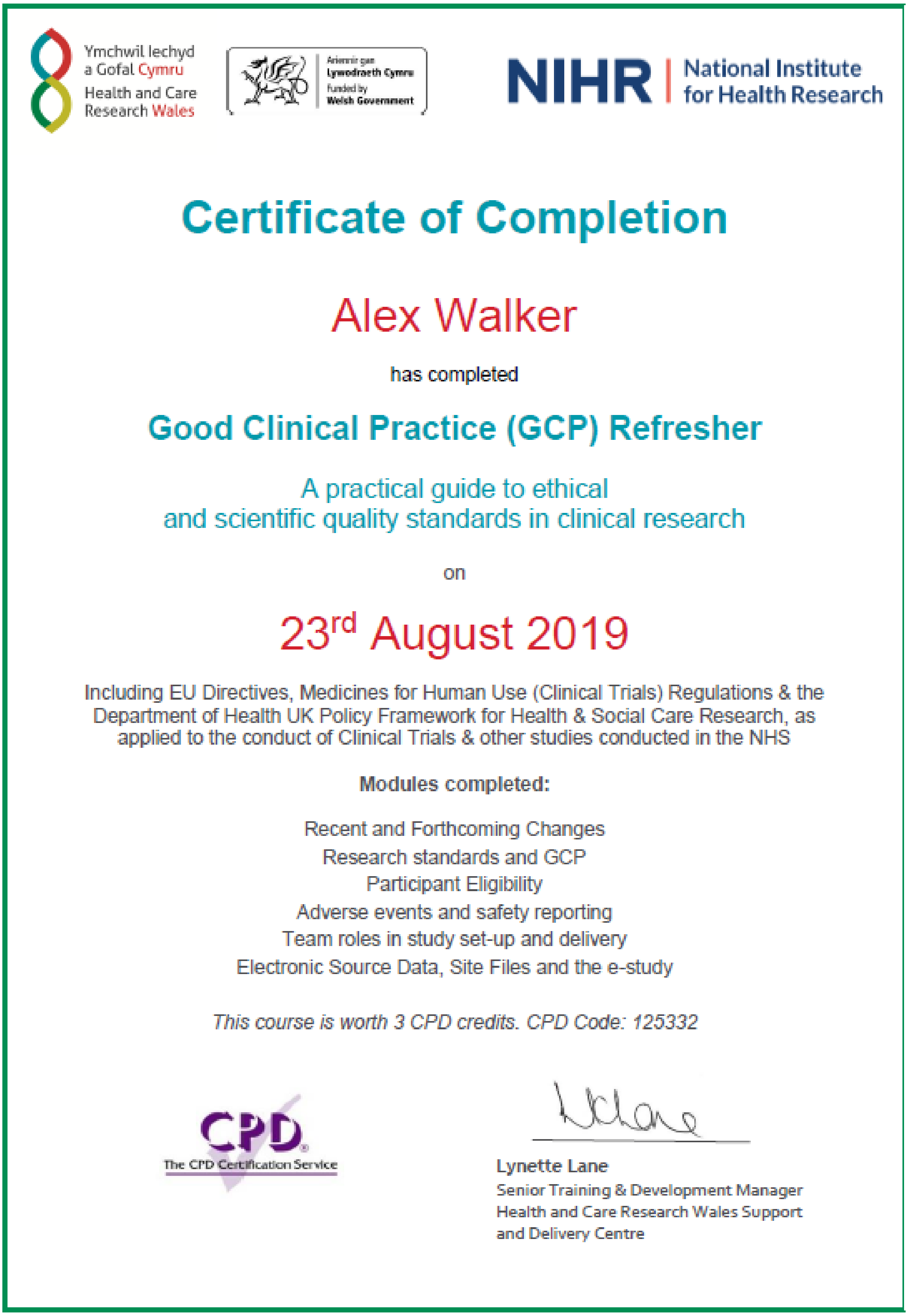
This course is accredited by the CPD Certification Service (6.5 Hours)

CPD MEMBER
The CPD Certification Service

Lynette Lane
Senior Training & Development Manager
Health and Care Research Wales Support Centre

Emma Lowe
NIHR CRN Learning & Development Lead

R.2 Good clinical practice refresher



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

NIHR | National Institute for Health Research

Certificate of Completion

Alex Walker

has completed

Good Clinical Practice (GCP) Refresher

A practical guide to ethical
and scientific quality standards in clinical research

on

23rd August 2019

Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations & the Department of Health UK Policy Framework for Health & Social Care Research, as applied to the conduct of Clinical Trials & other studies conducted in the NHS

Modules completed:

Recent and Forthcoming Changes
Research standards and GCP
Participant Eligibility
Adverse events and safety reporting
Team roles in study set-up and delivery
Electronic Source Data, Site Files and the e-study

This course is worth 3 CPD credits. CPD Code: 125332

CPD
The CPD Certification Service

Lynette Lane
Senior Training & Development Manager
Health and Care Research Wales Support
and Delivery Centre

R.3 Valid informed consent

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Certificate of Attendance

This is to certify that

Alex Walker

attended the training entitled

Valid Informed Consent in Research

on 11 January 2018

at

Health and Care Research Wales Support Centre,
Cardiff

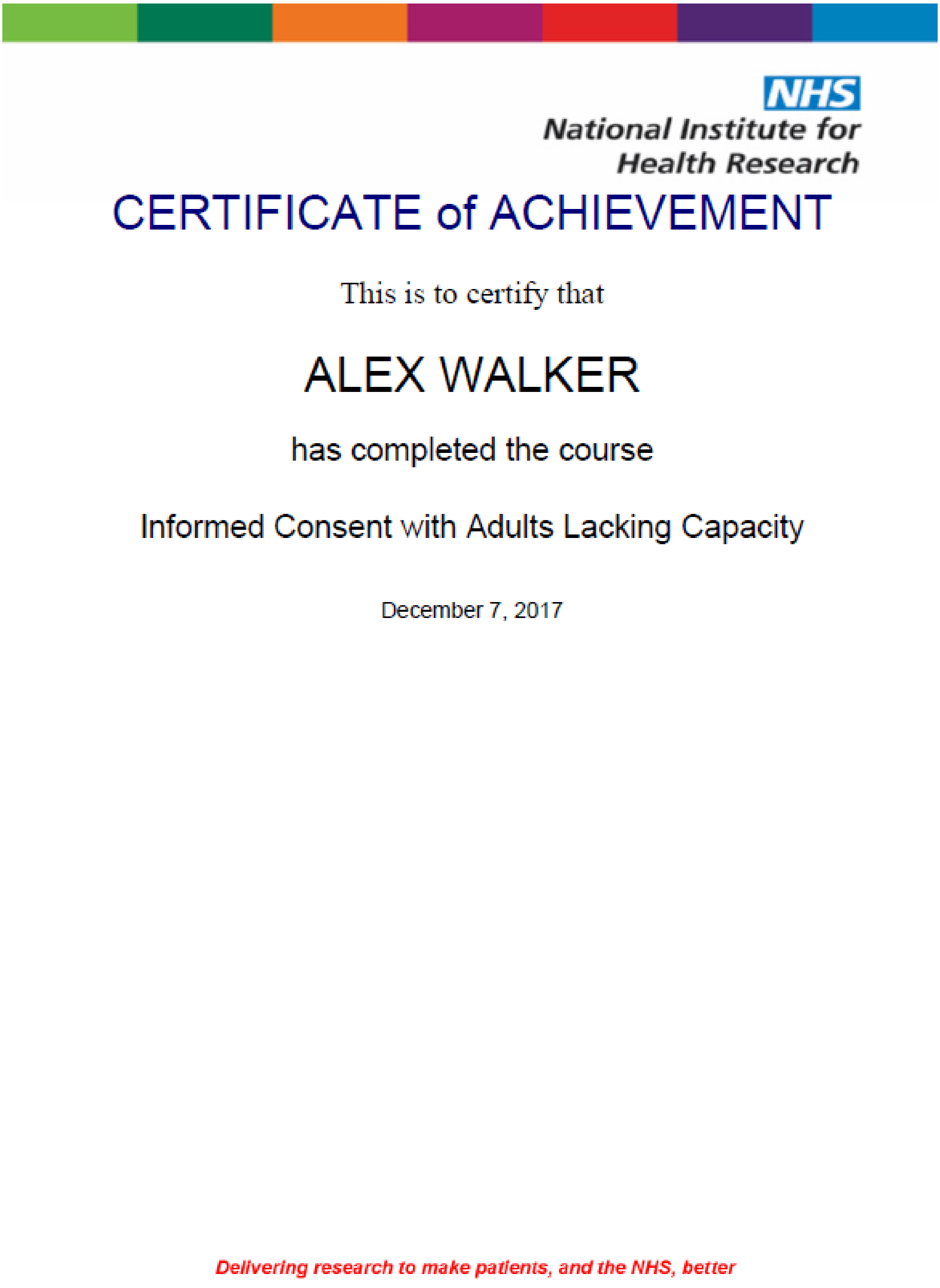
CPD
MEMBER
The CPD Certification
Service

CPD Hours = 4

NHS
WALES
GIG
CYMRU

Lynette Lane
Senior Training & Development Manager
Health and Care Research Wales
Support Centre

R.4 Informed consent from adults lacking capacity



NHS
National Institute for
Health Research

CERTIFICATE of ACHIEVEMENT

This is to certify that

ALEX WALKER

has completed the course

Informed Consent with Adults Lacking Capacity

December 7, 2017

Delivering research to make patients, and the NHS, better

R.5 Managing essential documents in research

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Certificate of Attendance

This is to certify that

Alex Walker

attended the training entitled

Managing Essential Documentation in Research

on 28th March 2018

at

ILS1, Swansea University

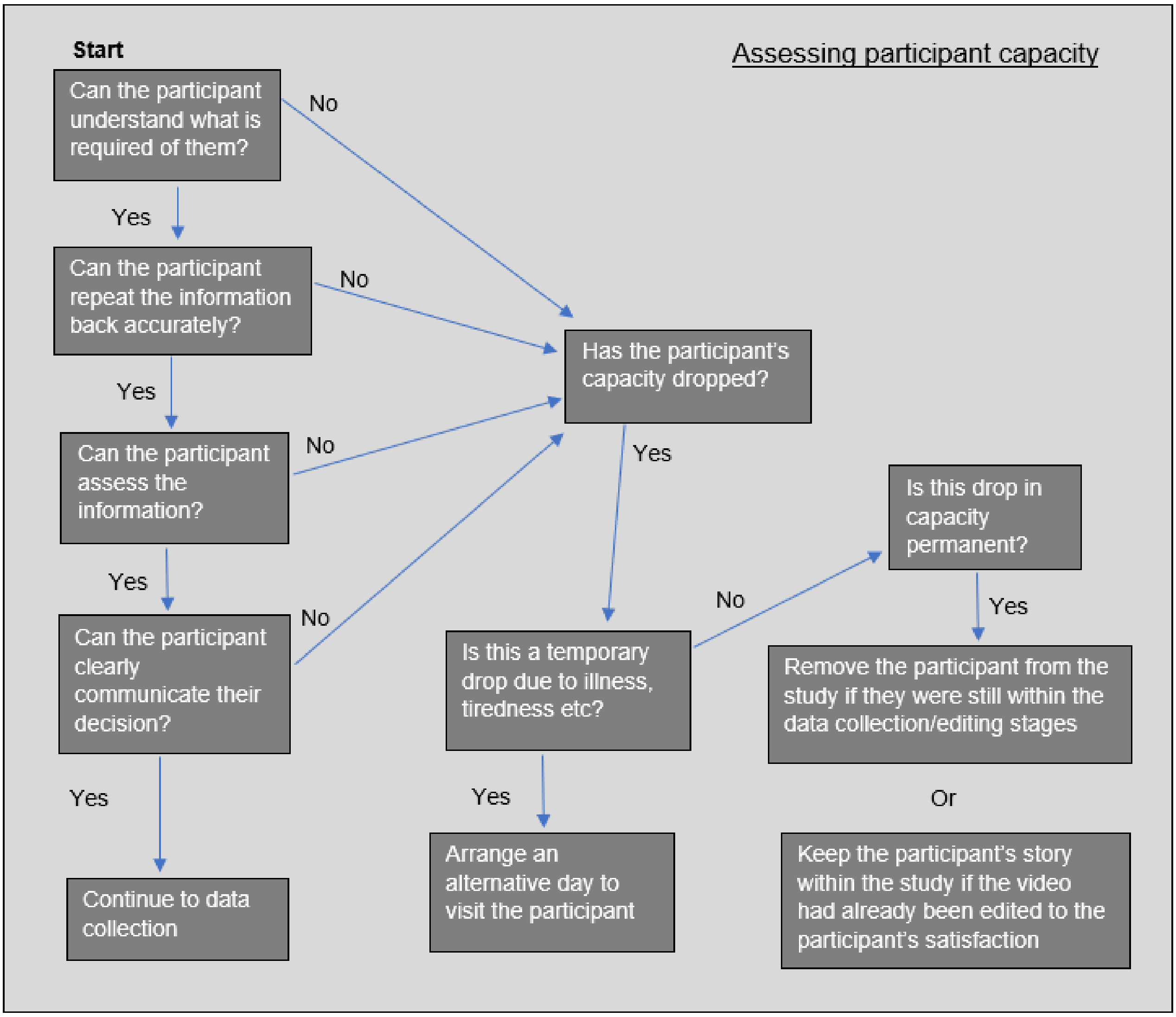
CPD
MEMBER
The CPD Certification Service

CPD Hours = 4

NHS
WALES
GIG
CYMRU

Lynette Lane
Senior Training & Development Manager
Health and Care Research Wales
Support Centre

S: Flow diagram for assessing capacity



T: Sample of transcript

Alex: Can you just start by telling me your name please?

Darren: My name is Darren.

Alex: And you relationship to the person with dementia?

Darren: I am married to Louise, have been for over 20 years.

Alex: So can you tell me a little bit about your wife?

Darren: She's very caring, very demanding. So far we've had a fantastic life together and hope to have a number of more years with her, regardless of the Alzheimer's. Used to enjoy foreign holidays and travelling the world. Loves her dogs. Used to enjoy cooking. Looking after people, that was basically her main driving force ever since I met her, she has always been a carer whether it's been with children, working with children, or whether it's working with old people. So she knows what's coming because she's actually looked after people with Alzheimer's. So we are hoping that the medication that they have got these days will actually prolong it as long as possible. It's been difficult, but there you go.

Alex: Can you tell me what your relationship was like with Louise before she had the memory problems?

Darren: Adventurous. We've done a number of cruises, we have been all around the world; that stopped the day she came out of hospital after she had the heart operation. She never wanted to travel any more, she is only willing to go now, basically, within this country. She doesn't want to leave the dogs, they are like her lifeline, simple as that. It has changed quite a bit since the Alzheimer's has come on. The cooking has stopped, I do all of the cooking now. The baking has gone through the window, we have given all of that stuff away because I don't want to do baking, and I'm not getting involved in that as well. I still work full time at the moment, I'm on the sick at the moment but we know that there will come a day where I'll probably have to finish work to stay at home but hopefully that's a number of years down the road and that I can work my way almost up until retirement where financially we'll be better off because obviously there is a lot of financial worries as well that come along with this; how you manage if you have got to give up work to become a carer and of course, the way that the government has got it stacked against you at the moment where you've got to pay for everything if you've got any savings. So yeah, there's a number of issues that you have got to deal with.

Alex: Yup. When did you start to notice that your wife was having dementia related problems?

Darren: We noticed when she came out of hospital after her major heart surgery but we associated that with the result of the anaesthesia. But looking back on it, it wasn't. It was more to do with the Alzheimer's being brought to the front because of the operation so we ignored it for a number of years, we just thought it was down to the operation. But it is only after I started to notice; it's like where, like I said, where she stopped cooking, she didn't want to do any cooking. She was forgetting to put things on the plate, wasn't you? I would go in the microwave the next day and there would be stuff in the microwave which had been warmed up that should have gone along with the meal and it was becoming obvious that there was other things, so we noticed it pretty much straight after the operation which was, coming up for eight years now, but we didn't get her tested until 18 months ago. I started to really notice other things coming in on top of what we thought was down to the operation so it has been pretty much for the last eight years, we have noticed things happening.

Alex: So how did your wife react to her doing these things that were out of the ordinary?

Darren: She just thought it was part of getting old and down to the operation. It is just normal for people, as they get older, to forget things. And of course, we kept getting, because of the heart operation, things are going to be different so we just put it down to that. Whereas like I said, it wasn't until a couple of years after that, and I thought surely it should be getting better if it's down to the anaesthetic, but it didn't get better, it started to get worse. Which is when I started pushing for Louise to be tested. But of course, being a woman, she dug her heels in and said no there's nothing wrong with me, I'm just getting older [laughing].

Alex: How did you find the diagnosis process?

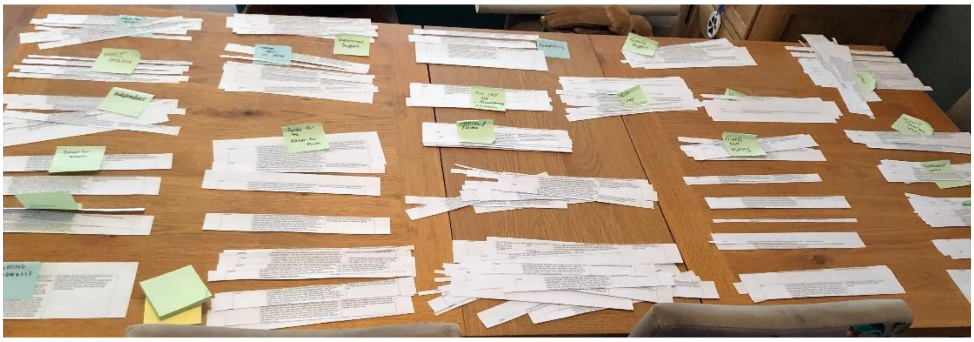
Darren: To be honest, not brilliant because I still don't know where I stand and where Louise stands with the diagnosis. That's all we've been told is yes you have it. We haven't been told if it's a certain type of, or if there's any sort of prognosis on how long things can stay the same or whether they will deteriorate very quickly because that's all the psychiatrist told us is everybody is different, nobody knows. It leaves you in the dark a lot so we just try to stay positive and think positively that we could be fifteen years down the line and she's not much worse than what she is now. And that's the way we try to look at it. You know, we watch that thing with the couple that does the canals, Prunella Scales, and she's had Alzheimer's for a number of years and she doesn't seem to be deteriorating that quickly, and that's all we can do is hope for the best and say well you know, we might have another fifteen years of you being pretty much like you are now. So that's what we hope for, we just try to stay positive. It's all you can do.

Alex: Has your relationship with other family members and friends changed since your wife has been diagnosed?

Darren: No. No. We have always been pretty independent, we don't have this really really tight nit family bond which a lot of families get basically because me and Louise got together twenty five years ago, it was a second marriage for Louise. Fair play, Jenny, my stepdaughter, looks at me as her dad anyway, but you know, she was twenty nearly when me and Louise got together. My daughter from a previous relationship; you get you know, splintered families. I was brought up by my mother, my father buggered off when I was seven. Louise's mother died very young in her life so it's like you don't get that very close family bond so really it hasn't changed. They still rely on us for things and they still come to visit us but they are not here every other day. It's pretty much, I'm left to get on with everything.

U: Data analysis process photographs

All significant statements and formulated meanings were cut into strips and manually arranged into theme clusters.



Theme clusters waiting to be arranged into themes

V: Completed analysis tables

V.1 Participants with dementia

Location of Statement	Statement	Formulated Meaning	Theme Cluster (Subtheme)	Theme
Lynne	You’re still the same Lynne.	Trying to maintain her identity	*Former self*	**Identity**
Beverley	I’m just Beverley.	Still feels like her usual self and expects people to treat her that way	*Former self*	**Identity**
Nancy	I thought well if I’m Nancy now, I’m going to be Nancy then.	Does not understand how the dementia might change her in the future	*Former self*	**Identity**
Nancy	They don’t realise that you’re a person, you’re still the person that you used to be just you’re not as clever as, or you can’t remember things like you used to.	People do not realise that you are still the same person that you used to be	*Former self*	**Identity**
Lynne	I said to them, just leave me alone now so that I can sort it out in my head and that’s what I’ve done and I have, my good friend has said don’t be silly…And I can understand that, but it takes a bit of accepting because part of you is gone and you’re losing that part that you want desperately to have.	Feels like part of her is gone and that took a while to come to terms with	*Former self*	**Identity**

Nancy	I know it has ruined our house and ruined our marriage because I'm so nasty with him now.	Feels that her change of temperament has ruined their marriage	*Threats to accepting new self*	**Identity**
Nancy	We just celebrated our golden wedding, I never ever answered him back, he would start and I would shut up, leave him shout and rant and rave and then nothing was said …If he shouts at me, I shout at him, and I've gone very aggressive towards him.	Increased aggression towards her husband	*Threats to accepting new self*	**Identity**
David	Patience, that's what is starting to lack	Noticed that his temperament has changed	*Threats to accepting new self*	**Identity**
Nancy	I'm the type of person, I just don't want it done when Tryst, you know… I want it done when I've asked.	Not as patient as she used to be.	*Threats to accepting new self*	**Identity**
Nancy	She [consultant] said "oh you've only got the vascular dementia", which I thought was a lot easier, a lot better the way she said it to me, but I think it's just as bad as ordinary dementia. And I still don't know what the difference between ordinary, vascular dementia and just plain dementia is.	Unclear about the difference between her diagnosis [vascular] and the other diagnoses of dementia	*Threats to accepting new self*	**Identity**
Nancy	Alex: How did it make you feel? Noticing these changes? Noticing that you were forgetting things? Nancy: Very strange. I thought, I really thought I was going, I didn't know much about dementia then but I thought I was going insane and when they were sending me to see the psychiatrist and they told me who she was, what she did, I really thought I was going insane.	Did not know what dementia was. Thought a psychiatrist was for insane people.	*Threats to accepting new self*	**Identity**
June	June: If all these millions of people are the same, have they all got dementia? Geraint: Yeah.	Thinks that forgetting is normal and not necessarily dementia.	*Threats to accepting new self*	**Identity**

	June: Probably not, they just forget, it is the same thing I suppose.			
David	What is dementia? That’s what I try to work out? It is just loss of memory or is it other things you know? And like I say, you don’t see a lot of it, you never hear a lot about it to tell the truth. I hear a lot about it now because I’m involved in it and this is it you know.	Tries to make sense of what dementia is.	*Threats to accepting new self*	**Identity**
Nancy	I have vascular dementia, now I don’t understand the difference because they said they would explain it to me, but I still don’t understand the difference between vascular and ordinary dementia.	Does not understand her diagnosis	*Threats to accepting new self*	**Identity**
June	I just can’t remember…I suppose millions of people are the same.	Thinks that millions of people have the same memory problems as her	*Threats to accepting new self*	**Identity**
Pat	It isn’t only the Alzheimer’s, and it’s a little bit of everything [all of her health problems causing her troubles]. But its old age isn’t it, that’s what I’m putting it down to. I mean I’m eighty-five, I’m not too bad for eighty-five am I?	Putting it down to old age- has lots of health problems impacting on her life, not just her dementia	*Threats to accepting new self*	**Identity**
Louise	Like shit…because I look after the clients and I don’t want to be told that I’m one of those I suppose.	Negative reaction to being told her dementia diagnosis. She was a carer and now she would need to be cared for.	*Threats to accepting new self*	**Identity**
Nancy	I mean it frightened me when I realised he [Dad] had dementia and when he died that really drove me crackers because I thought that’s how I’m going to die	Seeing the way her father died with dementia scared her, she thinks that is how she will die	*Threats to accepting new self*	**Identity**

Pat	Came on very suddenly and he [her husband] got quite nasty…After seeing my mother and my grandmother, they both got nasty in the end…my mother was nasty, and my grandmother was, they were both very, very nasty	A lot of experience of people with dementia becoming aggressive	*Threats to accepting new self*	**Identity**
Lynne	I think because I had nursed so many people with dementia and I was expecting to be like them, we used to have some pretty bad dementia patients and I think that had a lot to do with it and older people would say she's gone a bit funny you know, and I was holding back from it, I didn't want to talk about myself	Past work experience [nursing] was influencing her opinion of people with dementia- and scaring her.	*Threats to accepting new self*	**Identity**
Lynne	I think because we had so many dementia patients that I felt well why is this happening to me now but it's happening to loads of people you know…I just felt that it wasn't happening to me, but I knew it was. It wasn't a very, I felt devastated.	Devastated because of her past experiences of nursing people with dementia.	*Threats to accepting new self*	**Identity**
May	The ladies I'm with, they're all of them are a little bit [points to head], got something wrong with them. And sometimes I forget. And the one lady that I am friendly with, she just looks at me sometimes and she forgets who I am.	Forgets that she also has dementia, the same as the women she lives with in the residential home.	*New sense of self*	**Identity**
Nancy	When you see it on the television, you see these people and you can tell straight away before they even try to speak to them that they just don't know where they are or who they are and I thought well I'm not like that, when I go out, I talk to people.	Compares herself to the people with dementia on television	*New sense of self*	**Identity**
May	There's other people, they're not so [points to head] as me. Some of them are really bad. It's a pity with some of them. And I forget sometimes that I have got a bit more up here [points to head] than them you know. But it is sad to see some of them...The ladies I'm with,	Compares herself to the other people with dementia living in the same care home.	*New sense of self*	**Identity**

	they're all a little bit [points to head], got something wrong with them. And sometimes I forget I have too			
Nancy	Not very happy about it, not very happy one bit. Because I see it this way, when I married Trystan, we were a wife and a husband, and we had children. Now I don't feel that way anymore, I just feel that Trystan is a man and I'm a woman because what I should be doing, now he does it and what he does, he does himself as well, he does his own life for himself and then he has to do my life for me because I can't do it myself. So, I don't like it one bit… He's a good cook…But that's my job, when I married him, that was my job, to look after him and the house and to have a family if you were lucky enough to and keep on going but I'm not going to keep on going am I, I'm just going to be like this all the time.	Does not like the way her dementia has changed the dynamic of her marriage	*New sense of self*	**Identity**
June	If it has happened [receiving a dementia diagnosis], and you're nervous about it, it means that those nerves will go on the rest of your life, and you know, you have got to try and avoid that kind of thing. So, I wouldn't want to be nervous about it, I just accepted it and, and I don't worry that much about it.	Accepting of her dementia diagnosis	*New sense of self*	**Identity**
June	I did love to volunteer for anything that was going on… I am more or less in here [bedroom] all of the time you know… Lonely, but I am getting used to it. I don't go downstairs very often, no, I don't go down at all really unless I've got to but I don't know what goes on downstairs you know, I don't know if people get together or not	Loved to help other people but now her life has changed and she can no longer do the things she used to enjoy, she does not like the change	*New sense of self*	**Identity**
Rob	She [Kim] thinks that I'm not the man that I used to be, which I'm not, I know but I can't do anything about it. If	His relationship with his wife has	*New sense of self*	**Identity**

	I could change it, I would. I would love to go back to the way I was and that sort of thing but I don’t know, I just can’t do it, it’s not going to happen and I don’t know what to do about it. There’s nothing I can do about it. Kim has changed a lot towards me because of this I think, I don’t know why. She, umm, I don’t know, she’s changed a lot so. Whether she hates me for it, I don’t know, because I’ve got it and she hates me, I really don’t know but she has changed a lot. And that, I regret, we had a great relationship previously but now I get, I can’t, I always say the wrong things, especially to Kim and it doesn’t pan out because I say something and she gets on her high horse and that and tells me why did I say that for? And why did you say that? And I say well I’m telling you what I said and she says that’s not right, that’s not nice and I say oh sorry. I just think you asked me a question and I told you, you know, but I always say the wrong thing or do the wrong thing. I think I’m being nice and offering her a cup of tea and she’ll say oh yeah that will be nice, so I’ll get her a cup of tea and stand on her foot sort of thing.	completely changed- he thinks she hates him		
Rose	Having the condition [dementia], I just want to be how I was, outgoing and being how I was. I’m sorry [gets upset]… it is all of the frustration that you get inside of you and everything builds up inside of you and you can’t really do much to get rid of it because it’s there and depending on your day, and how you feel when you get up, because it can make you feel down and depressed and all of them kind of things and because you lose what you’re talking about, it just gets so frustrating and I don’t like to be like that. I like to be	Gets upset when thinking back to how she used to be and how she is now.	*New sense of self*	**Identity**

	happy and joyful and things like that, you know. I don't feel, and I'm not like I was.			
Louise	Tearful. Angry. Why me? And then all of the things that my ex-husband said I was, horrible things, I felt like that. I just felt that this has happened because of what I've done. But I had a marriage like that, it was like everything was my fault so this was just another thing that was my fault.	Gets upset when thinking about why she has developed dementia	*New sense of self*	**Identity**
Lynne	I just want to be normal and this isn't normality, its, one minute you think that's not too bad and then another minute its, your head isn't your own, it's in the shed again you know. I'm always in the shed. But I do try.	Wants things to go back to normal.	*New sense of self*	**Identity**
Lynne	I'm miserable for starters, I'm not happy like I was and I feel poorly every day which I don't know whether its due to the dementia or the tablets I'm taking…I've slowed down, my whole body has slowed down…It's not a nice feeling.	Noticing changes within herself. Mood and slowed body.	*New sense of self*	**Identity**
Beverley	It is partly because I look at something, it's my old self, not being able to appreciate how good I am.	Getting upset about the way that she used to be compared to now	*New sense of self*	**Identity**
Nancy	I don't feel that I've got any worth at all and I don't feel anything about myself is worth knowing. As far as I'm concerned, I'm just Nancy, another patient with dementia.	Feels like she has no worth, she's just another dementia patient.	*New sense of self*	**Identity**
Nancy	It's hard to accept it is. I still don't accept myself as being, as having dementia	Does not identify herself as having dementia	*New sense of self*	**Identity**
David	When they say that's what I've got, I'm not saying, at the moment, you could say this is the first time that I have said it out loud because when people ask me	Participating in the study was the first time David said out	*New sense of self*	**Identity**

	when I’m up this day centre that I go to, I say well and they say oh I know and that’s is. I haven’t said it you know, I have got dementia, I will say it out loud now and that’s it.	loud that he has dementia.		
Lynne	I’m not the happy person that I was, I feel devastated most of the time but I do try, I know I’ve got this, there’s bound to be changes in life	Feeling a change in herself, in her happiness.	*New sense of self*	**Identity**
Nancy	Like a blank, it’s like playing dominos, he’s a double six and I’m a blank, nothing at all, no number or nothing on me and that’s very upsetting.	She feels like a blank and her husband is a double six [dominos]	*New sense of self*	**Identity**
Nancy	I don’t think I’ve got any self-worth in me now; I don’t feel like I’ve got any self-worth at all.	Feels negatively about herself	*New sense of self*	**Identity**
Nancy	You just think of yourself as an empty shell because I can’t think of anything else to say about it, I’m just an empty shell because my body feels completely empty and especially up there [point to head] and when I’m trying to think of something and I can’t think of it	Feels like an empty shell	*New sense of self*	**Identity**
Lynne	Dreadful and it makes me feel dreadful now that I can’t, I don’t feel myself, I don’t. I do say that my head is in the shed because it is. You can’t think the same and as much as you try, it’s hard to think because this isn’t me. I just wish a light would click on and say you’re better, but I know that that isn’t going to happen, and I know I’ve got to understand that but it’s pretty hard to live with.	Feels awful about having dementia	*New sense of self*	**Identity**
Lynne	I think I can rationalise it but sometimes I just can’t cope with the thought of it.	Cannot cope with the thought that she has dementia	*New sense of self*	**Identity**
David	It’s hard isn’t it. My life has changed altogether…Well it has changed a little bit I suppose. In what way, I don’t know really.	Acknowledges that his life has changed but cannot describe how.	*New sense of self*	**Identity**

Rose	Frustrated. It [dementia] makes you, it gets you angry with yourself and frustrated and you want to basically bang your head against a wall sometimes or bang your feet because you can’t really do anything, it’s just part of where you’re at and I don’t know. I’ve always been a doing person and to want to keep doing things, its hard but I keep trying my best.	Gets frustrated that she can no longer do the things she used to. No longer as active.	*New sense of self*	**Identity**
Rose	I get impatient with myself [when she cannot remember things or the aphasia gets in the way of a conversation]	Frustration.	*New sense of self*	**Identity**
Rose	I think it’s when I get tired and things like that, that I notice my weaknesses and odd times I have forgotten how to do things I don’t know what I am supposed to do, I really don’t know what I am supposed to do and that’s when you get all of these emotions and all of this stuff that, you know, and I get stuff like that at times and you just don’t know what you’ve done with things and it’s so frustrating so I do try and do, I think I do try and cope.	Tries to think hard when she forgets things but it gets frustrating and she does not know what she is supposed to do about it.	*New sense of self*	**Identity**
Louise	I tried to read a book the other day and I was a great book reader and I started, my eyes, they need a new prescription, well I thought they did but I can’t seem to get it to concentrate. I keep on reading that line all the time so I’m going back in the book.	Tried to maintain old hobbies [reading] and struggles to concentrate	*Maintaining normality*	**Resilience**
Pat	I do crosswords and I watch the game shows on the television…I have always enjoyed doing crosswords. I used to enjoy doing jigsaws but I find that sitting by the table doing the jigsaw, my back gets painful…But it isn’t only my brain, it’s my physical condition that doesn’t help me.	Always enjoyed crosswords, game shows and jigsaws but struggles as her physical health is not so good	*Maintaining normality*	**Resilience**

Rob	Chickens, ducks, geese and goats. I’ve got them on a bit of land... Five minutes down the road… I used to go twice a day but I only go once now…The farming of them is easy enough but like I say, I will have to give it up some time. It’s sad because it’s by hobby.	Looks after a couple of animals	*Maintaining normality*	**Resilience**
June	I just took it as well lots of people have so you know if I have got it, it doesn’t really matter, but I didn’t think I was as bad as that. That is probably the way I looked at it because you know you can’t do anything about it, you can’t stop it, so I just had to accept it.	Very accepting of her dementia diagnosis- lots of people have it, you cannot stop it, have to accept it.	*Remaining positive*	**Resilience**
Rose	The consultant said, you’ve got Alzheimer’s and PPA, Primary Progressive Aphasia. I was like [confused], a bit shocked but I was glad that I had found out.	Shocked at her diagnosis but glad to have found out about it.	*Remaining positive*	**Resilience**
Pat	I was glad to go really [to see the doctor about her memory] because I knew that there was something wrong and I knew that they were finding treatments, so I thought let’s knock the nail on the head and go and see him. And I was glad that I went. I was disappointed with the results, naturally, but at least I thought, well at least they can do something about it now.	Glad that she went to see the doctor about her memory but disappointed with the results.	*Remaining positive*	**Resilience**
Rob	Happy in a way, that I knew there was something wrong and I wasn’t just making it up but sad in the way that it was going to change my life and I knew that, and Kim did. It wasn’t very good to think about it then, I didn’t, I tend to brush things under the carpet and keep my head in the sand, brush things under the carpet and when this happened, I sort of didn’t know what to do. My mother and father had died so I’ve got no family, I’m alone, so I didn’t have anyone to talk about	Mixed reaction to his diagnosis, happy that he finally had one but also struggled to come to terms with it.	*Remaining positive*	**Resilience**

	it so I was on my own. And I just kept thinking about it, thinking about it and eventually I got used to the idea			
June	If it is happening, and you're nervous about it, it means that those nerves will go on the rest of your life, and you know, you have got to try and avoid that kind of thing. So I wouldn't want to be nervous about it, I just accepted it and I don't worry that much about it so if it happens it happens.	You have to accept your dementia and stop worrying about it.	*Remaining positive*	**Resilience**
May	I mean it's not like your own home. But I can't be on my own so this is the best thing…on the whole, it is very good. Food is good. The staff are wonderful. Very caring…I am spoilt. Yep, when I look at other people, I think I have got nothing to grumble about. I am lucky. And it's company.	Understands that being in a care home is the best option for her at the moment	*Remaining positive*	**Resilience**
June	I have sort of accepted it now but still want to go from here back home. But I don't see that happening. It's got to happen.	Does not like living in a care home and wants to go back home.	*Remaining positive- opposite*	**Resilience**
Louise	Tearful. Angry. Why me? And then all of the things that my ex husband said I was, horrible things, I felt like that, you know, I just felt that this has happened because of what I've done, you know. But I had a marriage like that, it was like everything was my fault so this was just another thing that was my fault.	Negative reaction to her dementia diagnosis. Reaffirmed the negative comments she had from her ex-husband. Believed it was her fault.	*Remaining positive- opposite*	**Resilience**
Lynne	Devastated [with her diagnosis]. I couldn't believe it. It was always something we would say please God, I don't have that.	Always said that she hoped that she did not develop dementia- and she has. She's devastated.	*Remaining positive- opposite*	**Resilience**

Louise	[Learning to play the piano] thought it would be a challenge that I could learn something by but then when we try to put it into practice, it became more and more frustrating…it really upset me.	Tried to learn the piano but it was not a pleasant experience.	*Participating in meaningful activities*	**Resilience**
Nancy	The more you use it, I was always told, use it or lose it, so I said I try as much as I can to use it. Even if its only for bingo. Because then I know I am doing something to keep my brain occupied.	Use it or lose it- so she tries to use it as much as possible.	*Participating in meaningful activities*	**Resilience**
May	I do a little bit of reading. Sometimes I do a bit of sewing and I have done a bit of knitting. But it’s hard, the time just goes.	Tries to keep sewing, knitting and reading but struggles to find the time.	*Participating in meaningful activities*	**Resilience**
Rose	I play a little bit [of keyboard] but not, I sort of tinkle a bit…having a bit of fun and things like that.	Plays keyboard for a little bit of fun.	*Participating in meaningful activities*	**Resilience**
Rose	I’ve made my own life story books. I’ve got three almost finished, there are pictures from where I was a baby and if I’ve got a memory, I will write it by the side of the picture. There’s a little bit of history about other things in that sort of time.	Makes her own life story books- hobbies.	*Participating in meaningful activities*	**Resilience**
Rose	I make my own cards, greeting cards, Christmas cards, Easter cards, people give me their old cards but I also make my own cards and I sell them… I think it was £174 the last time I gave money in [to the charity].	Makes greetings cards and sells them. The proceeds go to Alzheimer’s Society. Hobbies.	*Participating in meaningful activities*	**Resilience**
Rose	I’ve also started a bit of painting that I sometimes do which helps.	Finds that painting helps with her stress.	*Participating in meaningful activities*	**Resilience**
Rose	I feel I am ok with other things at the moment so I don’t do a lot of cooking... It isn’t so much lazy... It’s a bit like brain saving instead of brain draining.	Does not do unnecessary tasks-	*Participating in meaningful activities*	**Resilience**

		brain saving instead of brain draining.		
May	Yes we have got a craft club. It is once a week. Gardening club which we have joined in and planted seeds and different things. Sometimes we paint, sometimes we just talk. It is interesting. The chair Zumba…Yes, all arms and exercise.	Participates in all of the activities at the care home	*Participating in meaningful activities*	**Resilience**
Nancy	Word search, I love word search yes.	Likes to do the word search to keep her brain active	*Participating in meaningful activities*	**Resilience**
David	I read a paper but I read two pages and I get fed up. I don't mind doing quizzes, but its quizzes that I like. I can't do sudoku, I haven't got a clue, I leave that alone, it's too easy. It's the noughts and crosses I do and find the words.	Reads the paper a little bit and enjoys quizzes.	*Participating in meaningful activities*	**Resilience**
May	I done a lot of cross stitch. Ordinary sewing. Knitting.	Hobbies	*Participating in meaningful activities*	**Resilience**
Rob	I've got my phone and my laptop, I've got a laptop and a tablet. The tablet I use mainly for films. My laptop I use for, my tablet I use for films and laptop I use for downloading stuff and that.	Likes technology – laptop, tablet, phone. Watching films.	*Participating in meaningful activities*	**Resilience**
Louise	I crochet don't I a little bit, scarfs and things for the kids, if its kept simple, I can still do that. I think that's a breakthrough.	Crochets a little bit	*Participating in meaningful activities*	**Resilience**
Rob	I'm having guitar lessons… two a week, Kim pays for them, it's a treat and its good for me… The only problem with that is that I forget. I get it written down all of the time which is brilliant, but I need the paper in front of me so I can read it because I can't remember the chords which is terrible.	Guitar lessons- a treat	*Participating in meaningful activities*	**Resilience**

David	The garden, I like the garden, that's one thing I would like, a bigger garden, nothing too big because we've got that thing round by the side and I think there's three trees there, they are only miniature trees I think but we have apples off them, we've had grapes, but we haven't had anu nectarines yet but tomatoes, potatoes, beans…and it's a hideaway right because she moans…it's just somewhere to get away from the wife that's all.	Likes gardening. It's his escape from his wife	*Participating in meaningful activities*	**Resilience**
June	Well just that things will go steady and, the rest of my life, and I'll be as happy as I am at the moment. I suppose. I've not, I'm not looking for anything out of the way. I just live the life that I've got to.	Hopes for the future- very humble. Just to remain happy.	*Being optimistic*	**Resilience**
Beverley	I would just like to be happy and all my friends, I've got around me, I'm not on my own. Its just lovely.	Positive hopes for the future- be surrounded by friends	*Being optimistic*	**Resilience**
Pat	I don't get any worse, that's my hopes. I mean, my mother lived until she was ninety-five so I've got another ten years to go. As long as I don't get any worse, I don't mind, but I've told Hannah if I do get any worse then push me in a home out of the way. I don't want her to go through what I went through with my mother and what we went through with my grandmother, you now, it was hard, very hard going. And that's what I feel, she wants me to go up there and I think well if I do go up there, at least she won't be back and fore. She can still go out and see her friends without, I mean, I'll be alright in the house	Hopes that she does not get any worse in the future. If she does, she has requested that her daughter arrange a care home. She worries that her daughter will have to look after her, and will have a tough time of it, like she did with her mother/grandmother.	*Being optimistic*	**Resilience**
Rose	I am hoping that I don't get too much worse. Everybody goes at a different speed on the journey and I am hoping, because I keep myself busy, that it will help to	Hopes that keeping the brain working and keeping busy will slow	*Being optimistic*	**Resilience**

	keep the grey matter going longer. And the longer that I keep going, the older I get, it will be better because then I will be as best as I can at an older age… People that have lost it, they don't understand things, I'm just hoping that I don't get there too quick.	down the progression of her dementia.		
David	If it stays like this, I will be brilliant I will. That's one thing I don't want to happen is when I can't do something for myself, I don't want that.	Happy the way he is, does not want thing to get worse.	*Being optimistic*	**Resilience**
Rob	The scary thing is, I don't like the way its going and how it's going to go. In some way, I would not like, I don't really want Kim seeing me like this, I don't want her to see me like this, I don't want her to see me get worse, you know, because I know how much I've changed now and she's finding it hard and when I change more, I can't bare how she's going to be and I don't know what to do, there's nothing I can do. Well there's plenty of things I can do about it but yeah, so yeah, it has changed me.	Worrying about how his dementia will progress and the impact this will have on his family	*Being optimistic*	**Resilience**
Beverley	I have told most of my friends, well it is only fair to let them know.	Was comfortable telling her friends about her dementia	*Disclosing their diagnosis*	**Acceptance**
LYNNE	I didn't want to tell anybody when I was diagnosed, I really didn't. I didn't want to tell anybody which is silly because I haven't done any wrong, I haven't done any harm to anybody. It's just unfortunate that it's us and not them you know. But I didn't feel good about it at all and I thought that I can't talk to people, people are going to treat me differently	Does not want to tell people about her diagnosis	*Disclosing their diagnosis*	**Acceptance**

Rose	I think my friends, it was a bit like, well it wasn't like I told you so, but it was like thank goodness, at least we know now	Friends were supportive of her diagnosis when she told them.	*Disclosing their diagnosis*	**Acceptance**
June	It was my business so you know, if I wanted to tell them [about my diagnosis] I would and if I didn't I didn't do it.	Did not feel pressured to tell people about her diagnosis	*Disclosing their diagnosis*	**Acceptance**
Pat	She has become more bossy. No, she's very good to me. I couldn't manage without her. I couldn't cope without her. I had to be adamant about her going back home because she was down here all of the time, day and night, and I thought well she's missing out, she wasn't seeing her friends. She has made a lot of friends up there by going to the yoga class and different classes in the sports centre, she's made a lot of friends and you know, I don't want her to miss out on her friends by being down here.	Very appreciative of her daughter's support but also very aware that her daughter has her own life. Tries to encourage her daughter to still do the things she enjoys.	*Good support systems*	**Acceptance**
Nancy	Trystan's support, without that I think I would have been dead long before now… Without him I think I would have been dead a long time ago. Because as I say, I've had no support other than what I've had off Trystan.	Recognises how essential her husband's help is	*Good support systems*	**Acceptance**
Pat	Hannah reminds me [about appointments] because she takes me anyway. We always arrange most appointments when she is available. Hospital appointments, they come early enough for her to organise her, she teaches at home see, so she can organise her pupils then but she hasn't got many pupils since Reg and I have been poorly because she's been back and fore here, she hasn't advertised for pupils.	Relies heavily on her daughter to take her to appointments. This is impacting on daughter's life too.	*Good support systems*	**Acceptance**

Beverley	Alex: You still keep in contact with your brother don't you? Beverley: Yes, he Skypes me every morning, every day to make sure that I'm alright.	Uses technology to keep in contact with family members far away.	*Good support systems*	**Acceptance**
Rose	I have got good neighbours and good friends and my family is understanding, I feel secure that people care for me but then again, when you're by yourself, it's not always easy	Has a good support system.	*Good support systems*	**Acceptance**
Rose	My son in Yorkshire didn't used to come down very often but since this, he comes down about three times a year… is there anything you want? And he didn't used to be like that but he phones up and he wants to know everything, so he's changed a lot, which is good. So you know, out of a negative thing, comes a positive. He's coming down this weekend actually so he'll take me somewhere to eat but he always knows somewhere that's quiet because if I go in a café and there's too many people, I can't, I won't hear what you're saying and I can't be relaxed. So you know, that's come out of it.	Son has become more involved in his mother's life, more supportive, more interested. Also ensures that she is comfortable when they go out for meals -quiet environment.	*Good support systems*	**Acceptance**
May	Towards the end, I don't think I was [maintaining a clean house]. I had all the gadgets. Lovely little house. Two bedrooms, stairs in the living room, and I had had a glass panel put down the staircase, it was lovely wasn't it Laura. The garden was nice because Laura and her husband looked after it. They did my shopping.	Relied heavily upon her daughter and son in law to maintain her house.	*Good support systems*	**Acceptance**
Pat	Hannah does such a lot…Hannah, she does all of my shopping for me and she does a lot of things for me. So, she's had a stair lift put in her house so that if I feel like going up there for a couple of nights, I can go up.	Daughter does a lot of things for her	*Good support systems*	**Acceptance**

Rose	The sing group that I go to…I feel that they are part of me and I am a part of them. Because we're all, maybe different stages, it doesn't matter because we all understand that we've all got some problem and we'll, we don't have to worry that we will feel different to normal people. And they can be like a family as well so it's good…it exercises your brain but it also tires your brain but its good because it's sort of gets the cogs working.	Attends a local dementia singing group. People there understand her and they are all in the same boat. Good exercise for her brain.	*Good support systems*	**Acceptance**
Rob	There's a church… a very quaint little church and it's in there, in a little hall on the first Thursday or Monday or vice versa and we go there. We sit down, we chat, we have a quiz and it's all everybody with Alzheimer's and things like that so we are all in the same sort of boat.	Enjoys chatting with other people who have dementia	*Good support systems*	**Acceptance**
Nancy	I tend to bother with the people that I know know that I have got the dementia and know me other than being a dementia patient. I'll talk to you because you treat me nice and I treat you nice. But I mean not everybody feels that way see.	Tends to surround herself with people who treat her nicely despite her dementia.	*Good support systems*	**Acceptance**
Rose	My friends are understanding but they forget because sometimes I talk ok, and other times I find it difficult because it's the stress. And this is a lot of why I don't go out much with things and going to the shops, I find difficult as well and going on the busses.	Gets stressed a lot. Friends understand but sometimes forget because she has good and bad days. Finds a lot of things difficult-shopping, public transport.	*Good support systems*	**Acceptance**
Rose	I think that my friends have always been caring but they understand more about me not going out and going places with them and not being in noisy places.	Friends are supportive and understanding.	*Good support systems*	**Acceptance**

	They do think about that more which I give them credit for and you know, that’s what good friends are for.			
Beverley	I started doing singing [dementia singing group]…singing reconnects everything…I just love singing, it is as simple as that… They are wonderful the people there. You come out feeling, I wish I could go again. It is lovely. Tony: You come out of there with a restoration of your faith in human beings.	Expressing how good the singing group makes her feel.	*Being with people in a similar situation*	**Acceptance**
Rose	The singing group that I go to…I feel that they are part of me, and I am a part of them. Because we’re all, maybe different stages, it doesn’t matter because we all understand that we’ve all got some problem and we don’t have to worry that we will feel different to normal people. And they can be like a family as well so it’s good.	The singing groups offers a support network as everyone who attends is in similar situations	*Being with people in a similar situation*	**Acceptance**
Rob	We have done a group here on a Thursday, a singing group and I loved that, it was good	Singing group at the local memory clinic	*Being with people in a similar situation*	**Acceptance**
Nancy	Brilliant because everybody was on the same level. They either had dementia or vascular dementia and we just all mixed in you know. Not for us to forget names, they used to pin our names on us so people wouldn’t forget the names and make it uncomfortable for them … And we’ll go there and we had a song and we would all sing it.	Really enjoyed attending a local dementia singing group	*Being with people in a similar situation*	**Acceptance**
Nancy	I had to tell my brothers and sisters that I had it, and my sister said oh you stupid thing, you haven’t got that, I said that’s the trouble, I have.	Her sister did not believe that she has dementia	*Negative reaction from family and friends*	**Isolation**

Louise	She [Louise’s sister] had been a nurse all her life but she didn’t want to accept it [Louise’s dementia diagnosis] at all.	Family did not want to accept that Louise had dementia	*Negative reaction from family and friends*	**Isolation**
Lynne	My sister is younger than me…and she’s continually saying you’ve done something or what have you done that for, look what you’ve done again and I resent that sometimes I think you shouldn’t, I said well look, this is the condition but she doesn’t accept that this is the condition that’s happening to me, I’m not doing anything to make it happen, please god, I wish I was a lot better but she doesn’t understand.	Does not like it when her sister points out her the things that she is doing wrong.	*Negative reaction from family and friends*	**Isolation**
Nancy	It’s as bad as my sister saying I was a hypochondriac. I mean that hurt that did and she didn’t realise, it didn’t bother her, she said I’m nothing but a hypochondriac, you imagine these things you do she said, I said well I must be very good I said I must deserve an Oscar …They said they made a mistake. Nobody as jolly as you could have a dementia…It wasn’t dementia, it was senile dementia. And that’s what they said, they said you haven’t got senile dementia, no way… But I’ve always been like that because I’d rather people laugh and joke than cry and be miserable.	Her sister does not believe that she has dementia. Refers to her as a hypochondriac	*Negative reaction from family and friends*	**Isolation**
David	My younger son thought I was joking when I said that, they were in stitches they were	Family thought his diagnosis was a joke	*Negative reaction from family and friends*	**Isolation**
Pat	They wouldn’t believe me [that she has dementia]. No, people still don’t believe me…Well I think it’s because it hasn’t materialised like Roy’s did... I have kept so good…Although I know that I’m worse than I was before Roy passed away, I’m still not that bad…But a lot of people have said you wouldn’t think that you’ve	People do not believe that she has Alzheimer’s disease because she is not at an advanced stage.	*Negative reaction from family and friends*	**Isolation**

	got it. But I think they think about people like Roy was, having progressive Alzheimer's.			
Nancy	I think everybody is judged on something, and to have this, it's like as if you've got some contagious disease that will jump from one person to the next and then from that person to another one until everybody is infected with it… I feel all the time now is miserable because I've got this and I'm, it's like I'm walking around with a big sign, beware, dementia.	Feels like people avoid her.	*Being avoided*	**Isolation**
David	Well I think they think something bad is going to happen to me and that's the impression they give me sometimes you know.	His family behave differently around him	*Being avoided*	**Isolation**
Nancy	I wear a piny when I have food, every time because I don't get it to my mouth, I either spill it down the front of me or whatever and I get the feeling that people will look at me to see what I will do, I don't know if they expect me to shove it up my nose or something like you know, but they are looking at me, I can see them looking at me when I'm doing things because they see if I'm doing something stupid… I do find that people do watch you to see if you're going to do something stupid and they can have a laugh at it…, I think people judge you every time they see you.	Feels self-conscious, and notices people looking at her.	*Being avoided*	**Isolation**
May	Alex: Do you think since you came to live in here that you see your friends more or less than you used to? MAY: Less… just some people have stigma about it…Lots of friends but you don't see them.	Thinks that friends do not visit her because of the stigma associated with dementia/care homes.	*Being avoided*	**Isolation**
Nancy	People look at me strange sometimes	Noticing that people are treating her differently	*Being avoided*	**Isolation**

Nancy	I felt a real idiot then. Going to the nut doctor [psychiatrist]	Felt like an idiot going to see a psychiatrist	*Being avoided*	**Isolation**
Rose	You get a brain freeze when you're talking and you just go blank and you can't think when you're talking to somebody and you're explaining something to somebody. I used to be able to have a good conversation and a good laugh and things like that but now it's completely the other way.	Feels that she can no longer converse like she used to, no longer able to have a laugh because her mind goes blank.	*Problems communicating*	**Isolation**
Louise	I'm making an effort all of the time, I can't just talk to people anymore, it's an effort.	Struggles to talk to people.	*Problems communicating*	**Isolation**
Rose	I get mentally tired very easily. I have to have a rest in the afternoon. Your body isn't tired but because you concentrate, because you are thinking about because you have got to talk, you are doing like three things at once which isn't easy. It is very stressful at times.	Gets mentally tired easy and stressed.	*Problems communicating*	**Isolation**
Rob	Not to be a burden on anybody if I can. Because I don't, Kim wasn't, Kim didn't marry me to look after me like I am now or like I'm going to get and that's the other thing that upsets me more than anything in my life, I regret this is happening to us because like I said, we had a great relationship, a great few years, really good. And this, it's not the same now, it's not the same and I'm sorry for that and I wish it wasn't. I would love to go back to the way I was but like I say, I keep saying the wrong things and doing the wrong thing and I just can't do that, I've tried to do it and do it right but the more I try, the more it gets worse and I can't, I don't know what to do about it, I cant do anything about it. I just don't know what to do. I want to get better, I must get better.	Worrying about the future and becoming a burden on his wife. Also thinks about the part and what he's lost – great relationship with his wife.	*Burden*	**Isolation**

Lynne	I'm independent, I like to do my own things and I haven't been able to, I'm relying on my daughters and that's an awful feeling where you, I don't want them to be burdened by me, they do say that I'm not a burden but I know it's not	Does not like relying on her family. Feels like a burden.	*Burden*	**Isolation**
May	If I could be a bit better I would like it. But that's what I wish, that my daughter, granddaughter and son in law-make life easy for them, it would be marvellous.	Wants to make life easier for her family.	*Burden*	**Isolation**
Pat	I'm hoping that it will stay and keep it [her dementia] at bay. I don't want to get any worse, after seeing them [her mother, grandmother and husband getting nasty], you know, I've said to Hannah, if I get like that put me in straight away somewhere. I don't want her looking after me on her own.	Worried that she will become nasty like her other family members and does not want her daughter having to look after her is she's like that.	*Burden*	**Isolation**
Rob	Kim says that I'm not the same person she married and she gets upset about that very much. Which I can understand. I mean the way I was told regarding that, as it goes on and on, I'm not going to know much about it. I'm going to go dodally or whatever it is and so I'm not going to know much about it. It will all be down to Kim. I don't know how she is going to cope. I think she's finding it hard now to be honest, I think I would if I thought there was something wrong with Kim. I just think, I feel sorry for her and my family because, like I say, I'm not going to know much about it, I'm going to forget and I might end up forgetting to eat and certain things,	Worrying about the future and that his family will not be able to cope.	*Burden*	**Isolation**
Louise	The plans were to get a villa in Spain and spend our holidays out there, so the kids could use it and everything else and continue working until we got to	Having to completely change plans for their retirement because of	*Burden*	**Isolation**

	the stage where we could just chuck everything, sell this place and move out…it makes me feel guilty because I know he really want to go, but we can't.	dementia – makes her feel guilty		
Rose	What I would say is trying to cope where I shouldn't be trying. I shouldn't be trying to cope, I should be me.	She feels that she should not have to try and cope, she should just be able to be herself and things come easily.	*Struggling to cope*	**Isolation**
Nancy	Life. That's true, life. I struggle with it every day when I get out of bed in the morning and my inside is struggling until I go to bed at night, and I go to sleep… when you feel like that, there's just no life at all that way.	Has an everyday struggle with life	*Struggling to cope*	**Isolation**
Rob	"Is there anything in particular that you struggle with?" Life, it's just hard, you know, I mean Kim will say a lot for me in that I'm not dangerous but I'm not the same, I know I'm not the same person and I'm so angry inside with myself, so angry with myself. I don't like it. This is what I really struggle with.	Struggles with life. Has a lot of anger towards himself.	*Struggling to cope*	**Isolation**

V.2 Family members

Location of Statement	Statement	Formulated Meaning	Theme Cluster (Subtheme)	Theme
Bethany	She liked to do her own thing and be quite independent, too independent sometimes, she wouldn't let you do anything for her…	Mother would not let her do anything for her, now she does everything.	*Acknowledging what has been lost*	**Loss**
Darren	It has changed quite a bit since the Alzheimer's has come on. The cooking has stopped…The baking has gone through the window.	Wife has stopped cooking	*Acknowledging what has been lost*	**Loss**
Darren	Sad. I would be lying if I said that I didn't miss my old life and I would have it back tomorrow if I could but that's not going to happen	Misses his old life	*Acknowledging what has been lost*	**Loss**
Gail	He is a lot quieter, he didn't talk so much, he was quite content to just sit in the chair, have the tele on. No he wasn't the person he'd been before. He had changed. Much more subdued because he was such a, a lively sort of man you know, you always knew he was around and he had views on everything and, but that changed.	Husbands temperament had changed, a lot more subdued.	*Acknowledging what has been lost*	**Loss**
Sara	It is more of a worry because you see things that you never thought you would ever see. And how people are. And it is so sad. Upsetting and sad. From what they are to what they have become. Very very sad. Very.	From what they are to what they have become.	*Acknowledging what has been lost*	**Loss**

Tony	It’s inevitable that it [their relationship] will change. I have to say that it has drawn us together a little bit more, now what I mean by that is she had a little bit of her life and I had a little bit of my life which were mutually exclusive from each other ..We are sort of joined at the hip now sort of thing you know. We still enjoy each other’s company.	They used to be individuals, now they are a pair.	*Acknowledging what has been lost*	**Loss**
Darren	Relationships change anyway, we understand this, people evolve, situations change and the part of being married is that you have got to change with it, it’s either you change or you break. It’s one or the other. I’ve got no intention of every going anywhere else or being with anyone else, as I said to her when I married her, it could have been me in this situation and I know for a fact that she wouldn’t have turned her back on me and there’s no way that I’m ever going to turn my back on her so that’s the way it is. We just get on with it.	Their marriage has adapted to their new situation and they will continue adapting it. No intention of being with anyone else and is committed to being with his wife.	*Acknowledging what has been lost*	**Loss**
Hannah	Well with Mam, things haven’t changed that much but Dad also had dementia and I found it difficult towards the end when he wasn’t talking much and getting annoyed, that was very difficult. So yeah. But I think it was difficult for Mam to cope with as well. He couldn’t understand what was going on towards the end.	Her mother’s dementia has not progressed much but her father had dementia towards the end of his life and Hannah found that difficult to cope with	*Acknowledging the loss to come*	**Loss**

Kim	He was offered a place in a day care centre, but we turned that down, I don't feel it would do him any good. Day care tend to be more further on down the line, people with dementia that's further advanced and I think that if you put him in that situation now, it would frighten him. Yes, he knows he's got dementia and yes, he probably knows exactly what is going to happen in the end, but he doesn't need it put in his face"	Worried that a care home would show Rob how bad his dementia could get and that would not be good for his mental health	*Acknowledging the loss to come*	**Loss**
Hannah	It was difficult to watch Dad going through it. When I, I suppose, I know what is to come from seeing Dad and I hope that Mam won't get that bad but she's doing very well at the moment.	Seen her father go through dementia and does not want that for her mother	*Acknowledging the loss to come*	**Loss**
Dianne	I mean I've got it easy compared to some of the people whose husbands and wives are really bad you know, and then I do look at them and I think oh god I've got that coming, I know it's horrible but it is hard. And this is at an easy stage really but it's still hard.	Struggling with her current situation but compares her life with others affected by dementia and can see what's to come.	*Acknowledging the loss to come*	**Loss**
Hannah	Not really because my Gran and her Gran had Alzheimer's, I think she realised that she needed to go and see somebody at the time.	The family history of dementia made it easier for Hannah to convince her mother to see about her memory problems	*Acknowledging the loss to come*	**Loss**
Gail	When you're in a home like this one, which is marvellous, but you see how they are all deteriorating all the time, and	Being around other people with dementia did	*Acknowledging the loss to come*	**Loss**

	how bad some of them are, and I think oh God, it’s around the corner for him isn’t it. He’s bad and he’s going to get even worse, and that is difficult, really difficult.	not help. Only increased her anxiety.		
Kim	It’s a gradual thing and you don’t know if he’s just getting old, just being daft, you just sort of write it off don’t you, oh he’s forgotten to do things, he’s just being daft, oh you’re getting old Rob, but it got to be a bit more than that and that’s when we started looking into it further and he had his diagnosis	Thought it was just old age not dementia	*Loss of awareness*	**Loss**
Sara	She still doesn’t know she’s got dementia, I don’t think. Well I know she doesn’t realise.	Her mother does not know that she has dementia	*Loss of awareness*	**Loss**
Tony	I think initially, she has the nature where she tried to block things out, I think there was an element of that to start with and it took quite some time for her to understand that she has that, she has Alzheimer’s. And I think when that sat with her more comfortably, things were a lot better then because Beverley would say to somebody, well I’ve got Alzheimer’s.	Wife tried to block out her diagnosis but once she came to terms with it, it made it easier for them to tell other people.	*Loss of awareness*	**Loss**
Kim	He wasn’t really reacting to them at all [his dementia symptoms]. It didn’t dawn on him I don’t think to start with, it was just. He did start to get frustrated by it, the fact that he couldn’t remember things and he kept losing things as well…But yeah,	Initially her husband did not notice his forgetfulness, but as it got worse, he began to get frustrated with himself for not remembering.	*Loss of awareness*	**Loss**

	frustration more than anything, the fact that he was forgetting stuff and all the rest of it, couldn’t remember what he was doing.			
Pippa	He doesn’t think he’s got a problem. He says to me sometimes “oh my memory is not what it was” or “I knew I meant to do something but I cant remember what it was” but if you say to him “Dad its your memory, you have dementia” he doesn’t have a problem, he refused to go to the memory clinic because he doesn’t have a problem, so as far as he’s concerned, it’s just absent mindedness.	Dad refuses to admit that he has a problem. Does not know that he has dementia	*Loss of awareness*	**Loss**
Gail	He knew it was a memory clinic, he knew he had problems, he used to say “I’ve got problems with my memory. I can’t remember things” but he didn’t say it was dementia.	Her husband knew that he had problems with him memory but did not know that he had been diagnosed with dementia		
Tony	When some of the symptoms of dementia started to show and I didn’t understand any of this…, it was Beverley’s twin sister who mentioned this …I felt a bit foolish to be truthful because you think the one you’re closest to, you would notice it first but apparently that’s not always the case.	Feels foolish that he did not pick up on the fact that his wife may have the onset of dementia. It was only when his sister in law mentioned it that he considered it.	*Loss of awareness*	**Loss**
Gail	I think it’s changed [her relationship with her friends] because I think a lot of it is with couples, and that if we’d gone out for whatever reason, I wasn’t a couple	Now like a single person	*Loss of a spouse*	**Loss**

	anymore, I'm on my own now, its like being a single person really.			
Gail	So that strong person that we all had is gone and everybody misses it, all the family miss it, it has had quite a devastating effect	All of the family miss the strong person that was their grandad	*Loss of a spouse*	**Loss**
Gail	It still looks like him but he's like a shell, there's this shell and him in there has gone, he isn't there anymore, he is just not there, he has gone, where ever he's gone. But I know its him and its just not fair that he's not there.	Her husband is gone and she has been left with an empty shell that looks like him	*Loss of a spouse*	**Loss**
Kim	Rob is not the person that I married now, that sounds hard doesn't it, sounds horrible. Rob now is a different person to the one that I married seventeen years ago. The person that I loved and married is gone, now its like living with, not like living with a stranger because obviously I know him, but its like living more with a friend. Its down to that emotional side of things again, that closeness that you have in a personal relationship. Yeah, its hard. Very hard.	He is no longer the person that she married. Her husband is gone and she's living with a stranger	*Loss of a spouse*	**Loss**
Kim	I miss, the closeness, the loving side of it, not so much the sexual side of it, its like the cuddles and the affection. Routine stuff, if it's a routine, he'll do it, Kim is going out of the door therefore I will get up out of my chair and give her a kiss goodbye because that's what I	Husband will do something if it is routine. Not the sexual side of things that she misses, just the affection.	*Loss of a spouse*	**Loss**

	do…That's scripted, routine, its programmed so that's what he does but it's the natural spontaneous stuff, stuff that he's got to pick up on, emotions, that he doesn't do anymore and that's really hard.			
Kim	I was going to say that there's no love, but he does love me in his own way, but it's a different kind of love, there's no sexual relationship either anymore	No sexual love within their marriage anymore.	*Loss of a spouse*	**Loss**
Kim	One of the things with Rob that I miss now is the closeness in the personal relationship, the natural spontaneous affection. Rob has got a diagnosis of frontal temporal lobe dementia, possible Alzheimer's variant as well, and one of the things that causes is changes in things like empathy, picking up on emotions, stuff like that, and that's what I miss. I miss the comfort and that side of things, the personal stuff.	Misses the natural spontaneous affection from her husband.	*Loss of a spouse*	**Loss**
Kim	Didn't sign up for this…I think because I am so much younger than him as well, I'm twenty years younger than him…I said how would you have felt then, twenty years ago if your life had just stopped? Because effectively that's what's happened to me. To think that I'm only forty-nine, and this is my life for the next god knows how many years, and that's the hard thing	Did not sign up to be a carer when she married Rob.	*Loss of a spouse*	**Loss**

Kim	My life is basically on hold, what do I do? Put up with it. Like I said, it’s not what I signed up for and to some extent, yes Rob is not the person that I married.	Did not sign up to care for Rob when they got married. Should she put her life on hold?	*Loss of a spouse*	**Loss**
Kim	Is it wrong for that partner to have another relationship, a sexual relationship we were talking about, because that partner is very much missing out on their life. Is it wrong for them to have a life outside of dementia?	Is it wrong to have an intimate relationship outside of your marriage?	*Loss of a spouse*	**Loss**
Kim	I really missed having somebody to realise I was upset and put their arms around me and give me a cuddle and tell me it will be alright, even if its not going to be alright, just sort of make you feel better.	Misses having someone to reassure her when she is upset	*Loss of a spouse*	**Loss**
Gail	I don’t think they [friends] would have taken very kindly to it, coming in here [care home] because they wouldn’t want to see him the way he is now, I don’t think.	Friends do not visit her husband in his care home.	*Loss of friends*	**Loss**
Sara	You’ve got to keep coming to see her, you can’t not, you can’t forget about her.	Insists on visiting her mother even though her family do not understand why.	*Loss of friends*	**Loss**
Pippa	His friends distanced themselves, and even now, nobody visits him…it is almost like they are frightened to approach him because they don’t know how he’s going to react or whether he’ll remember them	Her father’s old friends do not visit him in the care home. They are frightened to approach him.	*Loss of friends*	**Loss**

	or what he’s going to say but now it is just literally myself that visits.			
Laura	there are others, and I understand why, that have shied away. They say they will come and visit but they won’t. People have their own lives and there’s also that feeling of not knowing what to say…and there are others that I think have got a mental picture of someone who is sat in a chair, slumped, drooling. Not able to communicate. Because there is a stigma with the word. And it took me a long time to explain to my mother that it is just a word. That the word dementia covers a lot of different areas. It does not necessarily mean that someone is in a position where they can no longer do anything for themselves.	Old friends do not visit because they don’t know what to say – stigma with dementia and care homes	*Loss of friends*	**Loss**
Trystan	We got two sons and none of them do come near us.	Their son’s do not want anything to do with them	*Loss of friends*	**Loss**
Pippa	My husband is a bit sort of, well he wont remember you love so why are you bothering to go in? because if I have been in today now and I have spoken to him, if I go back in there now he wouldn’t remember I’d been in or given him his papers or anything.	Her husband does not understand why she needs to visit her dad regularly	*Loss of friends*	**Loss**
Darren	I still work full time at the moment…but we know that there will come a day where I’ll probably have to finish work to stay at	Still works full time but understands that he may	*Future*	**Conflict**

	home but hopefully that’s a number of years down the road and that I can work my way almost up until retirement where financially we’ll be better off	have to stop working to care for his wife		
Gail	I think when it was first diagnosed, well you hear of all these things where people can carry on as normal and it takes a long time and you can live with it but I think in reality, it wasn’t so, it was quite difficult. When he was at home, we knew that he had it and there were lots of problems then. Particularly in his personal care, in his falling, in his frustration because he knew he couldn’t do things like he was doing before… all this mounted up and he must have realised because he did say to me in about 2014, he said “you must take up power of attorney” so he must have realised then that he wasn’t coping very well.	When her husband was diagnosed with dementia, they had hoped that they could go on as normal for a while but that was not the care. Her husband deteriorated quickly.	*Future*	**Conflict**
Pippa	Occasionally now my Dad will use his hands, which is fine by me, if he eats using his hands, as far as I’m concerned, he’s eating but he occasionally forgets how to use a knife and fork, and I noticed the other day I came in particularly early and he was getting dressed and he was trying to shave but he hadn’t taken the guard off the razor and it was the wrong way around. So there’s little things that I think, well why is that happening?	Knows that her dad will deteriorate or forget how to do certain tasks (shaving or using a knife and fork) but this fine.	*Future*	**Conflict**

Darren	we just try to stay positive and think positively that we could be fifteen years down the line and she’s not much worse than what she is now. And that’s the way we try to look at it. You know, we watch that thing with the couple that does the canals, Prunella Scales, and she’s had Alzheimer’s for a number of years and she doesn’t seem to be deteriorating that quickly, and that’s all we can do is hope for the best and say well you know, we might have another fifteen years of you being pretty much like you are now. So that’s what we hope for, we just try to stay positive. It’s all you can do.	Try to remain positive. Hoping that things will stay the same as they are now for the foreseeable future.	*Future*	**Conflict**
Trystan	Hopefully she doesn’t get any worse.	Does not want his wife to get any worse.	*Future*	**Conflict**
Darren	We know that the future is uncertain so we just hope for the best but whatever it is, we’ll deal with it.	Trying to remain positive	*Future*	**Conflict**
Dianne	I hope he doesn’t get too bad you know, that’s the only hope that you can really have. If he stays like this or even, I know at some point he’s going to go downhill a little bit but as things are, I can manage, I can cope.	Hopes that her husband does not get to the point where they cannot cope	*Future*	**Conflict**
Sara	I just hope she stays happy and content and I hope she doesn’t get too bad that she’s just in bed or you know, drugged. I don’t want that for her. I just hope she dies peacefully in her sleep or something	Hopes her mother stays happy and dies peacefully in her sleep before she gets too bad.	*Future*	**Conflict**

	you know, before she gets really bad. If she's going to which I presume they all go down that slope don't they. So I hope she stays happy.			
Pippa	That he stays happy, relatively calm, at the moment we're on an even keel, I know there's going to be highs and lows, he has good days, he has bad days, bad days when he's pacing he can't be distracted, I hope and this may sound really hard that if something were to happen, because it will and I'm realistic about that, it happens quick and that he's here and he's warm and comfortable but at the moment he's enjoying himself…as things stand at the moment he's having probably a more fulfilling life here than he did in the last year of living in his own house, so if things carry on like that, until such time when he's unable to, then no I think that's the way to go forward really.	Wants her Dad to remain happy and comfortable. If something were to happen, she hopes it will be quick and that he is in the environment that he is familiar with.	*Future*	**Conflict**
Laura	She'll stay happy, I hope she doesn't decline any further, but I know she will be taken care of if she does.	Hopes that her mother will remain happy and does not decline further	*Future*	**Conflict**
Pippa	I think well he's going a bit further along but as long as he's happy, then that's fine and If I do go in and he doesn't recognise me then that's fine so long as he's happy and he's well cared for	Her Dad being happy and well cared for is all that matters	*Future*	**Conflict**

Darren	So far we've had a fantastic life together and hope to have a number of more years with her, regardless of the Alzheimer's.	Does not want the dementia to influence their lives together	*Future*	**Conflict**
Darren	We had every intention of spending our retirement abroad and that was also part of the personality changes that when she came out of hospital, that was put straight in the bin...all of that is completely gone. It's no fault of Louise's, it's just the way it is.	Plans for their retirement have been put in the bin. No longer a possibility. No one to blame, just the way things are.	*Future*	**Conflict**
Darren	We are hoping that the medication that they have got these days will actually prolong it as long as possible.	Putting a lot of faith in the medication to slow down the dementia progression	*Future*	**Conflict**
Darren	Hopefully she gets run over by a bus or something before that happens [her dementia gets too bad].	Wants his wife to die from something quickly rather than experience the slow deterioration of dementia	*Future*	**Conflict**
Darren	Nothing surprises me. If I've got to wipe her arse, I'll wipe her arse as well [laughing].	Maintains a sense of humour about the possibility of his wife's condition deteriorating. Also demonstrates his commitment to he.	*Future*	**Conflict**
Gail	In one word, horrendous. Absolutely horrendous, my life is turned upside down, but I've got to cope, I don't have a choice and, I don't know, I think it's because you don't know how its going to be, you don't know what's around the corner, how long is it going to keep going	Life with dementia is horrendous. She knows what the end is going to be like and that's hard but she has to cope.	*Future*	**Conflict**

	like this? I know what the end is going to be, that he can't survive it, and things are going to get worse than they are now, and that's hard. So there's no other answer is there really. You just have to cope the best way you can.			
Kim	My hope for the future is to survive and that's all you can do.	Just hopes to survive.	*Future*	**Conflict**
Gail	I was given enough [information about dementia in a nursing home] to know what the outcome was going to be and how it was going to go, I realised from early on that this is something that's bad and that there's no cure and there's nothing that I can do about it, and you just give him as much care as you can, and make him as comfortable as possible really.	Nursing home ensured she was aware of how bad the situation could get	*Future*	**Conflict**
Pippa	I don't want my father dying on a hospital bed in a corridor with six other people near some doors, when he's got a lovely bed here in the surroundings he knows with people he recognises and that's what I want for him so we're all in agreement with that. So that's to come and that's hard, that's, that's a bit I'm not trying to think about at the moment but it is there in my mind it is all something like we'll have a chat with palliative care nurse and I'm thinking it's too early but I don't know, I don't know when its going to happen.	Very prepared for the future. Made palliative arrangements within the care home.	*Future*	**Conflict**

Gail	Future hopes, that he won’t deteriorate much more than he is at the moment. And I don’t know what else to think because we know the prognosis is pretty awful and I’m trying not to think of that, just for him to be as content and as comfortable as possible	Tries not to think about the future because it is too upsetting	*Future*	**Conflict**
Gail	It is as well that I didn’t know, in hindsight, I wouldn’t have wanted to know how it is now, it was better that I didn’t know I think. That, how bad it can be.	Was not aware early on in the dementia that it would get as bad as it did.	*Future*	**Conflict**
Bethany	It just seems never ending and you know that there’s no way that things will get better, so I think that’s in the back of your mind all of the time as well. It’s really stressful, it is really stressful. I’m constantly worried about her. There’s no solution for us either	No way for things to get better. A constant worry	*Future*	**Conflict**
Geraint	I’m hoping that she doesn’t get into a situation where she just goes into a recluse and she doesn’t want to do anything because at the moment, even though she doesn’t, says she doesn’t do anything, she does get involved, but I know that some of the women down there won’t even come down to the thing because they don’t want to, they don’t want to participate with everybody else so I am just hoping that she just enjoys what time she’s got left you know and makes the most of it really, because I’ve noticed	Does not want his mother to stop participating in social activities.	*Future*	**Conflict**

	that she is deteriorating you know compared to when she came in six seven months ago she's definitely deteriorating, but it breaks my heart really.			
Kim	He was offered a place in a day care centre that he could have gone to x number of times a week or whatever but we turned that down at this stage because I don't feel that he's at the stage for that at the moment, I don't feel it would do him any good. Day care tend to be more further on down the line, people with dementia that's further advanced and I think that if you put him in that situation now, one I think it would frighten him and depress him. Yes he knows he's got dementia and yes he probably knows exactly what is going to happen in the end but he doesn't need it put in his face.	Did not think it would be helpful for her husband to go to day centre. It would frighten him to see what the future may hold for him.	*Future*	**Conflict**
Gail	It's hard to cope with, the fact that I cannot do anything what so ever about it and that its going to get worse, its very upsetting to see how he is now and how he's likely to become because you look around and you see how they're all falling down on it, on the journey, and there's no rhyme or reason to the time of it, because they're all different	Feels helpless, nothing she can do. Things will get worse and there's no information available regarding when or how.	*Coping*	**Conflict**
Geraint	My sister said that she couldn't cope anymore in the house with her [June] because it was just too much work …	His sister could not cope with caring for his mother	*Coping*	**Conflict**

	they [social workers] did an assessment and they said that she wouldn’t be able to live on her own anyway even if my sister could cope			
Sara	We had loads of discussions and it was horrible to think that she would never go back home again …she’s happy as Larry here. It’s us that’s the problem, not her, because we get upset that she’s in here… It is very hard to think that your Mother is in a home, even now when people ask me, I fill up. I say “oh she’s in a home, she’s got dementia” but at the end of the day, it is what they need isn’t it	Struggling to accept that her mother is in a care home	*Coping*	**Conflict**
Dianne	Hard, there’s no two ways about it, it’s not knowing from one day to the next… You feel you’re treading on eggshells… He comes downstairs and I think can I say good morning now or? So, I wait. And if he says alright, I think oh we’re having a good day today, so I’ve just got to play it by ear	Every day is a struggle when she does not know what mood her husband will be in one minute from the next	*Coping*	**Conflict**
Kim	He is forgetting stuff and not remembering stuff now because he will say something and then he’ll backtrack and oh it doesn’t matter, don’t worry about it because he can’t remember what he was saying and so he covers it up by saying that it doesn’t matter, don’t worry about it. But it’s his personality that’s changed, that I miss. The memory side of	The forgetfulness can be a problem but Kim finds it more difficult to deal with the personality changes.	*Emotionality*	**Conflict**

	it can be a nightmare, he forgets things, forgets to do things, forgets what he's doing and he gets frustrated but it's his personality changes that I miss more than anything.			
Trystan	She also suffers with Charles Bonnet syndrome, I don't know if you know that. She sees people, and people think, tell her that I'm no good and that to keep a knife under her pillow, which she's done on several occasions, so I got, so I normally check those.	His wife sometimes takes a knife to bed.	*Emotionality*	**Conflict**
Trystan	She didn't recognise me. Sometimes she don't recognise me now. Like this morning.	Wife does not always recognise him	*Emotionality*	**Conflict**
Tony	It can be stressful, I hope Beverley won't take this wrong, it can be stressful. Sleep is one of my problems.	Finds it stressful to care for his wife and sleeping has become a problem	*Emotionality*	**Conflict**
Gail	I must admit, I have all these different feelings, I feel guilty because sometimes I think look at the mess you've landed, I can't help it, I say "look at the mess you've landed me in", and then other times I feel guilty and I feel really sad and then I think of all the loss and what it is going to be like in the future and how long is it going to go on like this, its all mixed really.	Has all mixed emotions about her situation.	*Emotionality*	**Conflict**
Pippa	With my mother he was less tolerant, my father has never been a violent man, he's never raised his hand to anybody, I've	Her dad's temperament changed. Frustration and less tolerant	*Emotionality*	**Conflict**

	never even heard him swear, up until two years ago when he was getting frustrated with himself and when my mother kept saying to him “you’ve done that” it ended in a row …I could pull up outside [their house] and hear them screaming at each other on the drive way.			
Gail	All mixed emotions, of course I still love him but I get angry and I’ve got a loss and there’s nothing I can do about it and I don’t know, its so mixed up. And then I still feel guilty as well because I look at him and I think aww you poor man, why are you like this? And its all sad, absolutely sad.	All mixed emotions	*Emotionality*	**Conflict**
Tony	I can be very impatient, but I’ve learnt to control that a little bit now…I have learnt to manage myself better, shall we say, although I still, now and again I get frustrated and I bark at you a little bit because I’m a human being and she feels the same about me sometimes.	Tries to be more patient with his wife but sometimes his frustration gets the better of him and he will “bark” at his wife.	*Emotionality*	**Conflict**
Kim	He lies in bed on his tablet watching a film because he doesn’t pick up on it…I tend to go off on one because I lose my temper, he then gets upset because he doesn’t realise and then he will turn around and say well come here, do you want me to give you a cuddle? Well then I throw my toys out of the pram and say no I don’t because you don’t really want to	Loses her temper sometimes when her husband does not realise she is upset. Then does not want his affection because she has had to ask for it.	*Emotionality*	**Conflict**

	give me a cuddle, you’re only doing it because I’ve asked you.			
Dianne	I try not to show it but I do get angry at some of the silly little things that he does and says you know.	Can get angry with her husband but tried not to show it.	*Emotionality*	**Conflict**
Laura	Frustrating. I can’t think of any other word to describe it. It is frustrating. Even this morning I have sat here and I have listened to my mother talk to you and I can hear discrepancies in the things that she has said to you. It is hard not to jump in when she says something that is not accurate, I would not say untrue because in her head it is true, but it is inaccurate. To me it is just really frustrating. It can wind me up the fact that she is very repetitive. I know that she cannot help it but when you have heard the same story over and over and over and over it does tend to get to you.	Finds it frustrating when her mother repeats herself or says things that are not accurate.	*Emotionality*	**Conflict**
Laura	As someone who is short tempered, I am fiery, I have calmed down over the years, I have learned to accept that she can’t help what she is doing. I try to bite my tongue. I try not to correct her. Sometimes I do. Sometimes it just blurts out. Sometimes I can’t take a step back and let her get on with it.	Tries to bite her tongue but occasionally she cannot help herself.	*Emotionality*	**Conflict**
Geraint	We are up here every day or every other day, so yeah, it is quite difficult, her relationship is, even though I know she	Tries to see his mother regularly but knows that	*Emotionality*	**Conflict**

	still loves us both to bits, when we see her, she's like all over us but within twenty minutes of me disappearing she probably tells everybody "I haven't seen my son for months"	she cannot remember him visiting		
Darren	[Life with dementia is] Stressful, yes, and sometimes hilarious. It is more difficult when you're trying to work and trying to balance everything and fit other things in around it and try and maintain a bit of sanity for yourself, that's the hard bit. But I seem to be doing alright.	Struggles to juggle everything but tried to maintain a sense of humour	*Emotionality*	**Conflict**
Darren	Nothing surprises me. If I've got to wipe her arse, I'll wipe her arse as well [laughing].	Maintains a sense of humour about the possibility of his wife's condition deteriorating. Also demonstrates his commitment to he.	*Emotionality*	**Conflict**
Bethany	We've tried to be as upbeat as we possibly can about it so we do laugh as much as we can about things as well. We got lost in the car the other day and my mother ended up telling us the way	Finds humour in situations	*Emotionality*	**Conflict**
Gail	He is ever so funny at times because it's still somehow lodged in this brain of his and he said to me recently "this place" he said "is costing a lot of money" oh I said "is it?" "one hundred pounds" now a hundred pounds to him is absolutely nothing but you can see and I sometimes, a lot of them do it here, they have a cup	Manages to see the funny side of things	*Emotionality*	**Conflict**

	of tea or whatever “how much do I owe you for this?”			
Dianne	He’ll forget which child he is talking to and, you know, silly little things. So I said to him I’ll write labels out and when they come here, I’ll put them on them so you know which one you’re talking to. You’ve got to pass it off as a joke, it’s not funny but you’ve got to try and make it funny haven’t you.	Trying to add humour to the situation	*Emotionality*	**Conflict**
Sara	She was very strong, her personality has changed…She would sit there with a poker face, she would never see the funny side of anything, we always used to pull her leg about it, but now, she’s gone the other way, she’s more funny, type of thing…like she was quite strict, strict as a mother you know and strict-ish as a grandmother and didn’t like you messing about … but now she’s different.	Her mother’s humour has changed. Used to be very strict and serious, now she’s more funny	*Emotionality*	**Conflict**
Bethany	I know she wants to stay in her own home for as long as she possibly can, so we want to do that for her.	Does everything she can to keep her mother in her own home.	*Independent living*	**Conflict**
Gail	We had assessments done, an assessment on him, an assessment on me and then we arranged for some sort of package and to start with it was that minimum package where you have shower nurses or shower carers coming in a couple of times, where we had the lady who was coming in to sit with him for	Tried several different things to ensure her husband could stay home as long as possible but it was not enough. Would have needed house renovations as the next stage.	*Independent living*	**Conflict**

	two hours, where he could go to the day centre, and that for a little while was ok but then it turned out it wasn’t enough. We needed a bigger package. And for the bigger package, I think it would have meant doing renovations in the house			
Laura	We had hoped that, by the end of the respite, that she might be able to go home…when we came back my mother decided that she wanted to go into full time care…and we were making the provisions for her to go home. And while I wanted that to work, I knew deep down that even if she did go home, she wouldn’t be at home for long. But I wanted to give her the chance because I know it is possible for people to live with dementia in their own home with the right care. But it was her decision to come in here.	Laura wanted her mother to go home after being in respite, and had made provisions in her home for this to happen but her mother decided that she wanted to stay in care.	*Independent living*	**Conflict**
Kim	He was in the hospital, and I had to stay in the hospital with him, twenty four seven, because he didn’t want the nurses doing personal care and looking after him, he wanted me to look after him and it was really, really difficult because the nurses wouldn’t look after me, looking after him. Half of them didn’t even want to give me a cup of tea, it was lousy, it was really bad. And that’s where you need more support for carers. If you’ve got a	Had to stay in hospital to care for her husband and was not looked after by the staff.	*Hospital problems*	**Conflict**

	carer that's caring for somebody, that carer needs to be cared for as well. And that's what's lacking.			
Geraint	I took her up there [memory clinic] and I went in with her and the doctor was asking her questions you know, just general questions and then we had to go sit in the corridor then and he called her back in and he said "I don't think you've got dementia" or Alzheimer's, I don't, because she thought she had early stages and he said no its not. So I said to him at the time, I said "well why is she forgetting all these things you know, why"… We knew there was something not right but it was difficult, the doctors wouldn't sort of, because she had a test done, they said it wasn't, they said it wasn't really there, they couldn't do anything about it then.	Doctor said she did not have dementia and did not offer an alternative explanation for her forgetfulness.	*Hospital problems*	**Conflict**
Tony	Torturous [the diagnosis process] because the doctor consistently looked at Beverley's depression, his view was that his diagnosis was pitched at depression and I couldn't see that because I have seen the effects of Beverley's depression. I know its cyclic, Beverley would get very anxious, it was different to that but he persisted on that and I couldn't understand why that was and apparently I'm not alone in that with other people	Found it difficult to obtain a diagnosis because the doctor was focused on Beverley's depression. Took a long time for the doctor to come to a diagnosis of dementia.	*Hospital problems*	**Conflict**

	who have gone there. With the doctor, the diagnosis, he is very resistant at making a diagnosis and I don't know what his agenda is for that but he takes an awful long time to make a diagnosis.			
Sara	She went to town…and we didn't know where she was…and it was six o'clock at night, and we knew if she ever went anywhere she was always back by 4…we was out and about in the cars, we couldn't find her, and then in the end she pulled in in a taxi, and she had fallen down apparently, [in town] they got an ambulance, took her to the hospital, and she had had a head injury, a little head injury, but it was something like, they couldn't open her handbag unless she said they could so they didn't really know where she was from to ring us to get a number because we had it all in her bag, and so they got her a taxi and she came home.	Mother has been taken to A & E after a fall and the hospital did not contact her next of kins. Just got her a taxi and sent her home.	*Hospital problems*	**Conflict**
Sara	She was just, in the hospital, it was nice, it was clean and all but she was just sitting there … nothing was happening, and she was getting worse and then they put pads on her, and where she wasn't even incontinent, but she became it.	No stimulation while her mother was in hospital and her mother became incontinent because they insisted she wear pads.	*Hospital problems*	**Conflict**
Darren	To be honest, not brilliant because I still don't know where I stand and where Louise stands with the diagnosis. That's	Did not find the diagnosis process very helpful. Needed more	*Hospital problems*	**Conflict**

	all we've been told is yes you have it. We haven't been told if it's a certain type of, or if there's any sort of prognosis on how long things can stay the same or whether they will deteriorate very quickly because that's all the psychiatrist told us is everybody is different, nobody knows. It leaves you in the dark a lot.	information. Do not know where they stand.		
Sara	we went to a clinic, to a memory clinic, and they did tests there but they said she wasn't too bad, but I found that, umm, more so with the consultant, when she come back out of the room after filling her sheet in, he goes through it. He was sort of telling, he was looking and saying, and then sort of almost prompting her to say different things so she wasn't coming out too bad. Whereas I knew she didn't have a clue.	Found that the consultant in the memory clinic was changing her mother's answers to the memory test	*Hospital problems*	**Conflict**
Pippa	He was coming to the end of the 13 weeks [sectioning] where they do the review and the doctor saw him for about six minutes and ascertained that he was of sound mind and capable of going home. And alarm bells went off …that can't be right …I said he'll die if he goes home, he will because he will be looking for my mother, he can't take care of himself, he can't cook, he can't even make a cup of tea…two visits a day from the carers, and I said no I'm not having	Hospital wanted to send her Dad back to his own home after his sectioning was complete. He was not safe to go back to his own home and Pippa had to take photographs of his hospital notes as proof that he was not safe to live alone.	*Hospital problems*	**Conflict**

	it…so I had to fight …and it got to the stage where I would go in and visit my dad and I would take photographs of all his notes, of his falls, his aggression, his wandering, once they told me, they didn't tell me he actually got out and went up to Ystrad town in his underpants and I wasn't told that but it was in his notes. So we went to a meeting, a 117 meeting, and we all sat there and I said right I've got all day, I've got about 100 pages here and I've highlighted on every page aggression, mood swings, TIAs, escaping, hitting the walls, now you tell me that he's capable of going home… They adjourned the meeting and they came back and they said "no I think we're in agreement with you, he's not fit to go home". So I had to do that and fight for it myself.			
Bethany	We did have a bit of an issue with support, we didn't hear anything for about 9 weeks after she was diagnosed which we found really difficult because when we went and spoke to the doctor, he's lovely, he's so good, he was great with Mam and he explained everything to us completely and said about a care package or support that could come in and the medication she could change onto, a medication that would help the memory loss, but then we	Had to wait 9 weeks to hear back from the memory clinic about medication/ support/ more information. Family were lost during this time, did not know what to do.	*Hospital problems*	**Conflict**

	sort of didn't hear anything for weeks and weeks and weeks so I had to keep chasing it up during that time…we just didn't know what to do, we didn't really know what we were dealing with.			
Gail	You reach a point where you think yes, it sounds selfish, but I've got a life too and I've got to try and look after myself otherwise I'm not going to be any good to anybody.	She has a life too and she has to look after herself as well as her husband	*Self-care*	**Conflict**
Kim	I do make a point occasionally of going out if something is going on, I do try to go out… I have got to make time for me.	Makes of point of making time for herself	*Self-care*	**Conflict**
Laura	I needed to look after myself too to be able to look after my mother, and that I have a life as well, which you feel selfish about at first.	Felt selfish insisting that she has some "me time"	*Self-care*	**Conflict**
Dianne	We've been going up there [local dementia support group] now over a twelve month. It's something to look forward to, he goes and plays curling with the men and I've got two hours when I don't have to worry and that is heaven. Believe you me. That is heaven. And he's fine when he's up there and he'll laugh and he'll joke and then he can come home and he can just turn into himself you know, so, sometimes I do think it's like living with a time bomb.	Finds the dementia support group as something to look forward to. She does not have to worry about him. But when he gets home, his temperament changes rapidly- like a ticking time bomb.	*Self-care*	**Conflict**

Dianne	I feel now that I am sort of confined then…I can't say I'm afraid to leave him on his own but when I'm out, I can't wait to get back to make sure that everything is alright.	Does not want to go out without him, but does not want to stay home all of the time either.	*Self-care*	**Conflict**
Dianne	There's a lot of women in the same position and like there's a lot of men who go up with their wives because their wives have got it as well. But it's a lovely group and I do enjoy my time up there you know, like I said, its freedom. I know it sounds silly but it is, it's freedom. When I haven't got to worry and like I said, made quite a few friends up there who are in the same position so we can have a chat about this and that.	Enjoys the support group. Made friends. A bit of time away from her husband where she does not have to worry about him.	*Self-care*	**Conflict**
Trystan	I used to like a drink, don't get me wrong, when I was younger, but since she's had this, I don't drink at all now. I used to go out to watch rugby because I used to be a rugby player but I don't go out and leave her that long now at all.	His social life is gone.	*Self-care*	**Conflict**
Tony	One of the things I should say is I'm an outdoor person and that's one of the big things that I miss. I miss being able to go out in the garden or sit outside for a cup of coffee because I'm always nervous about leaving Beverley on her own… Perhaps in the summer when she can come out as well, it'll be alright but for the winter, I do get a bit of cabin fever.	Misses being able to go outdoors.	*Self-care*	**Conflict**

Darren	I've still got a couple of friends who, I'll go out for a pint and have a couple, in the village and have a bit of release. I sing in a choir so I still look for other releases.	Has his own hobbies as a release from caring for his wife	*Self-care*	**Conflict**
Kim	I suppose it's having somebody to talk to about things, having somebody to vent to, rant and rave when you're getting fed up and upset about things. And sometimes just having down time away from it all.	Needs some time to herself or someone to vent to.	*Self-care*	**Conflict**
Kim	Sometimes I wish somebody else would decide what we're having for tea and go shopping and cook it… it would just be nice to be looked after occasionally.	Would like a day free of responsibilities occasionally	*Self-care*	**Conflict**
Kim	I have got less time. I'm not a going out clubbing it type person anyway so from that side of things I haven't lost that.	Has less time to do what she wants to do now she is caring for her husband	*Self-care*	**Conflict**
Tony	It's mainly been the singing and [support group] that are very useful and of course I talk to people as well when we go there. I talk to some of the people who are there with their husbands and wives, at Widdershins, yes. She loves it and she has lunch there. And I come back here [home] and do all of the things or whatever.	Finds the dementia groups helpful as he can speak to other spouses in the same situation or have a little break and do things for himself.	*Self-care*	**Conflict**
Kim	It's not fair on him especially at this sort of stage because he knows that things are changing and there's nothing he can do about it because obviously, in some ways, this stage is the crueller stage because he's still aware. As they	Her husband is in the crueller stage of dementia where he's aware of what is happening to him	*Cruel but kind*	**Conflict**

	progress and they become less aware, less understanding, then it’s not so bad because they don’t know what they are missing.			
Pippa	A rocky road. Very steep learning curve, there are times when its funny… but its been a journey, and its still ongoing and I’m now coming to the stage where I think its going to be a slightly harder journey for me but easier for him because as he’s slipping in, further in to the dementia, no longer does he come to the door when I go to say goodbye… So some things are funny, and you’ve got to take it light heartedly because you cant dwell on things.	It’s a rocky road. A journey. Steep learning curve. As the dementia progresses, it will be an easier road for her Dad but harder for her.	*Cruel but kind*	**Conflict**
Bethany	I think that this stage that she is at is probably the most cruellest stage because she is very aware of everything and obviously because she has nursed patients with dementia, she sort of knows what’s coming next so it’s really scary. She’s really brave…I would be a wreck if it was me but she doesn’t really show it, that, she doesn’t have any sort of meltdowns or anything about the condition but I would just like her to be a bit, I know it’s not going to be level, but, it’s really difficult to say, I don’t want her to get any worse, obviously I don’t want her to get worse, but I hate the fact that	This is the hardest stage of dementia. Her mother is aware of what is going on and it is cruel. Based on her past employment, she knows what will come and what came before. Torn between wanting their mother to get a little worse so she is less aware and not wanting her to get worse.	*Cruel but kind*	**Conflict**

	she knows so much now about it as well so we feel like we're in between at the moment, it's like not bad enough for her to not be aware of things and that's what we find the hardest because we know that she knows about everything whereas sometimes you think when they get further into dementia, they don't actually know about things, it seems easier on the person. Harder on the relatives but easier on the person so I think that's what we find really difficult, we want her to just be where she isn't suffering, or she isn't having any pain or isn't sort of constantly anxious or on edge. That's sort of what we want more than anything really, for her to feel comfortable.			
Darren	She just thought it was part of getting old…It is just normal for people, as they get older, to forget things.	Thought the forgetfulness was a normal part of aging	*Normal part of aging*	**Acceptance**
Darren	When I started pushing for Louise to be tested. But of course, being a woman, she dug her heels in and said no there's nothing wrong with me, I'm just getting older.	Wife was reluctant to get tested for dementia. Says that she was just getting old	*Normal part of aging*	**Acceptance**
Dianne	Our other son said oh well he's getting older Mam, what do you expect you know? And that's it and they've accepted the fact that he's got it.	The son accepted it as a normal part of aging.	*Normal part of aging*	**Acceptance**

Kim	He is forgetting stuff and not remembering stuff now because he will say something and then he'll backtrack and oh it doesn't matter, don't worry about it because he can't remember what he was saying and so he covers it up by saying that it doesn't matter, don't worry about it. But it's his personality that's changed, that I miss. The memory side of it can be a nightmare, he forgets things, forgets to do things, forgets what he's doing and he gets frustrated but it's his personality changes that I miss more than anything.	The forgetfulness can be a problem but Kim finds it more difficult to deal with the personality changes.	*Normal part of aging*	**Acceptance**
Gail	He loves chocolate, they revert back to childhood don't they.	Thinks her husband has reverted back to childhood	*Normal part of aging*	**Acceptance**
Kim	But his conversation, he'll say what he thinks now, its like having a toddler you know, when they just say what they think, it's a bit like that at times and he'll say things, inappropriate things, he hasn't got to the stage of being rude yet but I suppose that will probably come but he just, whereas you or I might think it	Compares him to a toddler. Has no filter on what he is saying. Not rude yet but can be inappropriate and say things out loud that other people may think.	*Normal part of aging*	**Acceptance**
Sara	Upsetting. Worrying. Are you going to get it?	Lots of negative emotions associated with her experience of dementia. Worried about it being hereditary too.	*Genetic predisposition*	**Acceptance**

Laura	My Grandmother had dementia and my Mother has got a cousin with dementia...So the fact that maybe it is in the family has never really been a worry. It is something that you can’t control it is, if you’ve got dementia, you’ve got dementia, it is not something that you can really do anything about. I am really forgetful, and it would not surprise me in the future if I am diagnosed with it so it has never been a fear. Just always felt that it might be there within the family.	Very aware of a family history of dementia. Not worried that she may develop it one day	*Genetic predisposition*	**Acceptance**
Geraint	I don’t know whether it is hereditary…I’m getting worse and worse and I don’t know if I’m just joking about with it or whether I seriously am. And it does worry me you know, it could be hereditary, it would be something happening to me… I’m terrible I am only 58, I don’t know whether it’s the onset or whether it’s just, just being cautious or whatever it is…honestly, I’m hopeless…seriously so I don’t know whether I’ve got it, the start of it or not, I don’t really know and it does worry me that, you know, I’m 58, I’ve got grandchildren, I’ve got you know my own children, grandchildren, my wife, I don’t really want them to have to go through what I’m going through with my sister like, do you know what I mean, so it does worry me…I’m trying to ignore it at the	Worries that his memory is getting worse and he does not know if dementia is hereditary.	*Genetic predisposition*	**Acceptance**

	moment and pretend it's not happening to me			
Pippa	The hospital, so we went there and he had all the tests and he had a head scan a CT scan and they came back with vascular dementia. And I think once it was labelled, it was right ok, we know what it is, we knew all along what it is but now we've got a definite diagnosis on it, you know, where do we go from here? So I think the diagnosis was the key.	The diagnosis was vital to the family being able to plan services/ the future etc.	*Positive reaction to loved one's diagnosis*	**Acceptance**
Darren	Relieved [when the diagnosis was confirmed], it confirmed what I was thinking all along…it's like, right we know what that is, now we can try and deal with it. So yeah, there was a certain amount of relief but obviously, what's the word? Trepidation at what's to come. But at least with the diagnosis, we could say right, this is what it is, right, what can we do about it rather than being in the dark. Yeah so relief and trepidation.	Experienced relief and trepidation at the diagnosis	*Positive reaction to loved one's diagnosis*	**Acceptance**
Pippa	Just accept what's going on because you can't stop it once the tidal wave starts coming in, its coming in and you cant stop it so you have just got to go with the flow so.	You cannot stop dementia so you just have to go with the flow	*Positive reaction to loved one's diagnosis*	**Acceptance**
Laura	In some ways, I do feel a little bit redundant because I used to go to all the hospital appointments or doctors appointments…I just felt that excluded	Struggled to come to terms with her mother being in a care home and	*Change of responsibility*	**Acceptance**

	then from that point of view. I felt that I was on the outside…But I feels slightly redundant then because you spend your time running around doing things, and then suddenly its taken away from you. And while it is nice to start and get your life back, you start to feel a little bit redundant then. It takes a while to settle in to the, it's a new routine basically.	no longer being so reliant on her.		
Darren	There is a lot of financial worries as well that come along with this; how you manage if you have got to give up work to become a carer.	Worries how he will manage when/if he has to take on the role of full-time carer for his wife	*Change of responsibility*	**Acceptance**
Bethany	I constantly feel bad if I'm not here, if I know I'm going home knowing that she'll be here for hours on her own, I feel awful, and I think I've got to go home because my husband is there, go home if the children are visiting or I've got something else to do I feel really bad so I think there's this constant guilt and worry all of the time basically, that's my main experience of it.	Feels torn between her own family and spending time with her mother	*Change of responsibility*	**Acceptance**
Pippa	I am not sure that he recognises me all the time as being me, but I think I'm more now the adult whereas before I was the child and dad was always there and any problems I went to my father now I think the tables are turning a bit because his behaviours are becoming more childlike and I feel more like the responsible adult	Not sure her dad always recognises her. She is now the responsible adult and her dad is more child like.	*Change of responsibility*	**Acceptance**

	so I think the roles are reversing so yes in a way I think it has changed.			
Laura	We have taken on all the responsibilities we recently had to sell the house so that was down to us. We make sure that her board and lodge gets paid, her care. We make sure that her pensions and any anything she is entitled to is correct. We look after her bank account. We have got power of attorney which has not been enforced yet because she still has got reasonable amount of capacity but we discuss everything with her. Unfortunately she just waves her hand and says "I trust you, I trust you". I wish she would be a little bit more involved in it because even though she trusts us and we are trustworthy, I wish she would show more interest. It is like she has relinquished everything to us and we do literally deal with everything for her… even now while she's here and being taken care of, there is still a lot of responsibilities on us that do impact on our lives.	Have taken on all of her mother's responsibilities. Even though her mother is now in a care home, Laura still takes charge of everything.	*Change of responsibility*	**Acceptance**
Laura	I was going down there, I was putting meals, I was buying convenience meals to try and make life easier for her. I was basically spending more time down there than at home.	Had to juggle her own family and her mother.	*Change of responsibility*	**Acceptance**

Darren	I'm here 24/7. Even if I'm not here, I'm at the end of the phone and she knows that she's only got to pick it up and I'll be back straight away.	Has to be on call whenever his wife needs him.	*Change of responsibility*	**Acceptance**
Tony	I comb her hair and do her make up…This would be a nice one for you to wear today [dress] and that sort of thing you know.	Now helps his wife with her personal appearance	*Change of responsibility*	**Acceptance**
Tony	There's very little that matters. It's only the life affecting stuff. It's a people thing now, more of a people thing.	Has to prioritise the important things- his wife.	*Change of responsibility*	**Acceptance**
Trystan	I do dress her, I do everything for her now because I had to give up work	Had to give up work to care for his wife.	*Change of responsibility*	**Acceptance**
Trystan	I wouldn't feel in myself that, perhaps she would get looked after tidy, but I feel myself that I'd rather do it myself.	Would rather care for his wife himself, instead of having carers. So he knows that she is being cared for properly.	*Change of responsibility*	**Acceptance**
Trystan	I had to give up work because I had a bad health myself, and then I had to take, takeover everything, do the washing, cleaning, cooking, dressing, I'll bathe her, everything.	Despite his own ill health, caring for his wife is the priority.	*Change of responsibility*	**Acceptance**
Trystan	From doing absolutely nothing, I would just go out to work, come home, tea, and the food would be on the table, you know, she would do the ironing, cooking, everything. But she does nothing like that now, I've got to do everything. I don't allow her in the kitchen at all, she do want to go in there but I do stop her, I don't	Has taken over household chores in fear of his wife hurting herself.	*Change of responsibility*	**Acceptance**

	allow her in there because I'm frightened she'll scold or burn so I do everything in that way.			
Trystan	She's got stress incontinence, so I've got to see to all of that now …It's just part and parcel of looking after my wife.	Does not mind providing personal care/toileting.	*Change of responsibility*	**Acceptance**
Hannah	I am back and fore here a lot more than I was so I'm taking her places at least three days a week and I will probably stay here maybe two or three nights a week.	Spends a lot of time with her mother, instead of being in her own house	*Change of responsibility*	**Acceptance**
Bethany	We are taking on the role of carers as well as just daughters but it is difficult sometimes to, I wouldn't say lose my temper, but to take in some of the things she says that I know she doesn't mean but she still says them so you think oh God, I feel really bad. Or sometimes she takes things completely out of context and then we go on about it for hours and hours and you thinking why? This is something really simple or she decides that she really doesn't want to do something and she's really stubborn, she won't do it so like I said, I feel like I'm nagging her all of the time whereas before she was so independent, she didn't really need us to do that much for her or wouldn't let us do that much for her and now its complete role reversal really. So, she won't take part or do anything without us. She's much more dependent.	Struggles to juggle being a daughter and being a carer. Her mother is now completely dependent on her whereas before, she was independent. Feels like she is nagging her.	*Change of responsibility*	**Acceptance**

Darren	[Life with dementia is] Stressful, yes, and sometimes hilarious. It is more difficult when you're trying to work and trying to balance everything and fit other things in around it and try and maintain a bit of sanity for yourself, that's the hard bit. But I seem to be doing alright.	Struggles to juggle everything but tried to maintain a sense of humour	*Change of responsibility*	**Acceptance**
Tony	Well the focus has changed now. It has changed because my role has become supportive, I've had to learn to be patient to the point where the first thing I must think about is Beverley's needs, that always comes first now I've learnt that. If I wanted to do something or other, I'll do that if I can find the time to do it. So as I say, I don't do any of the things that I used to do because I was always potching about, shall we say, doing something or other, a lot of that, I don't do that now. So I am very much a supportive thing so it is a huge change for me.	Has to find a balance between doing what he wants and what is best for his wife	*Change of responsibility*	**Acceptance**
Bethany	It is the physical side of things that has been really difficult for us so physically cleaning and ironing and cooking and washing and how much time everything takes up. The mental side of things, we try and do as much as we can.	Has poor health but tries to help her Mam as much as possible - Struggle with the physical side of caring, the additional housework	*Change of responsibility*	**Acceptance**
Bethany	I am just exhausted to be honest; I don't seem to have time to do anything else now…we have to do all of the household things now, the cleaning, the cooking, the	Has taken over running her mother's household. Caring for her mother has taken over her life –	*Change of responsibility*	**Acceptance**

	ironing. Sort of visiting a couple of times a day with meals and things. Yeah, it's changed the whole family dynamics really because we are struggling. it seems to be a constant. Nothing nice, just really hard all of the time, there's no break from it. Like I don't mind doing anything for my mother at all, that's not the issue, it's just pacing everything in your life then isn't it, so I seem to miss the good things... It has changed my relationship with my husband because I spend so much time here and he's really good, he spends so much time here as well. And me and my sister, we tend to try and, where we used to do a lot together, we now try to do a day each at a time so we try rest on the day that we haven't got to come down so we don't get together as much either.	impacted on relationships with her husband and sister. Seems to miss out on the fun things because she is always with her mother.		
Hannah	If the Alzheimer's Society could organise transport to these various groups, I'm sure she isn't the only one who would benefit from that.	Hannah's mother can only attend groups if Hannah is available to take her. If transport was provided, her mother would attend a lot more groups.	*Change of responsibility*	**Acceptance**
Dianne	The majority of the time, they just treat him as, they don't treat him as if he's got dementia because I mean, some people treat them like children don't they. But	His children still treat him the same- go to him when they need something.	*Maintaining normality*	**Acceptance**

	they still treat him, well he’s their Dad, if they want anything, they can go to him …they don’t treat him as if there’s anything wrong with him then, they just treat him normally like they’ve always treated him.			
Darren	I try to step back quite a bit and made Louise get on with things because I think that the more she gets on with life, the better it is because if you step in all of the time, you’re just taking that way, you’re stopping that thinking process anyway. So I do try to push her forward and make her do things that she doesn’t want to do… I still make her do my ironing though. I can iron, I’m not doing it though, I’ve got to leave you to do something.	Tries to push his wife to continue as normal.	*Maintaining normality*	**Acceptance**
Bethany	We have decided to try and be as normal as possible really and try to talk about any issues that she’s got, which she does sometimes, sometimes she doesn’t. I think we’ve tried to just, well we’ve both tried to say to her that there’s no solution to the problem, we’ve just got to work with it as it is and we have just tried to take that attitude really of one day at a time, see how you feel and we’ll try and do the bits that you can do.	Tries to be as normal and open as possible. Takes everyday one at a time.	*Maintaining normality*	**Acceptance**
Sara	She don’t join in no more like she used to. You can have a bit of a conversation with her but she doesn’t know what she’s	Try to include her mother in conversations as normal even though her	*Maintaining normality*	**Acceptance**

	talking about, but we just carry on as normal, we don't never say "that's not right Mam or that's not right" we just carry on the conversation with her.	mother does not understand what they are talking about.		
Sara	ALEX: How has your life changes since your Mum was diagnosed? Sara: Oh, completely, completely, like I was always with her. Now I try to come down every other day but it's not the same…you can't have a proper conversation with her…she don't understand where she was always there. It is awful. Completely changed, even though I've got other family, it is not the same as your Mother. Or your Father. And being an only child as well, you can't share the responsibilities really.	Her life has completely changed since her mother developed dementia. No longer has her mother to confide in. Cannot share the responsibility as she is an only child	*Decision-maker*	**Isolation**
Pippa	Just the roller coaster of a journey that its been. Fighting every step of the way literally, having to go to court just because I didn't want him discharged and getting power of attorney over his health and welfare, fighting about what I want for him in the end with the doctors and them not admitting him every five minutes	Having to constantly be putting her Dad's best interests at the forefront and fighting to ensure they are taken into consideration	*Decision-maker*	**Isolation**
Pippa	You have got to be prepared to have a battle on your hands because it is not an easy ride by any means and you have to fight and at the end of the day you have got to think I've got to put my feelings	Had to fight for what she thought was right for her dad because he was no longer able to fight for himself.	*Decision-maker*	**Isolation**

	aside and think what is best for my relative irrespective of how I feel or how it affects me that person can no longer have the capacity to fight for themselves so you have got to be prepared to literally get in there and stand up and say what you think is right			
Tony	Beverley always looks to me for things you know, something needs sorting, and she will look to me to help.	Has to now make all the decisions within the marriage.	*Decision-maker*	**Isolation**
Hannah	I am more responsible, I have to make sure she's taking the right tablets and rather than her checking up on me, I'm the one who's checking up on her now.	As an only child, she's solely responsible for her mother's well-being.	*Decision-maker*	**Isolation**
Hannah	Family members who would originally ring Mam to make arrangements for things will also give me a ring just to check that I have had the message	Now has to co-ordinate her mother's activities as there is nobody else to do it.	*Decision-maker*	**Isolation**
Gail	I felt most of the time I was jogging along quite well, it takes me a long time with finances I can tell you that.	Deals with the finances alone.	*Decision-maker*	**Isolation**
Tony	Beverley used to do the paperwork and I found then that I had to start doing the paperwork which of course I hated, still do. Although I worked a lot in an office, innately, I hated doing the paperwork.	Deals with the finances alone.	*Decision-maker*	**Isolation**
Gail	I suppose he did rely on me quite a lot to do household things and shopping and all that but he was a great one with finances and he took that role on and I think because he took it on, it means that at the	Deals with the finances alone.	*Decision-maker*	**Isolation**

	moment, I have sometimes got problems because I didn't do anything with finances or anything to do with the house and what you had to pay for and he just took it in his stride and loved doing it because it was, well like a hobby really, investing money.			
Darren	I do all of the cooking now…. I do quite a bit of the cleaning	Taken on a lot of the household chores because his wife can no longer do them.	*Decision-maker*	**Isolation**
Gail	I've got a lot more responsibility, a lot on my shoulders, having to do things that I've never done before that he would have done, finding that I can do them, which is something, I've found I can do so many things that I'd never thought I could ever do, particularly with the house, things go wrong don't they, I have to get people in, finding out how to do a lot of things myself, making a mess of it and thinking well so what I've tried, can't worry about it.	Has to do a lot of the things that her husband used to do. Has to make her own decisions about house maintenance	*Decision-maker*	**Isolation**
Tony	I devote more of my time to Beverley and I am quite content with that so the friends we have got, are mutual friends, and they all know, so with the kids, the two boys and their families, it has changed that slightly although I don't call on them much, we try and be independent and we	Devotes all of his time to his wife. Does not call on his children for help, tries to remain independent.	*Independence*	**Isolation**

	are capable of being fairly independent now.			
Darren	Other people have got other shit in their lives that they have got to deal with. Louise's sister I'm a little bit disappointed in to be honest because she is an ex nurse and she hasn't offered any support in any way…our daughter's are around if we want them but we try not to put on them.	Does not expect people to help them. Do not ask people to help. Everyone has their own things to deal with.	*Independence*	**Isolation**
Darren	We have always been pretty independent, we don't have this really really tight nit family bond which a lot of families get…They [their daughters] still rely on us for things and they still come to visit us but they are not here every other day. It's pretty much, I'm left to get on with everything.	Very independent. Children rely on them for things but they do not ask anything in return. Husband is alone in caring for his wife.	*Independence*	**Isolation**
Bethany	We have struggled with kind of, sort of, care packages really. A- because Mam really doesn't want one, after nursing for years and years, she sees dementia in the way it used to be I think, because she actually worked with geriatric patients for most of her career so I think she thinks that it is still the way it used to be, so she's not really happy with any services that she has been offered, she doesn't want to take part in any.	Mother refuses to have outside support/care packages.	*Independence*	**Isolation**
Hannah	Don't get a lot of support from other family members.	Has to take care of her mother alone	*Independence*	**Isolation**

Kim	Obviously at the time…the doctor gave us information [about dementia] but it's very much information overload at the time, you are hit with this diagnosis, even though you are suspecting it, you are hit with this diagnosis and to be told this that and all the rest of it is very scary and very much information overload. So a lot of stuff that I have learnt is from reading, I do a lot of reading, internet, the Alzheimer's society provided a lot of information as well, books, webpages on the internet, that sort of thing, is where I got my information from and then a lot of my information I passed on to Rob. Limited information, need to know information. He knows that he's got dementia but he doesn't need to know the bad things about it.	Kim knows all of the information about her husband's dementia but only tells him what she feels that he needs to know.	*Withholding information*	**Isolation**
Gail	He didn't take it in because when we saw the consultant who diagnosed the dementia, and said it was dementia, we came out and it was like he wanted to turn a blind eye, he didn't want to even talk about it because he said to me "I didn't understand what he was saying" so I thought he's not ready to be told, I think this is going to destroy him because he was fit enough to know what dementia was at the time, so I said to him "he told us that the Parkinson's cells in your brain	Husband not understand that he had been diagnosed with dementia and wife decided it was best not to tell him because his reaction would not have been good.	*Withholding information*	**Isolation**

	are gradually dying off, he also mentioned that there are some other cells dying off" but I didn't say it was dementia because I know him pretty well to know how he would have reacted. In fact, I don't think he's hardly ever mentioned it.			
Sara	Terrible. Really upsetting… because I was always with her, and anything happened, she would always be with me. Of course all of that has changed now. She was always there for me, always, but now, she's not. So it was really difficult…she was always there for me, whereas now, she can't be can she. Really.	Finds it difficult that her mother is no longer there for her.	*Remaining strong*	**Isolation**
Gail	He was the sort of person that if there was ever a problem I could ask him about it, and I could rely on it and there isn't anybody to ask, I've got to keep an eye on myself haven't I.	Used to rely on her husbands advice but now she has no one to ask.	*Remaining strong*	**Isolation**
Kim	I tend to be the king pin in the family that sort of holds everything together and if I have a melt down and crack up then the family falls apart and they all look at me as if I've grown three heads. On the very rare occasions that I have an absolute hissy fit and throw my toys out of the pram its like what the hell is wrong with Mum and you find that they all disappear to their appropriate rooms and hide. But yeah I tend to be the one that sort of	She holds the whole family together. If she is having a bad day, the family avoid her.	*Remaining strong*	**Isolation**

	holds everything together and issues instructions and keep things running			
Sara	You have got to go on, you know, for everybody else, you have got to keep going haven't you. How can you not?	Has to stay strong and cope for the sake of the rest of the family	*Remaining strong*	**Isolation**
Trystan	We got two sons and none of them do come near us.	Their son's do not want anything to do with them	*Lack of consideration*	**Isolation**
Pippa	My husband is a bit sort of, well he wont remember you love so why are you bothering to go in? because if I have been in today now and I have spoken to him, if I go back in there now he wouldn't remember I'd been in or given him his papers or anything.	Her husband does not understand why she needs to visit her dad regularly	*Lack of consideration*	**Isolation**
Laura	there are others, and I understand why, that have shied away. They say they will come and visit but they won't. People have their own lives and there's also that feeling of not knowing what to say…and there are others that I think have got a mental picture of someone who is sat in a chair, slumped, drooling. Not able to communicate. Because there is a stigma with the word. And it took me a long time to explain to my mother that it is just a word. That the word dementia covers a lot of different areas. It does not necessarily mean that someone is in a position where they can no longer do anything for themselves.	Old friends do not visit because they don't know what to say – stigma with dementia and care homes	*Lack of consideration*	**Isolation**

Pippa	Relationship with my husband, he more or less shuts it out, he'll inquire occasionally how's your father? Have you been to see him today? But if I said to him we'll bring Dad home for the day, "no, we'll take him out. I don't want him to come here". So he last saw him Christmas time and I don't push it, if he doesn't want to go, I'm not going to force him to go.	Her husband does not want to talk about it. Does not want to see his father in law.	*Lack of consideration*	**Isolation**
Pippa	Regards neighbours and that, they don't talk to me, they've all got my phone number just to ring me and ask how he's doing…they deliberately avoid me.	Neighbours do not want to speak to her	*Lack of consideration*	**Isolation**
Gail	I don't think they [friends] would have taken very kindly to it, coming in here [care home] because they wouldn't want to see him the way he is now, I don't think.	Friends do not visit her husband in his care home.	*Lack of consideration*	**Isolation**
Sara	You've got to keep coming to see her, you can't not, you can't forget about her.	Insists on visiting her mother even though her family do not understand why.	*Lack of consideration*	**Isolation**
Pippa	His friends distanced themselves, and even now, nobody visits him…it is almost like they are frightened to approach him because they don't know how he's going to react or whether he'll remember them or what he's going to say but now it is just literally myself that visits.	Her father's old friends do not visit him in the care home. They are frightened to approach him.	*Lack of consideration*	**Isolation**

Kim	Sometimes you just need the support when you’re having a bad day. Physical support at this stage isn’t needed so much, that will come later on…there will come a stage when outside help will be needed but at this stage. The problem is as well, is that Rob is quite a private person who doesn’t like outside help.	Does not need physical help at the moment, needs emotional support	*No support*	**Isolation**
Pippa	I didn’t know what’s out there, even now I don’t know about whether there’s groups to visit you know or people you can chat to. I joined on Facebook, social media, the Alzheimer’s society, dementia society on there and found a lot out on there and I’ve asked a lot of questions on there, you know, I’ve been in to see my Dad today, I don’t think he actually knew who I was today, he can look right through me and I don’t think it registers who I am so again nobody really, its just what I’m trying to get off social media and the internet.	Does not know what support is available for carers locally. Uses social media as a source of support.	*No support*	**Isolation**
Darren	It would have been nice to have been approached by professionals who said right this is for you, because you will need support but no I haven’t had any contact with anybody basically. The support that seems to get put in place, seems to be for the person which is suffering with it rather than the people who have got to pick up the pieces after it. Like I said, I think it kicks in more for people which are older,	Would like a bespoke support service to someone in his situation. Younger, managing, still working.	*No support*	**Isolation**

	for people which are further down the line. I think that's when it will kick in, is as things do get progressively worse. Hopefully in years to come but at the start there doesn't seem to be anything in place for the partners or the support so I think that can be improved.			
Darren	We have had a number of people come to the house…which is for Louise but for me, nothing. I don't mind, I've got broad shoulders, I can get on with it but when I do need help, hopefully there will be some there	A lot of support for his wife but none for him.	*No support*	**Isolation**
Darren	They [memory clinic] gave us a lot of advice but really it doesn't really relate…it is sort of more geared towards people that are older and much further progressed. It doesn't really look at people who are younger with it and can still function, there should be a little bit more bringing in for that rather than older people with fairly progressed which is the impression that I got, that is mostly catered for… You get somebody like Louise and myself which you're still working, you're still trying to function in life, you're not an old age pensioner, you're not infirm, you don't need memory boards and everything else you know, you can still try and get on with it.	The advice and information provided by the memory clinic was not applicable to their situation.	*No support*	**Isolation**

Darren	There's all of this help there for when things get progressively worse but not at the start, I think there's a gap there. I don't think people really understand the depth of Alzheimer's.	Feels that there is a gap in support for those recently diagnosed and not in the later stages of dementia	*No support*	**Isolation**
Kim	Sometimes you just need the support when you're having a bad day. Physical support at this stage isn't needed so much, that will come later on…there will come a stage when outside help will be needed but at this stage. The problem is as well, is that Rob is quite a private person who doesn't like outside help.	Does not need physical help at the moment, needs emotional support	*No support*	**Isolation**
Pippa	I have sort of stumbled through as I have gone alone and looked on the internet [for information]…so it is only what I have read on the internet and my journey with my father really as to I have sort of found things out by asking along the way.	Found out information about dementia as she has gone alone.	*No support*	**Isolation**
Pippa	There were times when I think I don't know what's going on like the evening he was sectioned, I just saw them as taking him away in an ambulance. Nobody told me what's going to happen, where is he going to go, you know, where is he going to end up and all I was told is where ever there is a bed available, we'll be in touch. And I'm thinking but you've taken my Dad away and he is going to be on his own and frightened and can't I come and I was told no because he's sectioned I can no	When her dad was sectioned, there was no support, no information. Both were scared and did not know what was happening or what to expect. Left out in the wilderness.	*No support*	**Isolation**

	longer see him and I felt very much out of in the wilderness as to well what happens now? You know and I was scared for him and I was upset and people were saying “oh it’s the best thing” and I’m saying well I don’t agree with you at the moment			
Trystan	She changed vastly…she was placid and never lost her temper, totally the opposite way around, I can’t say a little word to her now and she flies off the handle… she’s a lot more aggressive now.	Has to be careful what he says to his wife; does not want to cause an argument.	*Criticism*	**Isolation**
Geraint	She was forgetting to bath and then she, she obviously thought she’d already had a bath, she would say to Angie “I don’t need a bath. I had one earlier” and Angie would say “Mum that was yesterday when I bathed you” “No I bathed my” she was, you know, she would argue that she had already had a bath but, I mean, it was quite difficult. It was hard for Angie because like I say she, she was having to put up with the brunt of it you know what I mean, Mum was getting quite aggressive with it at times because she felt that Angie was just being, picking on her and she wasn’t picking on her she was just saying you know “Mum you need a bath” “I don’t need a bath, I’ve had a bath leave me alone”	Mother’s personal hygiene started to deteriorate which caused aggression if her daughter reminded her to bath.	*Criticism*	**Isolation**
Dianne	Inadequate. Sometimes I feel that I’ve let him down in some way. I know I haven’t	Her husband can sometimes make her feel	*Criticism*	**Isolation**

	but it does make you feel like that, makes you feel useless…but I do feel like as if I've let him down in some way or I've done something to make him go like that but I haven't.	like this is her fault and she is not good enough.		
Dianne	I'm quite prepared to, you know, shut my mouth most of the time and get on with it but my daughter says Mam one day you're just going to let rip at him and it's no good saying you're not because you will and god help when you do she said. I said well I hope it never comes to that but she said it will Mam because he's pushing pushing pushing.	Tries not to retaliate when her husband is being awkward but her daughter things that one day, it will get too much and she will "let rip"	*Criticism*	**Isolation**
Trystan	It's stressful at times, stressful at times, you get frustrated because you can't do right from wrong but otherwise you've just got to take it as it comes because as I say, we do have rows now, I mean don't get me wrong, we do have rows now as I say she's so offhanded now. If I have a little joke with her, you know, she snaps at me and all that, I bite my tongue and all that, you've just got to let her carry on with it haven't you.	Finds it stressful looking after his wife especially with her short temper.	*Criticism*	**Isolation**
Laura	The social worker arranged for a lady from the Alzheimer's Society to come to the house…she signed me up for a carers course…It was well worth doing and I would advise anyone to do it, even though there was one day when I though,	Carers course was worth doing.	*Good support*	**Isolation**

	I'd had a busy day, I really could do without going and I am really glad I went. I met about a dozen other people who were in similar situations. Most of them were partners rather than the child. And it puts it in perspective for you. One you're not alone.			
Bethany	Then they sent us one of the memory clinic nurses, he's absolutely brilliant, my mother loved him straight away. Completely different attitude, she'll do whatever he asks her to do, we can argue all week, he will come and say well why don't you try it and she's gone…her medication has been sorted, she's been really happy…we've been really lucky because the nurses that they have sent in have been absolutely brilliant with her, it makes such a difference and she will actually participate in things if they say. It has been really good for them to be able to come and do that to be fair and it gives us sort of a break as well because sometimes we feel like we're constantly nagging her.	Dementia co-ordinator from the memory clinic has had a positive impact on Lynne's attitude. Gives the family a break from "nagging"	*Good support*	**Isolation**
Trystan	I think we've become closer to be honest with you.	Have become closer in their relationship.	*Good support*	**Isolation**
Laura	I have got a brilliant husband… His view was "you look after your mother, I will look after everything else". And he has. He has dealt with all the different	Has a lot of support from her husband	*Good support*	**Isolation**

	authorities that you have got to go through.			
Kim	Family members, we have got quite a small family. His parents are dead. My family we don’t have anything to do with and so it is literally our immediate family. Yeah, he had got a good relationship with them. I think the relationship with my older son Craig and to certain extents Matt as well, my younger son, has changed slightly in the fact that they tend to look out for him more. So, the roles have reversed slightly. If we go out anywhere, out for the day or something like that, they are very aware of what he is going, where he is and there’s always one of us sort of keeping an eye on him.	Has no wider family to rely on. Their sons have become more protective of their father.	*Good support*	**Isolation**
Dianne	They [family] are very supportive of me, if they think he is a being a little bit, say bombastic then for want of a better word, they won’t let him get away with it, they will tell him and then he’ll go and sit in his corner and he’ll have a little think about it and then he will realise then, yes he is being a little bit like it and then he will snap back into his happy go lucky self.	Family are supportive and will not let David get away with being nasty when he is in a bad mood.	*Good support*	**Isolation**
Dianne	They are there, they support me. They know sometimes that if I’m a little bit irritable, they know it’s because of him and they make allowances for that fact but no, we’re a lot closer now. We’ve	Family have become a lot closer and more supportive.	*Good support*	**Isolation**

	always been close but now, you know, they’ll phone and say Mam everything alright? Yeah fine. Whereas perhaps we wouldn’t see them from one week to the other you know, but now they are more supportive and closer.			
Sara	I could talk to my mother more than anybody else, so maybe I am a little bit more open with my daughter and daughter in law now than I would have been because it would have been our Mam [that I would talk to]	Confides in her daughter and daughter-in-law more now that she cannot turn to her mother.	*Good support*	**Isolation**

W: Dissemination activity

Conference Details				**Abstract**			
Date	**Name**	**Organiser**	**Location**	**Abstract Submitted**	**Abstract Accepted**	**Format of Presentation**	**Attended**
15.11.17	USW Research Conference	University of South Wales	Glyntaff Campus	Yes	Yes	Poster	Cancelled
16.2.18	Reaching Distant Voices	Welsh Psychotherapy Partnership	Park Inn, Cardiff	Yes	Yes	Poster	Yes
8.3.18	Research with Impact	Public Health Wales	Hadyn Ellis Building, Cardiff	Yes	Yes	Poster	Yes
25.4.18	Faculty of Life Science and Education Research Conference 2018	Faculty of Life Science and Education, University of South Wales	Conference Centre, Treforest Campus, USW	Yes	Yes	Poster	Yes
8.6.18	Postgraduate Researchers Presentation Day	Graduate Research Office, University of South Wales	Treforest Campus, USW	Yes	Yes	Poster	Yes
13.6.18	Journal Club	South Wales Mental Health Nursing	Glyntaff Campus, University of South Wales	Yes	Yes	Presentation	Yes

19.6.18	Research and Development	Aneurin Bevan University Health Board	Christchurch Centre, Malpas Rd, Newport	Yes	Yes	Poster	Yes
2.7.18 and 3.7.18	Faculty of the Psychology of Older People	British Psychological Society	Cambridge	Yes	Yes	Poster	Yes
10.7.18	KESS 2 Poster Presentation Event	KESS 2	Treforest Campus, USW	Yes	Yes	Poster	Yes
17.7.18	Transforming Community and Public Health: Inspiring Future Generations	International Collaboration for Community Health Nursing Research	Swansea University, Bay Campus, Swansea	Yes	Yes	Presentation	Yes
18.7.18 **And** **19.7.18**	WISERD Annual Research Conference	WISERD	Treforest Campus, USW	Yes	Yes	Poster	Yes
13.9.18	International Mental Health Nursing Research Conference	Royal College of Nursing	Museum of Science and Industry, Manchester	Yes	Yes	Presentation	Yes

29.11.18	Cwm Taf Research and Development Conference	Cwm Taf University Health Board	Treforest Campus, USW	Yes	Yes	Poster	Yes
11.06.19	Aneurin Bevan Research and Development Conference	Aneurin Bevan University Health Board	Christchurch Centre, Malpas Rd, Newport	Yes	Yes	Poster	Yes
12.06.19	Postgraduate Presentation Day	University of South Wales	University of South Wales	Yes	Yes	Presentation	Yes
04.07.19	FLSE Annual Faculty Learning, Teaching and Research Conference	University of South Wales	USW Sports Park	Yes	Yes	Poster	Yes
13.11.19	ABUHB Dementia Conference	ABUHB	Christchurch Centre, Newport	Yes	Yes	Poster	Yes
19.11.19	CTMUHB R&D Conference	CTMUHB	The Vale Resort	Yes	Yes	Poster	Yes