# Living within a Limited Freedom:
# the perceptions and experiences of early dementia from the perspectives of people with the diagnosis and the diagnosticians

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# Abstract

This thesis explores the impact of an early diagnosis of dementia on the person receiving that diagnosis and also on medical practitioners delivering the diagnosis, with the aim of developing a new understanding of what happens in the first six months of the post-diagnostic period. This study draws on a social constructionist perspective and utilises a reflexive ethnographic case study methodology to situate the experience of the person with the diagnosis within the context of everyday social relationships. A critical review of research into the process of giving a diagnosis, and the subjective experiences of people with dementia, is provided. Data were collected from five participants who had been diagnosed with Alzheimer's disease, their family members, and 19 doctors involved in treatment. The results of the study highlight the complexity of the diagnostic task for doctors, the immediate experiences of people with dementia in the post-diagnostic period, and the key therapeutic tasks and processes involved in supporting enduring relationships during this time. In addition, the findings of the study draw attention to the importance of "telling" the diagnosis as a means of sustaining a positive sense of self.

The evidence generated by this study demonstrates that people with supportive social interactions can engage in positive strategies and resist the social stigma attached to the experience of dementia. For those without access to positive social interactions the implications are more negative and they are likely to struggle with the inability to integrate the diagnosis and its effects into their everyday lives. The implications of these findings for the provision of post-diagnostic counselling for people with dementia are discussed. This thesis offers an evidence base from which to develop policy and practice guidance around the disclosing of a diagnosis of dementia and the delivery of support required to ensure that people with early dementia can have the opportunity to develop and experience a valued social identity.

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# Chapter 1

# Introduction

## 1.0 Preamble

This thesis reports on a study of the experience of people involved in the process of the diagnosis of early dementia. The ideas around which the study has been constructed were born out of many years of practice in the field of dementia care. From early years as a student nurse on placement in the locked wards of the asylum in 1975 up until my most recent post, which involved working with people with dementia living within a family context in their own homes, the feeling of affinity with people with a diagnosis of dementia has been something that has always been in my awareness. My own professional pathway has followed that of the changing patterns and progression of how people with dementia are treated within the health service. I witnessed the movement from the long term care wards of the early 1970s, through the ethos shifts in the 1980s with the development of day care designed to offer respite to caring families. From 1981-1987 I was sister in charge of a day hospital for people with dementia. Around this time the development of Community Psychiatric Nursing Services were underway, and it became normal practice for the most junior members of staff to be assigned to the care of people with dementia. While these nurses were very caring, their main focus was on physical care, with the psychological needs of families mainly left unattended. This was also a time when carers' voices began to be heard. Along with Social Worker colleagues, I was involved in the setting up and facilitating of carers' support groups, initially in a Day Hospital in 1984 and from 1988-2002 in various venues in the local community (Weaks 1999). During the late 1980s, following many years of discussion and negotiation, agreement was given to form a team of nurses in the community dedicated to the care of people with dementia and their families (Weaks and Boardman 2003). During the ensuing years from 1990 there was a sharper focus on care in the community, which saw me involved in developing new models of assessment and care for people with dementia (Archibald, Chapman and Weaks 1995). Our work became increasingly focused on establishing an earlier diagnosis, and alongside our Consultant colleagues, we campaigned to raise awareness especially in the wake of the development of the new anti-cholinesterase medications being prescribed.

It was in 1992 that I was asked, for the first time by a patient "what is this Alzheimer's disease that I've got?" As well as being completely shocked at being asked this, I felt inadequately prepared to answer his question and memories of this instance are still particularly vivid. Ensuing reflection led me to ponder, if we were advocating earlier diagnosis, what form of further training would equip me to answer such questions and be able to respond in a more meaningful way, and so it was that I embarked on a course of counselling training. This was very different to the nurse training I had undertaken, which had been heavily influenced by the medical model. The counselling training helped me to develop as a reflective, reflexive practitioner, and led me to become much more questioning of my practice and of my own reactions to situations. It also increased my level of self awareness. It encouraged me to see patients as people (Sabat 2006). This new way of thinking and practice stimulated an interest in research as a way of finding answers to some in-depth questions. Questions about what it meant to a person to have a diagnosis of dementia and how could we, as professionals, gain a better understanding of the experience people were learning to live with. Over the years these questions developed to an extent to which I needed to seek answers and this thesis is the result of my searching.

Underpinning motivations for my engagement in this work emanate from trying to live out the values of the Christian faith and the call to serve others with respect and humility. Within this faith community there is a commitment to care for people with dementia and the Social Care division of the Church of Scotland (Crossreach) is one of the main providers of care in Scotland. However, it is within the parameters of *NHSTayside* that this study is based.

## 1.1 The social and service context of the study

The setting for this study is confined to a single area health service in mid-Scotland. Tayside is an area which covers over 3,000 square miles in the central belt of Scotland and incorporates both urban and rural communities, with a population of 380,500 spread over three distinct regions of the area: Perth and Kinross, Angus, and Dundee. Within Tayside, the estimated number of people living with dementia is 5,576 (Booth 2006). There are a total of 72 GP practices operating in the area, all of which have direct access to psychiatry of old age services. These services consist of Community Mental Health Teams (CMHT) each with a differing variety of members and each with their own distinctive approach to practice. Defining the number of specialist workers for people with dementia has proved difficult as only one area operates a dementia specific service, while the others operate a service for all older people with mental health problems. There are seven full time Consultants in Psychiatry of Old Age, Tayside, with one working half time. As well as these teams, there is a memory clinic in Dundee city which was one of the first in Scotland, established in 1991.

The diagnostic pathway differs slightly in each area, as does the prescribing and monitoring of Cholinesterase Inhibitor Treatment (CIT). However, most people who seek a diagnosis will first visit their own General Practitioner (GP) for assessment and referral to the Old Age Psychiatrist if necessary. Waiting times for these services also differed markedly as do the services and personnel involved in dementia care. Once assessed by the Old Age Psychiatrist and the completion of investigations, a diagnosis will be made and given. There are varying levels of post-diagnostic support available in different areas, mostly from health service personnel at the time when this study was carried out but there was no specific post-diagnostic service, with only one rural area offering support from the time of diagnosis. In one small rural area of Perthshire it was normal practice for CPNs to be present in the clinic at the time of diagnosis to meet the patients, hear the diagnosis being given and arrange thereafter to visit them at home, in order to offer support and advice. There is currently no support for people waiting for a diagnosis.

Other initiatives include an Early Stage Dementia Service (ESDS) in Angus that provide support, education and monitoring by a co-ordinator employed by NHSTayside for people early in their illness and worked in close conjunction with the voluntary sector worker provided by Alzheimer Scotland who supported families in the same area. The ESDS worker supported 91 people over a two year period, although it is not known how many of them were involved with Alzheimer Scotland. This was one example of collaboration between NHS staff involved in early dementia work, and voluntary sector although this was not common. However, a Carer Involvement Officer had begun work trying to form a carers' panel and Alzheimer Scotland Carer Support Groups were available throughout the region. Alzheimer Scotland was the main voluntary organisation in the Tayside area offering support to people with dementia and their carers. There was no specific service provision for people with early dementia, although carer support groups, which were advertised in the local press, were open groups and could be attended by anyone. There were active groups in Arbroath, Forfar, Perth and Alyth which were advertised by Alzheimer Scotland locally and on their website. Although carer support was available in Dundee that seemed to be accessed through a day care facility rather than by an open group it would be more pertinent for people further on in the disease trajectory. There was no record of how many people accessed these groups and there was no record of any groups being specifically for people with an early diagnosis. As in many other Health Board areas in Scotland the extent and quality of post-diagnostic support tended to depend on the needs, wishes and presentation of the individual, needs of the carer, service resources and the individual clinician's views according to Booth (2006), who carried out a mapping project of the services available in Tayside on behalf of Tayside Managed Care Network for Dementia. Services could sometimes appear to be fragmented, having been allowed to develop locally in a way that lacked overall coherence. There seemed to be little consistency across the area, and it is against this backdrop that this study took place.

## 1.2 The Scottish policy context in relation to early dementia

As reflected in section 1.0, there had been a move from the traditional modes of caring for people with dementia in institutional settings, and it was in the late 1980s and early 1990s that care in the community became a reality for people with dementia. The change in the way that care was to be provided in the community was based on a report by the Audit Commission in 1986 which had highlighted major deficits in the provision of services in the community, including the care of people with dementia. This report recommended that a radical overhaul of service provision be undertaken and the government commissioned the Griffiths Report (HMSO 1988) to advise on possible options for the future delivery of care in the community. Among its recommendations, the report suggested that a free market delivery of care was a better option than public sector provision. Consequently, the government published the White Paper, Caring for People (DoH 1989a) which gave local authorities the lead role for community care, in which they were encouraged to integrate public and independent sector services. The White Paper then led to the NHS and Community Care Act 1990. This resulted in the transfer of funds from the social security system (that had previously funded residential and nursing home placement) to the local authority that then had responsibility for the allocation of such funds. This was deemed necessary in order to develop an alternative range of options for care in the community to residential care. Individuals would now receive their care following an assessment of need as well as a financial assessment. As well as the changes taking place within the social services, changes were also taking place within the NHS and these were set out in the White Paper, Working for Patients (DoH 1989b) which also influenced the NHS and Community Care Act 1990. This was the introduction of the internal market with the commissioning, purchasing and providing of services. Trusts no longer provided services for their own area alone and were expected to compete with each other.

It is beyond the scope of this PhD to review the impact of these policies in great detail, but rather to provide a context for how the provision of care for people with dementia had moved from the institutional setting into the community setting and to highlight the major shift from public to independent sector provision of social care and at the same time a more focussed approach by the NHS to concentrate on providing acute, rather than long term care.

This focus on people with dementia being cared for in the community has also paralleled the campaigns for earlier diagnosis of dementia which also began in the early 1990s.

Since devolution in 1999, Scotland has had much more responsibility for its own health and social policy and as this study concentrates on the Tayside region of Scotland, I have therefore made the decision in this section to concentrate on the Scottish policy context over the last decade.

One of the difficulties besetting practitioners giving an early diagnosis is the lack of government public policy framework or guidance for them to operate within. Unlike the prolific literature on dementia, little has been written on policy on early diagnosis, especially in Scotland, although some recommendations have been suggested both by the Scottish Executive and Alzheimer Scotland Action on Dementia, Scotland's leading dementia charity, in the Health Department Letter known as HDL (2004) 44. A more recent addition has been the updated Scottish Intercollegiate Guidelines Network (SIGN) guideline 86, which advises on the management of patients with dementia (Scottish Intercollegiate Guidelines Network 2006).

One of the early reports commissioned by Alzheimer Scotland concentrated on *The Right to Know* (Fearnley, McLennan and Weaks 1997), which incorporated a statement about treatment principles and a guide to good practice. This was followed by a report which aimed to inform policy makers and professionals about the needs of people with early dementia *(Life After Diagnosis: a Report on Meeting the Needs of*

*People in the Early Stages of Dementia*, 1998). This report built on the right to know report and included the call for early diagnosis and intervention, including emotional support and counselling. In an effort to inform policy makers, Alzheimer Scotland (2000) published a report that was a step-by-step guide to help planners of dementia care services, and which spelt out clearly the needs of people with an early diagnosis

> "Research indicates that early intervention can reduce morbidity and depression for people with dementia, carer stress, the need for expensive crisis intervention and may delay or prevent institutionalisation. Medical and psychosocial interventions can prolong the period for which people with dementia and their families continue to enjoy their normal pattern of life" (2000, p. 5).

This report plainly set out the advantages to be gained by responding to the needs of people with early dementia. Its message was acknowledged and incorporated into a report, *Adding Life to Years* (2002) from the Scottish Executive, that stated

> "Early and accurate diagnosis is now very important...best care can be achieved when Community Mental Health Teams for older people and primary care work together and with other agencies to deliver earlier diagnosis, followed by treatment and support tailored to individual circumstances and changing needs" (Report of the Expert Group on Healthcare of Older People 2002, p. 40-41).

The recommendations to NHS health boards were very explicit

> "NHS Boards should work to raise awareness of older people's mental health issues and to promote recognition and treatment of problems at an early stage...
>
> NHS Boards should ensure there are services to provide rapid assessment of cognitive impairment with appropriate access to modern drug treatment and follow up" (Report of the Expert Group on Healthcare of Older People 2002, p. 41).

In an attempt to endorse this report and encourage the development of services, Alzheimer Scotland (2003) produced yet another report specifically targeted at early diagnosis and support services for people with dementia and their carers, setting out much more explicitly the needs of people and their families at the time of early diagnosis, and which also included examples of good practice from around Scotland.

A jointly authored report by the Scottish Executive and Alzheimer Scotland examined the obstacles which beset the improvement of dementia care and suggested how to overcome them and was published as a Health Department Letter known as HDL (2004) 44. This report highlighted the principles of good dementia services which they extrapolated from the Needs Assessment Report (NHS Health Scotland 2003). The HDL (2004) 44 provided a template that could be used by Health Boards as an audit tool to monitor their levels of service provision for people with dementia and covers six specific groups of services: pre-diagnosis; diagnosis; post-diagnostic support; community services; continuing care and co-ordination and care management.

The most recent guideline to be published in Scotland was the Scottish Intercollegiate Guidelines Network (SIGN) Guideline 86 (2006), which recommends best practice based on evidence gleaned from research and on the clinical experience of the guideline development group. Included in their recommendations were recommendations for the disclosure of diagnosis for best practice

> "The wishes of the person with dementia should be upheld at all times.
> The diagnosis of dementia should be given by a healthcare professional skilled in communication or counselling.
> Where diagnosis is not disclosed there should be a clear record of this." (p. 22).

It is important to note that my interviews with doctors (Chapter 4) were conducted early in 2003 when many of the above documents were unavailable. The data collected from patients (Chapters 5 and 6) were collected between 2003-05, at which point the implementation of the guidelines discussed above had not yet started to take effect. However, the production of so many guidelines and reports over the space of a few years (1997-2006) reflects the degree of change within the field of dementia care in Scotland, and the context of uncertainty in which health professionals found themselves operating.

## 1.3 The study

The main aim of this study was to explore what happened to people around the time of an early diagnosis of dementia and in the first six months beyond. The main focus of the study was directed at two distinct groups of people: members of the medical profession (those who made the diagnosis), and the people who had an early dementia (those who had been diagnosed). Although the research study was designed as one complete project, for the purpose of this thesis it was necessary, because of different methods employed and to ensure clarity of reporting, to present the findings from the medical profession as Study 1 and from the people diagnosed with early dementia as Study 2. The key messages and issues from each study are drawn together in chapter 7.

## 1.4 Overview of the thesis

This section introduces the remaining Chapters of the thesis. Chapter 2 presents a critical review of theory and research relevant to the topic of the thesis. Because of the wide-ranging nature of the thesis, several different domains of the literature are discussed. To accommodate the scope of these reviews, the chapter is divided into a number of separate parts. Chapter 2 concludes by identifying a set of the research questions derived from analysis of the literature, which form the basis for the empirical work reported in this thesis.

Chapter 3 concentrates on methodological issues and choices and expands on the theoretical perspective employed in this study, that of social constructionism. The concept of reflexivity is introduced as a central methodological principle. The different methods of data collection employed in the study are described. The use of a qualitative analysis computer software package is discussed, as well as issues of ethical concern including consent.

Chapters 4, 5 and 6 report the findings of two empirical studies. Chapter 4 contains the data analysis of Study 1, which focuses on the experiences of doctors during the diagnosis of dementia, and which reports new findings based on the emotional impact of an early diagnosis, the influence of the personal experience of dementia on practice, the lack of a support system and the difference between Consultant and GP observations of the person's reaction to the diagnosis.

Chapters 5 and 6 report on the findings of Study 2, an ethnographic exploration of the experiences of 5 people diagnosed with dementia. Chapter 5 reports the pathway to diagnosis and provides an introduction to the participants. Chapter 6 reports on the analysis of the findings in more detail.

Chapter 7 brings the findings of the study together in a conclusion and discusses the findings in relation to the literature reported in Chapter 2. A new theoretical formulation is offered, which aims to make sense of the experiences of people who have received a diagnosis. Chapter 7 also highlights implications for various groups from the findings and ends with ideas for future research emanating from this thesis. An important thread throughout the whole thesis concerns the potential value of counselling as a means of facilitating personal integration of a diagnosis of dementia. Chapter 7 therefore includes a section that draws together this thread by offering an analysis of the therapeutic tasks associated with effective counselling or psychotherapeutic work with people with early dementia.

# Chapter 2

# Literature review: theoretical and empirical perspectives on psychosocial aspects of early dementia

## 2.0 Overview of the Chapter

This is a long chapter which seeks to provide the context for the thesis within a review of aspects of the theoretical perspectives and research that are pertinent to this study. The chapter is divided into six major sections, the concept of dementia; the social construction of dementia; a review of research into the doctor's role in early diagnosis of dementia; a review of research into the subjective experience of people diagnosed with dementia; a review of research into the role of counselling in early dementia and a final section on the key themes and emerging research questions.

Section 2.1 offers an outline of the origins of the meaning of dementia as a concept, and the recent introduction of the concept of early dementia, which leads into a description of the three perspectives that dominate contemporary theory and practice: medical, psychological and social.

A social constructionist perspective on dementia is then introduced in section 2.2, as an over-arching perspective, and discussed in relation to key theoretical contributions such as those of Tom Kitwood and Steven R. Sabat.

Section 2.3 provides a critical review of research on the role of the doctor in early dementia including the disclosure of diagnosis. Section 2.4 offers a critical review of research into the experiences of people with a diagnosis of dementia.

One of the intentions of the thesis is to generate knowledge that may be valuable in informing practice in relation to the psychosocial issues faced by people receiving a diagnosis of early dementia. Section 2.5 therefore focuses on research into the role of counselling in dementia.

The closing section of the chapter discusses the main themes within the literature, and presents a set of emerging research questions that have been addressed in the studies that are presented in the ensuing chapters.

## 2.1 The Concept of Dementia

The intention of this section is to provide a brief sketch of the general background to debates around research and practice in the field of dementia by outlining the origins of the term, and the contrasting contemporary discourses associated with it.

### *2.1.1 The history of the concept of dementia*

The concept of dementia is indeed older than Christianity and according to Barak and Achiron (1998) was construed by authors of the Old Testament of the Bible as comprising

> "a decreased ability to consult and distinguish right and wrong and also...a warning that old age often brings on foolishness and that the aged are unable 'to take care of themselves'" (Barak and Achiron 1998 p. 277)

These features were understood to reflect a probable frontal type of dementia, classified by a tendency to disinhibition and poor ability to self-care, which was often seen in demented subjects and viewed very differently from normal characteristics of old age. Many of the unknown scholars of biblical times interpreted the term old man as someone to whom a great deal of respect should be accorded. Older people were perceived as possessing great wisdom and sagely properties and the elders of that day were venerated, revered and consulted for their counsel and afforded a special place in society. Even in biblical times dementia was perceived as a different way of being old which denied people the ability to fulfil the role that their society had come to expect of them.

The concept of dementia was also mentioned in the writings of Plato (Hunter 1990), circa 427-347 BCE (Plato's lifespan), and authors have continued, throughout history, to offer a variety of descriptions, such as

> "amentia, imbecility, morosis, fatuitas, anoea, foolishness, stupidity, simplicity, carus, idiocy, dotage, and senility (but not dementia) were used to name in varying degree, states of cognitive and behavioural deterioration leading to psychosocial incompetence" (Berrios 2000, p. 3).

The origin of the word is a derivative of *demens*, from the Latin, which means 'without mind'. Much of the early use of the word can be traced to the translations of works of the French nosologist, Phillipe Pinel, and in the early 18th century was a common term for people who were incapable of managing their own affairs (Berrios 2000). It did have legal connotations; however, it was perceived to be an inadequate cause for matrimonial separation. Following the French Revolution it became an integral part of the Napoleonic Code which exonerated anyone 'in a state of dementia' from any crime or allegation (Berrios 1987, McKeith and Fairbairn 2001).

Dementia as a medical term began to develop from around the beginning of the nineteenth century and the meaning of the concept continues to evolve to the present time (Adams and Clarke 1999).

### *2.1.2 The idea of 'early dementia'*

The focus of this thesis is on early dementia. The definition of the terms early dementia and that of early onset dementia can become confused, but these words are sometimes used interchangeably; however, there is a clear distinction between the two expressions. According to Kelly (1995) the distinction lies within the time factor. The term early onset dementia alludes to someone who, at the time of diagnosis, is under the age of sixty-five years, while the term early dementia is used about someone who is at the outset of the disease process, regardless of their chronological age. It is possible for someone to experience both of these terms together if they are at the beginning of the dementia trajectory and are under sixty-five, which may add to the confusion between the terms However, it is not possible for someone over the age of sixty-five to be experiencing both of these terms simultaneously. Equally a person may be experiencing early onset but not early dementia if they are under sixty-five and have become severely impaired.

#### *2.1.2.1 The meaning of early dementia employed within this study*

The definition of early dementia provided within the previous paragraph clarifies one of the central tenets of this study. The term early dementia is used throughout the study to mean *the beginning of the dementia trajectory regardless of the age of onset of the person who has received that diagnosis.* The term early diagnosis is also used to mean diagnosis of dementia as early as possible within that trajectory, bearing in mind that early will mean different things to different people both experiencing and diagnosing dementia. Therefore, the terms early dementia and early diagnosis are used interchangeably within this study.

### *2.1.3 Diagnosing early dementia*

Diagnosing early dementia is fraught with complexity and difficulty primarily because "there are no definitive imaging or laboratory tests for the diagnosis of dementia or most of the disorders that cause dementia, including Alzheimer's disease" (Kawas 2003, p. 1057). A medical diagnosis of this condition relies on taking a detailed history with careful questioning, including medication, in order to elicit clues around the possibility of cognitive and functional impairment (Santacruz 2001). This interview should be with the patient and their supporter in order that the history be corroborated. This is followed by physical and neurological examinations, which will include blood tests, mental health status review, and also neuro-imaging, e.g. Computed Tomography (CT) scanning or Magnetic Resonance Imaging (MRI). Neuropsychological testing may also help to clarify the diagnosis. The results of all of these tests are reviewed cumulatively and checked against reliable and valid diagnostic criteria, e.g. DSM IV or ICD10 and provisional diagnosis made, and all other possible causes will have been eliminated. The diagnosis of dementia is frequently made by excluding other possible causes, and once other possibilities are exhausted it is only then will a diagnosis will be made. This will almost always be offered as a probable diagnosis as definitive diagnosis can only be made at post mortem examination.

One of the issues in early diagnosis was whether the clinical picture was one of dementia or mild cognitive impairment, and in order to clarify the diagnosis referral to specialist services was recommended (Kawas 2003). The term mild cognitive impairment (MCI), or minimal dementia as it is sometimes known (Visser 2002), has been utilised to describe a phenomenon that may or may not lead to the diagnosis of dementia and it continues to be a contentious issue. Bond (2002) suggested that while the diagnostic criteria of mild cognitive impairment were still being disputed, consensus appeared to have been reached that implied that they described the transitional state between the normal cognition of the elderly and dementia (Chertkow 2002). It was uncertain how many people diagnosed with mild cognitive impairment went on to develop early dementia, however this group of people were being targeted as a prospective treatment set in the prevention of Alzheimer's disease, and a recognition of MCI could be important in identifying the preclinical stage of the disease process. While there has been progress in defining the diagnosis of MCI and its likely linkage to the manifestation of Alzheimer's disease, there continued to be a current lack of certainty (Chertkow 2002) and therefore this study, while acknowledging the significance of MCI, is based on the early diagnosis of dementia.

#### *2.1.3.1 The imperative of an early diagnosis*

The imperative of an early diagnosis has been highlighted by many authors including Bond Chapman, et al. (2002), Bryans, et al. (2003), DeKosky (2003), Gustavo (2003), Hamilton (2001), LoGuidice (2002), Manthorpe, Iliffe and Eden (2003), Rait, Walters and Iliffe (1999) and Wackerbarth and Johnson (2002).

Many different reasons were offered as to why early diagnosis of dementia was deemed to be important. From a medical perspective, it became increasingly important to diagnose dementia early as more treatment options became available (Jha, Tabet and Orrell 2001, Santacruz and Swagerty 2001), and the possibility of being able to delay the disease process became a reality. Early diagnosis could be seen as a benchmark for good practice (Bryans, et al. 2003) and also allowed for people to be given their diagnosis at a time that would be meaningful to them (Rait, Walters and Iliffe 1999). Following this diagnosis people with dementia and their families can be introduced to appropriate support agencies and be able to access services (Illiffe, Manthorpe and Eden 2003), with a timely diagnosis also giving the opportunity for information sharing and service co-ordination across the disciplines (McIntosh, et al. 1999).

Early medical and psychosocial interventions have been hailed as essential ingredients in prolonging the time when both people with dementia and their families can enjoy their normal pattern of daily life. It also enabled the person to make plans for the future, attend to legal and financial affairs and become actively involved with service providers in their longer term plan of care (Alzheimer Scotland Action on Dementia 2000). A compelling case for early diagnosis of dementia has been outlined above.

There are presently three broad and very diverse schools of thought which reflect a representation of the contemporary meanings within today's society which are popularly portrayed in the literature. These are the medical, psychological and social models of understanding dementia, which are now presented.

### *2.1.4 The medical perspective on dementia*

The medical model espouses physiological causation for what is frequently referred to as organic brain syndrome. This can be caused by several different illnesses whose main feature is the progressive decline of numerous cerebral functions (Jacques and Jackson 2000). It is defined by the International Classification of Diseases (World Organisation Health 1992) which describes dementia in the following terms:

> "a syndrome due to disease of the brain, usually of a chronic or progressive nature in which there is disturbance of multiple higher cortical function including, memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded by deterioration in emotional, social behaviour and motivation." (p. 28).

Along with the ICD-10 the other most frequently used criteria for defining dementia in Britain is the USA Diagnostic and Statistical Manual of Mental Disorders (DSM 1V-1994). It is broadly similar to the ICD-10 and emphasises the disruption to the person's normal daily living activities (Ballard 2000). Indeed, most of the current criteria also make mention of a lack of clouding of consciousness, evidence of a gradual progression of symptoms, the limitations of functional abilities and an exclusion of other primary psychiatric disorders (Cervilla, Prince and Mann 1997).

Dementia is seen by some practitioners as a syndrome, with discrete pathologies of different illness, leading to the distinct pattern of clinical features known as dementia (Jacques and Jackson 2000) and by others (Brayne and Calloway 1988) as a continuum of normal aging through to dementia, thus posing the question of not whether it is dementia, but actually how much dementia is present. With this level of variance of how practitioners construe the puzzle of what actually is dementia it is perhaps understandable why coming to a diagnosis is not exactly a straightforward process. The medical diagnosis of dementia is a complex process and may be due to many of the signs and symptoms, or indeed the syndrome of dementia can be caused by many different illnesses or diseases of the brain.

The most common of these is Alzheimer's disease, which accounts for around 50% of people experiencing the condition of dementia. Alois Alzheimer initially described the illness and its trajectory in 1906 following his study of a single case, the now famous Auguste D, and in 1907 his colleague, Kraepelin, began to refer to this as Alzheimer's disease (Maurer, Volk and Gerbaldo 1997). Other forms include dementia with lewy bodies (20%), vascular dementia (10%), mixed Alzheimer's/vascular dementia (10%), with many other, much less common forms such as frontal lobe dementia, Huntington's disease, alcohol related dementia, Creutzfeldt-Jacob disease, and AIDS related dementia making up the other 10% (McKeith and Fairbairn 2001). Depression may also present as a pseudo-dementia.

The diagnosis of dementia can only be certain at post mortem (Ballard 2000), and therefore a diagnosis of probable dementia would be offered to a person following extensive cognitive, haematological, radiological and neuropsychological testing, with full physical examination and history of symptoms being taken by the medical practitioner. Only after all these tests were completed and other likely causes for the presenting symptoms eliminated, would the tentative diagnosis be made.

From a medical perspective, dementia is seen as a degenerative disease, which is rarely reversible and has no known cure to date, although there are now medications prescribed which claim to slow down the process of decline. It sometimes produces symptoms in 'sufferers' which lead to behavioural difficulties, and which require to be managed by medication such as tranquillisers. Treatment is perceived as prescribed medication and over the past five years pharmacological treatment has advanced with the introduction of the anti-cholinesterase range of medication; however, this is only available for people with Alzheimer's type dementia. Research concentrates on finding a cause, in order to effect a cure. The medical perspective continues to be the one most widely held within western society, and it dominates most discussions about the condition.

### *2.1.5 The psychological perspective on dementia*

The hallmarks of the psychological model are of concerns around cognition and behaviour with emphasis on the measurement of cognitive decline and the formulating of different behaviours into problems requiring intervention and management. Historically, psychologists working with the 'dementia service' were an adjunct to the physicians where their major input was testing intellectual capacity, memory and learning abilities in order to help work up a diagnosis (Maciejewski 2001) and define specific areas of brain damage. Common assessments used by clinical psychologists include the Clifton Assessment Procedure for the Elderly (CAPE) (Pattie and Gilleard 1976), and the Mini-Mental State Examination (MMSE) (Folstein, Folstein and McHugh 1975) which are fairly short and progress in complexity and length in order to target a much wider skills range. These include such tests as the Cambridge Examination for Mental Disorders in the Edlerly (CAMDEX) (Roth 1988), the Wechsler Adult Intelligence Scale-Revised (WAIS-R) (Wechsler 1982) and the National Adult Reading Test (NART) (Nelson 1982). Jacques and Jackson (2000) argue that it is rarely necessary for these specific tests to be carried out as they add little to the experienced clinicians' information and diagnosis continues to rely on the "subjective interpretation of the data" (Cheston and Bender 1999, p. 69).

Psychology is not only concerned with the neuropsychological testing but also with how the disease process affects the behaviour of the person with dementia and how that affects the carer, and one of the most common requests is for advice on how to cope with the challenging behaviours exhibited. The psychological understanding of dementia tends to work within a problem focused behaviour management paradigm and the work of Zarit, Orr and Zarit (1985), which proposes a stress management model, part of which is a problem solving process, and Stokes (1996), illustrate this approach well. This work is often directed at educating the caregiver in different strategies of how to approach difficulties and problems encountered in daily living with people with dementia and it concentrates on trying to find the root cause of the problem experienced and is highlighted as being "due to a memory-impairing disease"(Zarit 1997, p. 21). In recent years, a further development of the psychological perspective has involved the development of computer-aided devices to assist people diagnosed with dementia to maintain memory function (Alm, et al. 2004).

A number of therapeutic approaches have been developed from within a psychological perspective. In the early 1980s methods such as Validation Therapy (Fiel 1982), Reminiscence Therapy (Coleman 1986) and Reality Orientation Therapy (Holden and Woods 1988) were widely used. These were followed by a problem-focused behavioural approach developed by Stokes (1986a, 1986b, 1986c, 1986d). By trying to identify patterns of behaviour it was hoped that staff could anticipate and change problem behaviour. Also concentrating on a problem-solving model, Zarit, Orr and Zarit (1985) focused more on the family and utilising carer education and the psycho-educational approach to reduce the stress the families were believed to be suffering. These models continue to be developed and adapted for people with early dementia (Moniz-Cook, et al. 1998) with more recent advances made in Cognitive Rehabilitation by Clare et al. (2003).

The intervention strategies constructed by psychologists are largely organised around the view that all problems experienced by sufferers are caused by dementia and can be overcome if the person and their carer have sufficient education about the illness and its impact on them. Psychological interventions therefore primarily target the family/carer to take control and manage the situation and find the solution to the problem.

This continues to be a prevalent view, although the writings of Kitwood (1997) have changed the landscape of how the person with dementia is perceived. He suggests that we should be looking at the person first rather than the problem that is created by their organic brain disease, and that dementia care is blighted by what he refers to as a 'malignant social psychology' (see Section 2.2.3 for an expansion of this concept). The writings of Kitwood have opened up possibilities for psychotherapeutic counselling interventions with people diagnosed with dementia. For example, Cheston and Bender (1999) argued that psychotherapy was possible with people with dementia, and that cognitive impairment should not preclude people from engaging meaningfully in therapy. More recent developments in this field have included the use of psychodynamic-interpersonal psychotherapy (Brierly, et al. 2003). These psychotherapeutic applications of a psychological perspective are discussed in more detail below, in Section 2.5.

### *2.1.6 The sociological perspective on dementia*

The sociological model of understanding dementia is based on the premise that individuals and their significant others interpret and make meaning of their own unique experience of living with dementia. The beginning of the dementia trajectory is viewed as a significant 'life event' within the person's life course, and marks the dawning of an understanding of the implications, both personally and practically, that dementia creates for close family members as well as for the person. Key aspects of the development of the social model include the material resources and social and political situation but most crucially it is the meaning that is attached to these 'life events' and the circumstances in which individuals find themselves. Acknowledging the additional factors of both physiological and psychological changes within the disease process as well as the social circumstances, there is recognition of the temporality of the situation. Whilst the subjective experience which encompasses the individual's responses is central to the social model, this cannot be understood in isolation as purely as reaction to this 'life event'. Influencing this response will be the cultural context within which it is happening, along with the biography of the person with dementia and their families/significant others, which will also include their personal and financial resources, as well as the capacity for making meaning of the situation (Bond 2001). Other sociological perspectives influencing the perceptions of dementia include theories of labelling, ageism and stigma.

A leading sociological writer on dementia, Lyman (1998), has called for a phenomenological perspective to be adopted in order to establish "an understanding of dementia from the 'lived experience' of those who have the condition" (Lyman 1998, p. 49). She differentiates between disease and illness, qualifying this by an exposition of disease being a bio-physiological condition that is characteristically diagnosed by those in the healthcare profession, while the experience of 'an illness' is much more of a subjective perception that can be experienced in the absence of the disease or may not even occur despite the disease being present. She posits that "much of the experience of illness is social-psychological rather than physiological" (p. 50). She argues that as well as this differentiation between disease and illness, there are important differences between the concepts of impairment and disability. Impairment relates to the loss of function, both mental and physical, which is resultant from the disease process, while disability relates to the limitations in daily living activities experienced by the person, and the individual experience of disability may not match up to the assessment of the professionals measuring the impairment. Perceived disability is greatly influenced by the constraints and barriers which appear to be imposed by the social and physical environment experienced which is frequently based on the impairment of dementia being interpreted negatively within our culture (Lyman 1998).

The sociological perspective, therefore, draws attention to the meaning of dementia within society, and to the way that understandings of the condition influence the ways in which those diagnosed with dementia not only view themselves, but are treated by others.

### *2.1.7 Comparison of perspectives on dementia*

The models of dementia presented above are the basis of much of how dementia is understood in Western contemporary society. Within the *medical model*, the view of dementia is one of a physiological degenerative disease process which is characterised by cognitive decline and loss of function, with much of medical research focused on finding a cure for this disease and treatment in the main being chemically delivered with symptoms to be managed. Along with the intensive cognitive testing offered by psychologists, the view of the *psychological model* is mainly centred on changes in cognition and behaviour caused by the physiological changes with psychotherapeutic approaches continuing to be limited (the role of psychotherapeutic interventions is addressed in section 2.5, below). The main intervention is focused on a problem oriented psycho-educational approach initially targeted at the carer or supporter in order to educate them to recognise, minimise and manage the problem behaviours exhibited. More recent developments concentrate on personhood as a theory of dementia care, which will be examined in more detail in section 2.2.3 below.

The *sociological model* offers the view that dementia exists within a social context, perceived differently by different people as they each have their own unique experience of what it means to have dementia: by families/carers/supporters, by healthcare professionals and by society; with the impact of dementia being experienced in the social world of both people with dementia and by members of their social relationship network. It also offers different sociological theories to help make meaning of the experience.

These models of understanding dementia give us different ways to think about what dementia is and the different standpoints from which those diverse groups of professionals perceive and interpret dementia.

None of these three models can claim superiority to the other although the most commonly held discourse in contemporary society continues to be that of the medical model, which in turn largely determines how people are treated both by the medical profession and the wider society. This thesis seeks to understand dementia as a condition that is constructed within and by society. A view of dementia as a social construction does not negate the medical model; rather it posits that it is only one construction of many. The aim of this thesis, therefore, is to explore the ways in which these different discourses or perspectives interact within the lives of those involved in making and receiving an early diagnosis of dementia.

## 2.2 The Social Construction of Dementia

### *2.2.0 Introduction*

Within the research reported in this thesis, the medical, psychological and sociological perspectives that were described in the previous sections are regarded as representing discourses of dementia that are particularly influential within our culture. The intention of the thesis is to explore the way in which these discourses or ways of talking and making sense inform and shape the experiences of doctors, patients and family members around the time of a diagnosis of dementia. Social constructionism is an approach to social science that provides a framework for analysing the operation of discourses in everyday life (Gergen 1994, 1999, 2001). In Chapter 3 (Section 3.1.3), social constructionism is described in some detail, as the basis for the methodology adopted in this work. The aim of this section of the literature review is to provide a brief introduction to the key aspects of a social constructionist approach to dementia. According to Burr (2003), social constructionist analysis is based on a set of core epistemological principles:

- the adoption of a *critical stance* towards taken-for-granted ways of understanding the world
- an acknowledgement that *understanding is bound by both culture and history*; therefore it is dependent on particular social and economic factors prevalent at a specific time and place
- an assumption that *knowledge is produced by the co-constructions of people interacting together*
- a belief that *knowledge and social action are inextricably linked*

The sections that follow seek to illustrate some of the ways in which these analytic principles have been applied to deconstruct the concept of dementia, and to build an understanding of the reality of dementia as co-constructed.

### *2.2.1 Deconstructing the dominant dementia narrative*

The familiar and dominant medical discourse of dementia has been deconstructed by writers such as Harding and Palfrey (1997), Adams (1998), Hill (1999) and Davis (2004), all of whom have challenged the assumptions and claims of the current construction of dementia as a biomedical disease. For example, although investigations such as Magnetic Resonance Imaging and Computerised Tomography can be viewed as substantiating biomedical representations of dementia, biomedicine can be severely criticised for its inability to effect a cure, and for its management of people with dementia, who in the past have been 'warehoused' in large asylums waiting in the hope that a cure may be found (Adams, 1998).

The challenges to the dominant narrative from Harding and Palfrey (1997) come in the form of critical analyses of the many meanings that come from a singular definition of dementia. The definition they have chosen is from the Royal College of Physicians

> "Dementia is the global impairment of higher cortical functions, including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills and the control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive." (RCP 1981, p. 139)

Harding and Palfrey (1997) argue that this definition employs elusive and non-clinical concepts such as 'problems of day to day living' and 'correct use of social skills'. They question and challenge the basis for what is meant by 'correct'. They also point up the difficulties faced by the medical profession in reaching an accurate diagnosis. They further advance their argument by highlighting the lack of subjective evidence – the alleged experience of dementia is typically described through the eyes of observers. According to Harding and Palfrey (1997) the classical medical model of dementia is descriptive rather than one that provides society with a theoretical understanding, and the experience of dementia is thus seen by society as a 'medical problem'. They seek to contest the dominance of the medical perspective whilst respecting the severity of the experience of dementia for the person and their family.

Hill (1999), in his deconstruction of western medicine and dementia, argues that medical discourse is only one position amongst many. His goal is to 'deprivilege' medical accounts of dementia. For this, a historical perspective is adopted, and he cites the works of Berrios, a psychiatrist who has studied the history of dementia and written prolifically on this subject (see earlier citations in this thesis), acknowledging the only consistent feature of dementia throughout the ages as 'psychosocial incompetence'. Over the last three centuries there has been debate as to whether dementia is a 'distinct disease category' or a variation of the normal aging process. He contends that the ways in which dementia has been understood over the years closely relates to changes in medical thinking in general. Hill (1999) makes six key claims about the current practice and discipline of medicine:

- human beings are viewed within a medical perspective as machines with the physical malfunction of parts, rendering health and illness principally as physical

- medicine holds the view that the states of health and illness can be measured objectively
- causal links can be found between 'pathological agents' and disease outcomes;
- it is reductionist in its approach and consigns psychological, social and environmental issues to be less relevant in the causation of illness
- the predominant activity is the search for 'cures', which can in turn be given 'to' patients, leaving them with no personal responsibility for their own health
- medicine has a propensity to be expansionist and to embrace conflict and challenge by marginalising and/or incorporating what they perceive as potential threats into the realms of medicine.

For Hill (1999), the medical perspective is only one particular world view, which should be acknowledged as valid but not superior to other forms of knowledge. Hill (1999) stresses that scientific medical meanings can be seen as a construction but is only one of many possible representations which can allude to insights and explanations of health and illness states. They are not superior in any way to other understandings of dementia. Hill (1999) posits that scientific medical ideas around dependence and independence obscure the view that, in the main, human beings are all fundamentally interdependent, whether they are in a state of health or illness. For example, people involved in the 'caring professions' are dependent on 'patients' for their career, livelihood, and identity as 'professional carers' etc., just as much as patients are dependent on them for care and welfare. There is a reciprocity in these relationships that is rarely acknowledged by professional carers. Hill (1999) calls for a willingness to "understand dementia in its widest sense" (1999 p. 76).

The contribution of these authors, in deconstructing the dominant medical discourse around dementia, has been to create a space for different kinds of conversation about this condition to take place, which privilege the experiences of people with dementia rather than those with power.

### *2.2.2 Stigma associated with a diagnosis of dementia*

In an important essay Gloria Sterin (2002), who was diagnosed with Alzheimer's disease, highlighted the meaning and impact for her of the word 'dementia': "it implies a very derogatory and negative circumstance" (p. 7). She adds that the psychological consequences of labelling someone with dementia are extremely powerful. It has the implications of rendering someone as <u>mindless</u>, and with no mind we cannot be fully human. She argued that there was much more to personhood than an intact short term memory. Her personal experience was that once the label had been assigned people reacted differently; sometimes withdrawing and not including them in conversation; sometimes reacting with dismissal and disrespect; or sometimes smothering with kindness.

The stigma associated with mental illness has been well documented and researched (Brown and Bradley 2002, Byrne 2001, Crisp, et al. 2000, Sayce 1998). A seminal work on stigma, understood as a form of 'spoiled identity', was published in 1963 by Erving Goffman (1963). In this book, he defined stigma as

> "possessing an attribute that makes him different from others...of a less desirable kind...reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma...By definition, of course, we believe that the person with the stigma is not quite human...We construct a stigma theory, an ideology to explain his inferiority...we use specific terms such as cripple, bastard, moron in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning." (Goffman 1963, p. 12 and 15).

To Goffman's list of terms I would add the term 'demented'. The stigma associated with dementia has been recognised by the World Health Organisation, which in collaboration with the Old Age Psychiatry section of the World Psychiatric Association has published a position paper (Graham, et al. 2003) on the subject. This paper highlights the double burden of discrimination carried by older people with mental illness and demands that they receive special attention stating that "stigma tragically deprives people of their dignity and interferes with their full participation in society" (Graham, et al. 2003, p. 672). Graham et al (2003) identified six different ways in which a person with a diagnosis of dementia may be stigmatised:

- lack of recognition that it is not part of the normal ageing process, leading to inappropriate management
- specific behaviours can be 'powerfully stigmatising' such as incontinence or disturbed behaviour
- popular use of the term 'dementia' can be stigmatising
- loss of a past due to poor memory leading to cultural and religious beliefs and personal preferences being ignored

- being perceived as having no ability to enjoy pleasurable activities and no quality of life
- exclusion from some care situations like emergency resuscitation procedures, admission to some care homes and in-patient facilities.

Graham et al (2003) argue that defining dementia as having an organic aetiology may serve to lessen stigma in some cultures thus moving it from the realms of mental illness to that of a disease of physical origin. Despite the value of this article, it probably understates the extent of negative social attitudes toward dementia sufferers. It says little about the person who may be frightened to put themselves forward for a diagnosis because of the inherent stigma, nor does it address the newly diagnosed or how services could facilitate a person's pathway through the diagnostic process in order to reduce the stigma attached to the diagnosis. It concentrates mainly on the person who has had the diagnosis for some considerable time and is experiencing more severe difficulties. Warner (2001), however, promotes early diagnosis of dementia as a way to "help remove the atmosphere of secrecy and stigma the label still confers" (p. 289), and sees this being achieved by promoting early recognition through increased public awareness leading to early referral by general practitioners, and by health professionals constructing 'risk profiles' which could be predictive of a diagnosis of dementia.

Other writers who have highlighted the stigma associated with a diagnosis of dementia include De Mendonca et al (2003), Benbow and Reynolds (2000), and Post (1995). Sabat (2001) argues that for people living with dementia there are many assaults on self-esteem and self-worth that can be classed as being stigmatised. Throughout the diagnostic process people have to suffer such indignities as being asked if they know their own name or where they are, and he reports how one of his case study cohorts, Dr M., experienced the assessment procedures as being "disrespectful, disparaging and dismaying" (p115). Sabat (2001) suggests that having a diagnosis of Alzheimer's disease puts the person at risk of being perceived as "somehow less of a person" (p115), in much the same way as Goffman describes stigma. However, he proposes that people with a moderate to severe degree of dementia may continue to maintain their self-worth with appropriate support.

In conclusion, it can be seen that negative social attitudes and stigma provide a pervasive backdrop to the experience of dementia. However, despite the importance of these issues, relatively little research has been carried out into public attitudes toward dementia, or how these might be changed. In a survey of public opinion about how mental illness was perceived in Britain, Crisp et al (2000) found that the perception was that people with mental health problems were difficult to talk to, feel differently from other people, were unpredictable, will not improve with treatment and will never recover. These conclusions almost certainly hold true in relation to public attitudes to dementia.

### *2.2.2.1 The concept of 'courtesy stigma'*

Goffman (1963) describes how a person "who is related through the social structure to a stigmatised individual...leads the wider society to treat both individuals in some respects as one" (p. 43). He uses the term 'courtesy stigma' to describe the transfer of stigma from a person with a 'spoiled identity' to their family members. In his work, he cites examples of the loyal spouse of mental patient, or the daughter of an ex-convict, who are obligated to share in some of the discredit of their relative. Two studies have concentrated on how families of people with dementia are affected by stigma (Blum 1991, and MacRae 1999). MacRae (1999) found that it was not only direct caregivers of people with dementia who experienced courtesy stigma, but also relatives who were not part of the day to day caring regime. This study also found that families developed strategies for avoiding stigma, such as collusion and cover up. These were found to be stressful and isolating for the caregiver and could only be a temporary measure and much more difficult to achieve as the illness progressed.

In the study by Blum (1991), courtesy stigma is described as moving through two phases: first, the collusion of the family member and the stigmatized in order to manage information; and second, when management fails, where the activity of covering up takes over in order to minimise the shame and embarrassment felt by both. Once this fails the second phase is entered when the prevention and management of the inappropriate behaviours are exhibited by the person with dementia. Within this phase collusion is diminished and the caregiver disengages to maintain social order and to preserve his or her own dignity and in some cases adopt the position of 'pre-emptive disclosure'. In doing so, the family member gives an explanation of what behavioural problem might occur, therefore avoiding anticipated awkward and embarrassing social situations. The concept of courtesy stigma is valuable in allowing a clearer picture to emerge of the potential impact of dementia on the relatives and carers of those who have been diagnosed.

### *2.2.3 Challenging the 'dominant paradigm' in relation to practice: the work of Tom Kitwood*

Two of the leading proponents of alternative theories to that of the predominant medical model of dementia are Tom Kitwood and Steven Sabat. Their theories, which are based on social constructionist principles, were developed in the 1990s and represented the first attempts to move beyond deconstruction and critical analysis and devise methods of intervention and care that were consistent with the principles and values of social constructionism.

Throughout his work in the field of dementia, Tom Kitwood (Kitwood 1990a, 1990b, 1993, 1997, 1998) challenged the dominance of the medical model that he renamed the 'standard paradigm'. He argues that basing the diagnosis of dementia on organic features alone is very narrow, and that the condition is not the result of a simple linear biological sequence of cause and effect. He also challenges the time span of deterioration which may vary from months to many years. He asserts that simple neuropathological changes are not enough to explain the process the person with dementia is experiencing and questions whether the pathology of dementia lies in brain, mind or society. He also contends that the 'standard paradigm' has little to offer in terms of practice. He undermines the scientific medical position by positing that many of the losses in later life are socially constructed. Kitwood offers an alternative in which he reconceptualises dementia as an amalgam of personality, biography, healthy neurological impairment, and social psychology, each affecting the other.

The central tenet of Kitwood's argument is that the psychosocial environment is a much more important and prominent feature in the process of dementia than has been previously acknowledged. Much of Kitwood's research methods, which he describes as "ethological", have been criticised for being what he acknowledges himself to be "highly subjective and undisciplined". The psychobiographic method, which he has developed through two researchers interviewing families of people with dementia at length, can be seen as informed by the ethological or ethogenic approach of Harré (1993). From this perspective, individuals with dementia are considered as people in the fullest sense as agentic, relational, historical living beings. Kitwood developed the concept of Person-Centred Care of people with dementia around the concept of personhood. His definition of personhood is

> "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, p. 8).

Kitwood's assertion that the person should come first, and not the dementia, is reflected in the values he espouses in his definition of personhood.

### *2.2.4 The self in dementia: the work of Steven Sabat*

While the approach adopted by Kitwood focused to a large extent on the way that others (carers, family) treated the person with dementia, further social constructionist theorising carried out by Steven Sabat concentrated more specifically on the subjective experience and sense of self of such persons. Sabat and Harré (1992) were amongst the first to examine the nature of the self in Alzheimer's disease from a social constructionist perspective. In what is now regarded as a seminal paper, they studied three people with Dementia of the Alzheimer's type (DAT), who had each been diagnosed 4 years prior to the study and had experienced changes for up to 2 years prior to diagnosis. The researchers utilised a social constructionist model of the nature of self in conjunction with 'positioning theory' in order to expand our understanding of how self in Alzheimer's disease can be articulated, presented and maintained, and also explored the phenomenon of 'loss of self'. In this research, the idea of that a 'loss of self' (Cohen and Eisdorfer 1986) is an inevitable feature of dementia (Davis 2004), is both challenged and refuted. Sabat and Harré (1992) introduced two different meanings of self. The first of these, self$^1$, was expressed through the telling of their life stories, embracing responsibility for personal actions, expressing a personal worldview, together with thoughts, beliefs and feelings, which are generally coupled with one's own personal agency. Self$^1$ can be understood as the person's subjective sense of on-going identity.

By contrast, self$^2$ or 'selves$^2$' are described as the publicly presented repertoire of a multiplicity of selves which are revealed in the everyday interpersonal interactions and are known as 'personae'. These public personae which are enacted discursively to ensure that public performances conform to the expectations of one's peers, each community having recognisable and acceptable person types that are constantly being co-constructed through talk and interaction.

In everyday circumstances each human being is just one person, a singular identity, but with many ‘selves’. The self$^{1}$ does not require any other person in order to exist, and continues to exist in the face of incomplete remote and recent memory functioning. The existence of self$^{2}$ however, is not so independent. It requires cooperation from others in order to construct our social selves$^{2}$ and these social selves are only able to be validated if they are recognised by others. The self$^{2}$ can only assume some kind of significance if that affirmation is given, and if the behaviour is recognised by others as worthy of affirmation. If this is withheld for any reason, it can have a profound impact on both how the person is viewed and subsequently how that person will be perceived and treated by others. If what one says or does is taken to be out of context and deemed unacceptable, that person can be treated with disdain, distance and doubt. ‘Selves$^{2}$’ are the multiplicity of personae that are dependent on ‘the other’ and on the social context. Among these selves can be many characters: a loving husband, a hard-working employee, a devout and faithful Christian, a loyal friend or a hopeful golfer. In each of these personae the character and behaviour are different, dependent upon the context, and it is in the interaction between both parties that the forms of ‘selves$^{2}$’ becomes discernible. It is through these constant mutual exchanges and recognition of each other’s position that each distinct version of a ‘self$^{2}$’ is constructed. These mutual exchanges and constructions have been termed ‘positioning’.

The conclusion is that from a constructionist point of view, Alzheimer’s disease does not result in the ‘loss of self$^{1}$’ and contributes only indirectly to the losses of ‘selves$^{2}$’ when what is sometimes interpreted as symptoms has been misrepresented and misunderstood. Within the co-constructions of ‘selves$^{2}$’ the disease is sometimes blamed rather than trying to find new constructions, although there is evidence that ‘selves$^{2}$’ is manifested well into the trajectory of Alzheimer’s Disease, with the threat to ‘selves$^{2}$’coming from a social network not reacting positively, although it is acknowledged that this is not always easy.

Within this model, ‘positioning’ theory encompasses the same range of phenomena as ‘labelling’ theory although ‘positioning’ theory pays closer attention to linguistic devices that place people into ‘types’, positioned by their storylines. In many ways the losses in dementia have less to do with the neurofibrillary tangles and more to do with the ‘malignant positioning’. To allow humans to flourish, mutual co-operation is necessary and this is no less so in dementia.

Following on from this seminal paper Sabat further developed these social constructionist theories, and in more recent writings (Sabat 2001, Sabat and Collins 1999) has established the notion of Self[1], Self[2] and Self[3] where the Self[1] remains unchanged, Self[2] consists of a unique set of mental and physical personal attributes, some of which are fixed and others more flexible and likely to change over time. These attributes along with our beliefs about them are part of what is known as Self[2] and they can be both positive and negative and the Self[2] can still be seen as intact despite the person having dementia. In this new framework, Self[3] has become synonymous with the original Selves[2] which is the self that is dependent upon others for validation of the identity they are portraying. These roles or identities are much more vulnerable because of their need for the other to co-construct a meaning with them of each persona. Analysis of the interplay between Self[1], Self[2] and Self[3] can provide a basis for making sense of the ways in which people assimilate and deal with a diagnosis of dementia (see Chapter 7, Section 7.2.6 below).

Intrinsic to what Sabat sees as self is how we construct and are constructed by others through language. Language is also the medium through which we give to others and take for ourselves, and are given by others, different positions.

#### *2.2.4.1 Acknowledging language*

In Sabat's (2001) quest to come to a deeper understanding of people who had been diagnosed as having Alzheimer's disease he contends that in order to gain appreciation of their meaning making abilities we must study the discourse of the person with dementia utilising methods other than that of Classical Science, and he recommends Romantic Science as a way forward. Despite having no standard toolkit, this way of examining the lives of people with dementia allows the researcher to "obtain information which can be gathered only by observing life as it is lived and unfolds in the everyday world…the situations from which they derive meaning, and how meaning is expressed" (p. 171).

He invites us to look on people with dementia as semiotic subjects. What he means by this is a person whose behaviour is driven by meaning. The three key characteristics are

- Acting out of intention
- Interpreting events and situations
- Evaluating events, situations or actions (p. 171).

One way of exploring the person as a semiotic subject is through discourse and how the person with dementia communicates. He highlights the importance of paying attention to the use of language, especially later on in the disease trajectory when the person with dementia may be having trouble conveying what he/she wants the listener to hear, and may be experiencing word finding difficulty. Sabat (2001) suggests the listener takes

> "the intentional stance and thereby positioning the AD sufferer as one who has something meaningful to say and is, indeed trying to communicate, can easily lead to the use of an effective facilitative speech act ... indirect repair refers to inquiring about the intention of the speaker, through the use of questions marked not be interrogatives but by intonation patterns, to the use of rephrasing what you think the speaker said and checking to see if you understood his or her meaning correctly. Thus the responsibility for effective communication between people lies with the listener as well as the speaker" (p. 38-39).

This is in many ways akin to the active listening role in the therapeutic relationship and McLeod (2004) describes the counsellor's role as inevitably involving

> "listening to people talk in detail about complex situations in their lives. Often, the person's way of telling his or her life story may be halting, incoherent, or punctuated by strong emotion. Almost always, there will be gaps in the story – things not said things that may be too embarrassing or shameful to share with another person." (p. 45).

Indeed Sabat (2001) highlights the need for "therapeutic conversation" (p. 45). He also highlights the effects of distractions on conversations where the importance of the understanding and ability to pay close attention to what the person with dementia is trying to say is a very important component of the function of the healthy listener.

Paying attention to what the person with dementia has to say is a central tenet of this research project and it also engages the methodology of Romantic Science in the form of qualitative inquiry. Although language is not always obviously affected early in the disease trajectory the importance of the observational ability and need to understand the conversation of the people involved in this study is nevertheless of paramount importance.

### *2.2.5 The construction of self within the family*

This constructionist notion of Self[3] is supported by research carried out by Hanson (1997) who posits that "the social construction of senile dementia begins at home and is driven by families who construct and maintain problems" (1997, p. 17). Her model follows a tradition within mental health research which views families as constructing and maintaining the idea that a family member is 'sick'. From earlier work Hanson (1989) describes a basic model of family typology, portraying two different types of family, namely definitional equality family and definitional deficit family, based on observation of forty-five families all with at least one older person, and of these forty-five, twenty-nine families had a person with dementia living within them. The study set out to explore how information was socially constructed within families, and how it may affect the identification of behaviour and symptoms. Whilst she does not question the existence of underlying biological causes for dementia, regardless of its supposed origin, people make sense of dementia in different ways. This is most frequently processed within the family context, with family usually initiating, and mediating both diagnostic and treatment processes.

It was noted that families who excluded one member from their processes of reality construction would promote and magnify symptoms of dementia (or any other pathology). This would then lead to the emotional isolation of the excluded member, and being marginalised from the reality construction processes of the family the excluded member would have less likelihood of knowing what that family's reality was. These were the 'definitional deficit' families. Families that included everyone in their processes of reality construction (definitional equality families) were much more likely to work on problems within a shared framework and therefore make a positive meaning from symptoms. They were less likely to seek diagnosis and treatment and have their changes in behaviour accepted within their family system. It can be concluded from Hanson's study (1989) that 'definitional deficit' families fail to validate and co-construct a positive Self[3] with the member who has dementia, and within the 'definitional equality' families the reverse will be happening when a co-construction of a positive Self[3] with the person with dementia is evident.

Within the complex dynamics of the interpersonal processes of a family, symptoms of dementia are made meaningful, reacted to and acted upon, and it is within these family processes that the person with the diagnosis of dementia initially has to make meaning of that diagnosis. Hanson (1989) has shown that depending on whether the person is a member of a definitional deficit or definitional equality family will shape their journey through the dementia trajectory. Hanson's (1989) work is important in illustrating the ways in which the kinds of definitional or positioning processes described by Sabat can occur in a family context.

### *2.2.6 The role of health professionals in positioning*

The work of Adams (1998, Adams 2000, 2001) carries forward the ideas introduced in the previous sections into the domain of relationships between health professionals and people diagnosed with dementia. Adams (1998) urges practitioners to recognise the 'family politics of dementia' in order that health professionals can actively include people with dementia in the decision making processes that affects their care. Adams (2003) has proposed an inclusive approach to dementia care based on a triadic model (carer, person with dementia, and health professional). Building on earlier studies by Fortinsky (2001), the importance of the integration of a social constructionist understanding of dementia care within the notion of triadic interaction was highlighted where the identity of each member of the triad is mainly constructed through language. The potential of this new approach is to empower and enable people with dementia to be full and equal partners in the decision making process providing that none of the triad members make fixed alliances and coalitions between two of the three members. The professional involved has the responsibility to ensure an equal and appropriate distribution of power.

Each member of the triad is viewed as possessing their own sphere of knowledge: the person with dementia has a subjective experience that neither of the other two shares; the person caring has the subjective experience of caring for that person with dementia within a unique and personal relationship; the professional clinician will have experience of many others who have experienced dementia and have objective knowledge gleaned from professional training. Each is the expert within their own sphere and this can help towards the equal sharing of the power base. Conversely, if this different knowledge is not recognised and shared equally, the power that knowledge brings can then become disempowering. This disempowerment can be seen as a barrier to the social construction of a valued social identity.

The importance of the triadic model is highlighted by a single case study of a person with a mild to moderate degree of dementia published by Sabat, Napolitano and Fath (2004), in which they analyse psychosocial factors that significantly affect what the person with dementia does and says. These include the impact that the neuropathology has on the person, the reaction of healthy persons, and the reaction of the person with dementia to the ways in which he/she is treated by others. Constructing a valued social identity requires at least one other person with whom a positive social identity can be crafted. At times there is no-one who offers this kind of co-operation, even, and sometimes especially, within the family and the person with the diagnosis is trapped within the social identity of a victim of Alzheimer's disease, with no hope of escape from this vortex. The implication is that it may be someone outside the family, such as health professional or other helper that may best be able to supply this relationship.

### *2.2.7 The concepts of 'malignant positioning' and 'malignant social psychology'*

It is through the dialogical interactions taking place in the everyday world that people take for themselves, impose on others, and accept or reject positions that make their actions clear and understandable as social acts (Harré and Van Langenhove 1999). It is 'through such positions that a person's moral and personal attributes are defined, strengthened and diluted, and the means by which story lines or narratives about a person are developed and acted upon by others' (Sabat, Napolitano and Fath 2004). Positioning is one way by which behaviour can be explained and understood, both by the person and by others. Malignant positioning (Sabat 2003) and 'malignant social psychology' (Kitwood 1998, Kitwood and Bredin 1992), are two of the factors that negatively influence the experience and behaviour of people with dementia, affecting their ability to construct a valued social identity. When malignant positioning is enacted, it is highlighting a negative emphasis that is being placed on the qualities of the person's behaviour. People with dementia are vulnerable to being positioned in this 'malignant' way (interactive positioning), which can be detrimental to their sense of personhood, especially if they are not being validated in their social roles and identities (Self$^3$ ). People with dementia can be positioned negatively and do not always have the necessary skills to refute this positioning or place themselves in a more desirable position (reflexive positioning). This can lead to them being portrayed negatively by others, and will then affect their ability to construct a valued social identity.

Around the same time as Sabat and Harré (1992) were expounding their ideas about malignant positioning, Kitwood was developing his research around the notion of malignant social psychology. Through a growing awareness of the tendency to depersonalise people with dementia, (Kitwood 1990a) sought to classify the ways in which this was happening. This classification, which he named as 'malignant social psychology', was the reflection of an extremely harmful environment in which the personhood of the person with dementia was threatened. This, he said, was not an indication of deliberately harmful behaviour on the part of the caregiver; rather the malignancy is part of an inherited culture. Initially Kitwood (1990) identified ten elements of 'malignant social psychology', later adding another seven, and it was around these elements that the concept of Dementia Care Mapping (Kitwood and Bredin 1992) developed. Much of the work carried out by Kitwood concentrated on institutional care with people who had fairly advanced forms of dementia rather than people with dementia living at home coming to terms with a new diagnosis, which is what this study concentrates on. Nevertheless, there are at least five of the seventeen elements which are pertinent to this study. These are:

- *disempowerment* — when people begin to do things for the person with dementia who can do the same thing for themselves which can result in loss of confidence, functional ability and feeling of personal achievement
- *labelling* — giving a person a diagnosis of dementia which is then used as a means of identifying that person and leads to everything that person does and says as being filtered through and attributed to the disease whether it has anything to do with it or not
- *stigmatization* — treating the person as an object that is diseased or spoiled in some way which can lead to their being excluded and ostracized
- *outpacing* — providing information and expecting a person with dementia to process this at the same pace as before, thus failing to give the person time to make choices that are relevant to them which diminishes their sense of being consulted respectfully
- *invalidation* — lack of acceptance of who the person with dementia is and has become, failing to acknowledge their subjective reality as valid and worthwhile with little attention paid to their feelings.

For a full list of the seventeen elements, see Kitwood (1997), pages 46-47.

Whilst the work of Kitwood has undoubtedly enhanced the knowledge base of how people with dementia are treated by others and society, in view of the 'malignant social psychology', it is not without its critics. Adams (1996), while appreciating Kitwood's contribution, questions his methods, citing the lack of published psychobiographies and lack of convincing empirical evidence for his claims that do little to support his central argument of the correlation between life events and brain failure. (It might serve us well to remember here that Alzheimer's disease was based on the findings and writings of one single case study, Auguste D). Whilst acknowledging that Kitwood has done much to enhance the care of people with dementia, Adams (1996) questions whether his approach will be widely adopted within the healthcare profession. Davis (2004) has called for the seductive nature of Kitwood's arguments to be resisted in order that some debate can be ongoing pertaining to the status of people with dementia and their positioning with respect to their significant others. The need for what Davis calls the 'crumbling devastation' within relationships to be better understood throughout the process of dementia is seen as paramount.

The critique of Adams (1996) appears to be based on the view that the perspectives offered by Kitwood (and by implication, Sabat) are too optimistic, given the inevitable negative outcomes of Alzheimer's disease. However, within the context of the present study, which is oriented toward the enhancement of practice, the ideas of malignant positioning and malignant social psychology are hugely important because they point to the possibility of life-enhancing strategies for professional interactions with people who have received an early diagnosis.

### *2.2.8 Reflections on the social construction of dementia*

In this major section of Chapter 2, the theories of Kitwood and Sabat, along with other social constructionist perspectives, have been introduced. Kitwood's theories, built around the concept of personhood and person centred care, offer an alternative way of viewing the person with dementia. While these theories have influenced greatly the care of people with dementia, this has mainly been in institutional settings, with a lack of research into the application of these ideas in community settings during the early stages of dementia. The work of Sabat, who draws heavily on case study material to illustrate his model, is centred mainly on people who have had dementia for some years, mostly living within families but attending a day care facility. He has more recently begun to report work with people earlier in the dementia trajectory (Sabat, Napolitano and Fath 2004), again using case study material. There is clearly a need for further research that both extends the evidence base in relation to social constructionist ideas, and also provides a more detailed, fine-grained theoretical analysis.

Later in this chapter, in major Section 2.4, a review of research into the subjective experience of people who have received a diagnosis of dementia will be presented. Much of this research underscores the importance of social constructionist themes, even if the studies do not explicitly employ a social constructionist framework.

Specifically, the theoretical material that has been reviewed in this section, and the research that will be considered later, highlights the importance of relationships in dementia. What happens to people at the time of diagnosis, and later, is heavily influenced by the quality of the relationships within which they live their lives.

## 2.3 A Review of Research into the Doctor's Role in Early Diagnosis of Dementia

This section of the review of the literature concentrates primarily on empirical research within the field of early dementia, and some necessary background information is also provided. It will incorporate studies around the role of the GP and the Consultant in Old Age Psychiatry, and sections relevant to that role in early dementia, including a key section focusing on the disclosure of a diagnosis.

Within the context of diagnosing and treating early dementia two groups of doctors are prominent, namely GPs (General Practitioners) and Old Age Psychiatrists. It is acknowledged here that, whilst this is not exclusive and other groups of doctors such as Neurologists and Geriatricians also treat and diagnose people with early dementia, Psychiatry is by far the most common specialism to which people with probable dementia are likely to be referred by the GP.

### *2.3.1 The role of the Old Age Psychiatrist*

The role of the Old Age Psychiatrist in the diagnosis and management of early dementia is firmly established and in the UK their services are mainly supplied to the public as part of the National Health Service. As a specialty, Old Age Psychiatry goes back to the 1950s (Omu, Butt and Shabbir 2002) but was only granted subspecialty status by the Royal College of Psychiatry in 1989. This status reflected a recognition of the unique needs of older people with mental health problems and the specialist skills and knowledge required to treat older people, and which were acknowledged as different from those of general adult psychiatry (Wattis 1996). While the core skills required in order to practice Old Age Psychiatry are not clearly specified in the training curriculum, Draper (2003) suggests that these are "a competent ability to assess, diagnose, treat and manage psychiatric problems in old age in a comprehensive manner and in partnership with older people and their carers" (Draper 2003, p. 683). Old Age Psychiatrists generally work with people with mental health issues over the age of 65 years. Although people under 65 years with probable dementia would frequently be seen as part of their remit, this practice is not uniform throughout the country (Wattis 1999). The work of Old Age Psychiatrists encompasses many different mental illnesses, with the three major categories being depression, delirium and dementia. As much of their time spent in the community as in hospitals (Wattis 1996) with perhaps a half to one-third of the patients referred to them because of cognitive problems (Omu, Butt and Shabbir 2002).

In relation to dementia, the role of the Old Age Psychiatrist includes direct and indirect patient care in a variety of settings. Direct care involves assessment, diagnosis and disease management, while indirect care is in providing information and education to other disciplines working with people with dementia with the main aim of influencing their practice. According to Wattis (1996) the latter function is necessary because the prevalence of mental illness is too high for all patients to be receiving direct care from psychiatrists, with the result that much of their work is spent in multi-disciplinary community mental health teams and working in partnership with hospital doctors and general practitioners.

### *2.3.2 The General Practitioner and early dementia*

The literature giving an account of the General Practitioner in relation to dementia describes their role as central, pivotal, front line, holding a unique position and the gateway to the services (Downs 1996, Downs, et al. 2000, Vassilas and Donaldson 1998, Wilkinson and Milne 2003). This position is not always recognised by the practitioner, which means that diagnostic practice in primary care of early dementia continues to be variable (Eefsting, et al. 1996, Vassilas 1999, Wind, et al. 1994).

Research examining the ability of GPs to diagnose and detect early dementia has returned very mixed results. In a American study, 1480 caregivers were asked to complete a self-administered postal questionnaire in order to elicit factors associated with diagnosis of dementia, and a correct diagnosis was found in only 38% of cases at initial physician contact (Knopman, Donohue and Gutterman 2000). In Sweden, in a study comparing the medical records of 350 patients over seventy years of age with a psychiatric review by a GP, of those diagnosed at review, a detection rate of only 25% was recorded (Olafsdottir, Skoog and Marcusson 2000) in the patient records. This result stands in contrast to an Australian study which showed a 50% detection rate (Bowers, et al. 1990), and a study in Germany in which it was found that GPs were able to identify most of the mild as well as the severe cases of dementia (Cooper, Bickel and Schaufele 1992). In all, 24 GP practices took part in the Cooper et al (1992) study, with 21 providing a stratified sub-sample of patients to be examined by the research team using a standardised interview and test procedure. Practitioners achieved 92% sensitivity and 76% specificity and identified most of the mild cases. This is a higher rate than has been reported elsewhere which may have been due to GPs following guidelines that had been supplied by the research team. It may be that these GPs were extra sensitive to potential diagnosis of dementia because they knew that they were part of a research study.

More recently an Audit Commission (2002) report in England revealed that 40% of General Practitioners were reluctant to diagnose dementia early on in the disease trajectory. Over 1000 GPs from twelve health authorities were targeted by the Audit Commission, which was undertaking a national study of metal health services for older people. A postal survey was sent to 1827 GPs in 611 practices, with responses from 1005 GPs recorded. 55% felt it was important to look for early signs of dementia while only 53% felt that the patient would benefit from early diagnosis (Renshaw, et al. 2001).

The attitude of GPs is important in the provision of care for people with early dementia because there are many key tasks to perform. The General Practitioner is frequently the first physician who is consulted by the person seeking a diagnosis, and at times is the only doctor to be involved in making the diagnosis (Van Hout, et al. 2000). In a mixed method study to identify the perceptions of tasks GPs perceived as central to their role in the management of dementia, Van Hout et al (2000) used focus group interviews and questionnaires to collect data from 28 GPs in the UK. These participants viewed their core tasks as diagnosing, informing and managing people with dementia and their families, preferably early in the disease process, in order to encourage care in their own home for an optimum period. Van Hout et al (2000) found that there was a discrepancy between their perceived role and their practice, highlighting that most people were actually diagnosed when the disease had progressed quite markedly. The General Practitioners cited patients not coming forward for consultation, uncertainty of diagnosis in the early stages, being too embarrassed to offer and apply cognitive testing or communicate the diagnosis, and a lack of time to carry out the investigations and procedures required to reach a diagnosis as obstacles delaying diagnosis.

Another of the key tasks of GPs is to refer to appropriate specialist services. Van Hout et al (2000) found that referral was sometimes not instituted unless family members insisted, and that sometimes GPs made referrals to unburden themselves of clinical responsibility. As many as 75% of all referrals to Old Age Psychiatry come from General Practitioners (Wattis 1996), although referral patterns differ throughout the country with examples of 'high' and 'low' referral rates from doctors to both community and hospital Old Age Psychiatry services. Butler, Oyewole and Pitt (2000) examined records of all referrals (1397) to their Old Age Psychiatry Service over a 6 year period and found evidence that GPs under-refer patients with dementia. In a retrospective audit of 209 referrals to an Old Age Psychiatry Service to examine the quality of referral information available to the old age psychiatrist at the time of assessment, Brown and Trotter (1994) found that there were differences between telephone and written referral requests. Although the telephone information was less complete, diagnostic agreement was higher than for written referrals and they recommended that clearer guidelines needed to be put in place to improve the quality of referral information together with a call for greater communication between GPs and Old Age Psychiatrists. Sometimes the referral depends on the working and social relationships experienced between the GP and the Consultant.

In a qualitative study to explore how well General Practitioners and Hospital Consultants work together, Marshall (1998) found that the professional relationship is better than anecdotal evidence suggests. General Practitioners and Hospital Consultants participated in semi-structured interviews and focus groups. The most important factor for both GPs and psychiatrists was that they gave high priority to a personal relationship, which reflected trust and respect and had built up over the years. They felt this was the most important feature that would enhance patient care. They were aware that several factors could damage this relationship, like pressure of work and too little time to attend to the relationship, with an increasing trend for the expectation of having to send more formal referral letters rather than informal verbal referrals. However, this did not remove their enthusiasm and desire to work together. The sample of Hospital Consultants was not taken specifically from the field of Old Age Psychiatry but reflected a generic sample from across different specialties.

In summary, it can be seen that the role of the GP in relation to early diagnosis is complex and challenging, and requires a capacity for maintaining effective relationships with Old Age Psychiatrists. It also seems clear that there are wide differences across GPs regarding their knowledge and awareness of diagnostic issues around this condition.

### 2.3.3 *Attitudes of GPs and Old Age Psychiatrists to dementia*

A vital factor influencing the care of people with dementia is the attitude of staff towards this disease. Understanding the attitudes of doctors towards dementia is crucial to the development of any kind of model of how the meaning of dementia is socially constructed.

In a quantitative study on doctors' attitudes to patients with dementia, Wolff, Woods and Reid (1995) administered a postal questionnaire to thirty-five Old Age Psychiatrists throughout Scotland and interviewed thirty-five General Practitioners in Glasgow, asking them the same questions verbally that were contained in the questionnaire. The attitudes towards dementia of General Practitioners and Old Age Psychiatrists were compared and found to be significantly different, with the majority of GPs feeling that they had little to offer people with dementia and that the problem was mainly social in nature. In addition, they felt that there was little to be gained by early referral and that access to long term care was what was needed. Old Age Psychiatrists, on the other hand, felt that early diagnosis and referral was beneficial to the patient and saw the 'problem' as having both medical and social dimensions. They did not agree about the importance of access to long term beds (Wolff, Woods and Reid 1995).

In a further Scottish study investigating the attitudes of General Practitioners to dementia, McIntosh et al (1999) asked GPs attending a continual professional development programme to complete a questionnaire. This study found that the management of people with dementia and their family carers was viewed by GPs as both difficult and stressful. In addition, over 40% of these GPs reported that they had very little or nothing to offer people with dementia. More recent research by Milne et al (2005) suggested that there may be some signs of change in the attitudes of GPs towards early diagnosis of dementia. In contrast to an earlier questionnaire-based study carried out by the same author (Milne 2000), a later survey of GPs showed a significantly greater commitment towards early diagnosis, with a significantly higher proportion of GPs considering that early diagnosis had positive benefits and fewer regarding early diagnosis to have negative consequences.

The shift in attitudes over time appeared to be associated with greater accessibility to psychiatric services, greater investment in support services, with an enhanced policy and clinical emphasis on early diagnosis and its value. These studies were based in the same area of the south of England and it would be interesting to note if these results are generalisable throughout the United Kingdom, or whether Scotland would show any significant change since the studies reported above. One of the explanations for the shift in attitude was given as greater accessibility to the specialist Old Age Psychiatry services. Most GPs reported wanting a lot of help in all aspects of care of people with dementia, with surprisingly least help being requested around the area of diagnosis (Williams 2000). This is in contrast to literature which cites the diagnostic process as one of the most complex and difficult and not really the sphere of General Practitioners (see section 2.3.5).

The research into doctors' attitudes to dementia suggests that many GPs regard this as a difficult area of work, and that they view themselves as not having much to offer patients. However, there is some evidence of more positive attitudes in a more recent study. No studies have explored the existence in GPs or psychiatrists in stigmatising attitudes toward dementia, and clearly it would be valuable to determine the extent to which doctors' attitudes to dementia are determined by professional constraints regarding their role in relation to dementia sufferers, or reflect more widely held social attitudes toward the condition.

### *2.3.4 Stress and support in doctors working in the field of dementia*

It has been established that health professionals find it stressful working with people with dementia (McIntosh, et al. 1999). In a study that aimed to test the hypothesis that the management of dementia evoked stress in professionals, McIntosh et al (1999) utilised a self-report structured questionnaire administered opportunistically to GPs attending dementia education seminars. Two hundred and ninety-eight doctors participated and there was a return rate of 98%. Findings showed that 60% of the GPs who took part in the survey reported that they found dealing with people with dementia to be either moderately or very stressful, while dealing with their families provoked even higher stress levels with 66% of GPs reporting moderate or severe levels of stress. However, it is not only GPs who find that dealing with dementia is stressful. Consultants' stress was highlighted as focused on volume of work rather than the types of patients that they were constantly dealing with, whereas GPs' stress was directly related to the disease of the presenting patient and their families.

In Old Age Consultants it was thought that being part of a multi-disciplinary team would protect them from being exposed to the stressful experiences of their chosen profession, but this was proved not to be the case.

In a series of studies examining stress and burnout in Old Age Psychiatry, Benbow (1998), along with Jolley (1997, 1999), found in response to three questionnaires that consultants identified their most significant categories of stress during a working week to be an overloaded work schedule, organisational structure and political climate. Unavoidable stress, which was classified as working with people with dementia, being part of a 'Cinderella' service and being frequently in contact with people with a progressively degenerative physical and mental condition, were not cited as causing them stress. They hypothesise that it is only people who can cope with these inherent stressors who elect to enter this specialty. The repeated and frequent changes coupled with high expectation of increased performance within the provision of service and delivery of care is also highlighted as an increased burden on clinicians. Benbow and Jolley (1999) have suggested that debriefing sessions or counselling might be introduced to ease the strain on consultants and other staff and should be offered within a sensitive change management structure. Benbow and Jolley (1999) found that there were no real unique stressors within the field of Old Age Psychiatry relating to the care of older people with mental health problems. However, there was a need for increased supervision and support for consultants, with suggested use of mentoring to clarify boundaries, work responsibilities and areas of personal and professional development that require further development (Benbow 1998). Peer support was also encouraged, with consultants working more than fifty hours per week advised to review their pattern of work. For GPs, part of the stress was related to their anxieties about early diagnosis and in some way this stress compounded the barriers to early diagnosis that GPs experience. There was no mention of support for GPs in this field of work.

Although there has been only a limited amount of research into the stress experienced by doctors working with patients with dementia, the studies that have been carried out suggest that GPs in particular find this area of their work to be highly stressful. For consultants, organisational aspects of their jobs are reported as being most stressful, while specific contact with people diagnosed with dementia was not rated as unusually stressful. It would be valuable, in further research, to examine the extent to which the stress experienced by GPs is due to lack of training in working with dementia, lack of resources to offer these patients, or the actual contact with patients in distress (or other factors).

### *2.3.5 Barriers to early diagnosis by GPs*

Many barriers to early GP diagnosis of dementia have been cited including lack of training in the diagnosis and management of people with dementia (Audit Commission 2002, Audit Commission 2002, Cody, et al. 2002, Downs 1996, Illiffe, Manthorpe and Eden 2003, Illiffe 2003), practitioners' attitudes and values (Boise, et al. 1999, Milne, Hamilton-West and Hatzidimitriadou 2005, Milne, et al. 2000), the inaccuracy of informant (relatives) reports (Kemp, et al. 2002), while De Lepeleire and Heyrman (1999) question the perception of the GP role as holding the central position within the field of dementia.

In an American study which recruited 78 primary care physicians into 18 focus groups to elicit how patients are assessed for dementia and highlight barriers to early diagnosis, Boise et al (1999) discovered that barriers fell into four areas: failure to recognise and respond to symptoms of dementia; lack of need to determine a specific diagnosis; limited time; and negative attitudes towards the importance of assessment and diagnosis. As a result of these barriers, people with dementia and their families were being denied the help that they needed. Fortinsky, Leighton and Wasson (1995) suggest that barriers must be overcome in order to improve the diagnostic and management behaviours of primary care physicians if they are to play an optimal role in the care of a person with dementia and their families (Fortinsky, Leighton and Wasson 1995). One of these behaviours, the discussion of the diagnosis with the person with dementia, is extremely common and the next section of this thesis will concentrate more fully on that specific issue.

### *2.3.6 Issues in disclosure of a diagnosis of dementia by GPs and Consultants*

This section of the literature review examines research into the decision about whether or not to share a diagnosis of dementia with a parent and his/her family. The background to the debate over whether or not the diagnosis of dementia should be disclosed to the person is presented first, and is followed by a section outlining moral dimensions of the decision-making process. There is then a detailed review of empirical research into doctors' diagnostic practices.

#### *2.3.6.1 The background to the dilemma*

For more than a decade there has been ongoing debate relating to issues around whether people with dementia should be given their diagnosis, and to date there seems to be no great consensus. Despite the legal requirement of informed consent prior to treatment, and the introduction of the anti-cholinesterase inhibitors, a decade of research has failed to reach a clear conclusion in relation to the advantages and disadvantages of disclosure. This uncertainty is reflected in the titles of recently published studies such as '*Secrets and lies: the dilemma of disclosing the diagnosis to an adult with dementia*' (Fahy, et al. 2003), and '*Should dementia patients be informed about their diagnosis?*' (Biernacki 2003), which confirm that these issues continue to preoccupy clinicians and researchers alike. Justification for this is often cloaked in ethical arguments that espouse the principles and duties of beneficence (promotion of the patient's welfare) and non-malfeasance (the avoidance of doing harm), rather than being guided by the need of the patient for autonomy. As co-author of the report, '*The Right to Know*', (Fearnley, McLennan and Weaks 1997), which sets out the argument from the person with dementia's perspective, I find it somewhat disappointing that this discussion appears to have made very little progress over the past nine years. The literature pertaining to this debate can be classified around ***'the telling'***, with argument and counter-argument based on whether to tell, who to tell, who will tell, what to tell, when to tell, how to tell and what happens when you do tell.

### *2.3.6.2 Moral issues associated with the decision to disclose a diagnosis of dementia*

The decision of whether to tell people their diagnosis of dementia or not remains a contentious moral issue within the field of Old Age Psychiatry. Early on in the debate, Erde, Nadal and Scholl (1988) highlighted the ethical dilemma of the medical practitioner when delivering a 'grim diagnosis' to a patient. They described two contrasting moral positions

- '*deontologists*', who uphold the moral right of the patient to know their diagnosis

- '*consequentialists*', who disclose the diagnosis only if it is expected to be beneficial to the patient to know.

These schools of thought are akin to what Pinner (2000) describes as the principles of respect of autonomy *(deontologists)* and the principles of beneficence *(consequentialists).* The principal of non-malfeasance (the duty to avoid harm intentionally) may also be in operation when justification for withholding information is being rationalised, for example when the diagnosis would confuse or upset the patient. These appear to be the main ethical principles which underpin the decision making process and can be identified in the majority of the cases, both for and against the disclosure of a diagnosis of dementia, put forward by various professionals.

Drickamer and Lachs (1992) stress the high value that our present culture accords individual autonomy and its belief that this value is reflected in medical decision making. They liken the discussion around dementia disclosure to that of the previous generation around the disclosure of a diagnosis of cancer. The two studies frequently cited in order to compare disclosing the diagnosis of dementia with the diagnosis of cancer are Ocken (1961) and Novack et al (1979). In North America, in 1961, a study of doctors showed that 90% of practitioners usually withheld a diagnosis of cancer (Oken 1961). When this study was repeated by Novack et al (1979), nearly twenty years later, 98% of physicians were found to 'tell the truth' about the diagnosis of cancer to their patients. This shift is widely believed to have been made possible by new and more effective treatments, increased public awareness, and an expectation of society for an increased openness and honesty reflecting the right for patient autonomy. Drickamer and Lachs (1992) believed that this was a situation which had evolved with our increasing understanding and posit that this evolution will also occur in the realm of dementia. However, Vassilas and Donaldson (1998) found little evidence of a change in attitude when they asked General Practitioners whether (and what frequency) they disclosed the diagnosis of dementia and cancer: 5% always, and 34% often (total 39%) told the diagnosis of dementia, while 27% always, and 67% often (total 94%), told the diagnosis of cancer. They, along with Drickamer and Lachs (1992) advocate telling the diagnoses with the caveat that each individual case should be evaluated.

Replying to this call for disclosure Markle (1993), a doctor whose wife died of the 'scourge' of Alzheimer's disease, took the decision that she should not be informed of a formal diagnosis and monitored what she watched on television and read regarding dementia. He viewed that the only reason for her to know her diagnosis would have been if appropriate treatment had been available. As this was not the case in 1993, he did not want his wife to have to deal with what he anticipated would be a fearful reaction, and on these grounds her diagnosis was withheld. He had taken the moral stance of the *consequentialists,* invoking the principles of beneficence and non-malfeasance. Questions may be raised as to the right of a husband to invoke that power, and it is not clear if he had diagnosed her himself, or if her own physician had diagnosed her. Had it been a case of the latter, then that practitioner/patient confidentiality may have been called to question, if the patient's husband had been informed but not the patient. Markle's stance is compounded by another health professional. Hesketh (2001), a senior nurse and relative of someone who has dementia but has not been told their diagnosis, operates on the belief that it would be totally wrong for many patients to be told, and has no regrets about withholding the diagnosis from her relative. She advocates that those in the caring profession discuss and make decisions with the relatives rather than the person, and feels justified in withholding a diagnosis on the basis that it may undermine the will to live.

These comments by health professionals leave us to ponder on how strong an influence the subjective experience of having a close relative with the diagnosis has to bear on their practice and indeed conversely, how strong is the influence of personal experience for practitioners in relation to their decisions to withhold the diagnosis from their relatives. The continuing existence of this ethical debate means that the decision about whether or not to disclose a dementia diagnosis cannot be made on moral grounds alone since there are powerful moral arguments on both sides.

#### *2.3.6.3 Disclosing the diagnosis – the medical stance*

The medical stance plays a powerful role in shaping the experiences of patients and their families during the period around the diagnosis of dementia. The aim of this section is to present an overview of studies into issues associated with medical disclosure of a diagnosis by GPs and Consultants in Old Age Psychiatry. The research that has been carried out has focused on a set of interlocking questions:

- Whether the diagnosis is disclosed
- To whom (the patient and/or carers) a diagnosis is disclosed
- The process of disclosure (e.g. whether written material is employed)
- The factors influencing whether or not disclosure takes place
- Doctors' perceptions of the impact of a diagnosis on patients and carers

- The challenges and difficulties reported by doctors in relation to this aspect of their work

The following paragraphs describe the main studies that have been carried out into these questions. This review concentrates only on studies carried out on doctors since the mid-1990s on the grounds that both the patients' rights movement and advances in treatment options that began to emerge at this time provided a context for diagnosis that was quite different from the previous era. The studies that are discussed are presented, as far as possible, in chronological order to provide a sense of the development of medical attitudes and practice around this topic thinking over the last fifteen years. The key findings within this body of research are summarised in Table 1.

The analysis that follows also seeks to highlight methodological issues in this area of research, for example differences between studies based on questionnaires administered to doctors, qualitative studies that have allowed doctors to describe their practice in a more open-ended manner, and doctors' studies that incorporate the views and experiences of patients and carers. These studies are presented mainly in chronological order.

In an effort to define the difficulties experienced by GPs in Australia in the area of diagnosis and management of dementia, Brodaty et al (1994) used a postal questionnaire to elicit their views. Responding to the questionnaire, 20% of the 1473 GPs of the sample thought that disclosure was more harmful than helpful, while 13% felt that patients and families may deny the diagnosis at first. In a further two studies utilising postal questionnaires (Rice and Warner 1994, Rice, et al 1997), findings showed that the likelihood of disclosure varied with the degree of severity of dementia, with a disclosure to carers much more common and with a number of respondents seeking to avoid the use of the term dementia.

A postal questionnaire was also the method of choice when Fortinsky, Leighton and Wasson (1995) were assessing the response of Primary Care Physicians in three different regions of the USA to a vignette with follow up questions. They found that 55% would definitely, or very likely, tell a patient that they had dementia, while 90% would inform the family. Around one third of the doctors said that they would separate the patient and their caregiver/family to disclose the diagnosis. The most common factor influencing disclosure was severity of symptoms of dementia with the greatest likelihood of disclosure being to those deigned to be in the 'moderate' group.

In a study by Wolff, Woods and Reid (1995) to compare whether attitudes to dementia differ between the two groups of doctors mentioned above a survey postal questionnaire was administered to survey Consultants across Scotland. This yielded 35 returns, which were then compared with the answers to the same questionnaire that was administered in interview format to a representative sample of 35 GPs in Glasgow. The results showed that GPs were more likely to avoid the use of the term dementia than the Consultants, while 33% of GPs and 20% of Consultants were unsure whether patients with early dementia should be given their diagnosis.

To ascertain the practice of staff working in memory clinics, Gilleard and Gwilliam (1996) sent a postal questionnaire to staff in 20 memory clinics in the UK, and received an 80% return. They found that 56% told patients the precise diagnosis, with 81% sharing something of the diagnosis, while 100% informed the carers/families. 25% would not discuss the information routinely but would answer honestly if patients asked. In one of the few studies to ask whether the patient was given the diagnosis prior to disclosure to the carer, 12.5% claimed to practice in this way, whilst 19% shared the diagnosis with the carer only. In their disclosure they avoided words like Alzheimer's disease and gave careful consideration to the wording used.

In a Scottish study of psychiatrists, Clafferty, Brown and McCabe (1998) also utilised a postal questionnaire to ascertain how many consultants give a diagnosis that yielded a 75% return (246) and reported that 44% incorporate 'the telling' of an exact diagnosis into their normal practice. This study included every psychiatrist rather than just those with special responsibility for people with dementia as there are not always specialists in each area, and some psychiatrists operate on a generic basis. Comparison was drawn to disclosure of other psychiatric diagnoses and was found to be much less than most other conditions: depression (98%), schizophrenia (89%), although only 42% gave the diagnosis of personality disorder to the patient.

Qualitative methods were adopted to explore how a diagnosis of dementia was given and received and this study included five Consultants, five people with dementia and five carers. This study, (McWilliams 1998), employed a grounded theory methodology in the hope of providing a theory of the process of diagnostic disclosure. It was reported that the majority of Consultants did not disclose the diagnosis but use euphemisms rather than specific terminology. The majority of carers would prefer that the person with dementia was not informed, but both carers and Consultants believe that the person with dementia should only have access to limited information although she says nothing on this topic about the thoughts of the person with dementia. There was a lack of sharing of information because each group wanted to protect someone, with the result that no-one ever discussed the implications of the diagnosis with the other. The way in which the diagnosis was being given and received resulted in dissatisfaction and stress for everyone concerned. There was also evidence that the diagnosis evoked powerful emotions in the Consultants who were touched by the impact of the diagnosis on the person with dementia and the family. "Consultants were inconsistent both within and between themselves, demonstrating a high degree of confusion" (McWilliams 1998 p. 24) .

Implications for service developments included the provision of professional support for the Consultants, who may need help to understand their own fears. This study (McWilliams 1998) recommended that in future dementia care, based on these results, would acknowledge that sharing information between all parties is difficult, with the working hypothesis that would proclaim the desirability of sharing the diagnosis with the person with dementia in order to allow them to make sense of what is happening to them, to plan for the future and come to terms with their loss. This would offer the chance of better support for the person with the diagnosis and remove the feeling of isolation. This would allow for better psychological adjustment.

In a comparison study between diagnosing dementia and cancer (Vassilas and Donaldson 1998) to discover the extent of truth telling in diagnosis in a cohort of 281 GPs, it was found that they were much more likely to disclose a diagnosis of terminal cancer (95%) than dementia (39%), with influencing factors in giving the diagnosis of dementia cited as diagnostic certainty, the emotional stability of the patient, and the patients' desire to be given their diagnosis.

Boise et al (1999) favoured qualitative methods to explore how Primary Care Physicians (PCPs) approach the diagnosis of dementia, and to define the barriers to diagnosis 78 PCPs were engaged in 18 focus groups. They came from three different regions in America and the majority thought that neither the patient nor their family would want to them to diagnose dementia and even when they did, they chose the words very carefully when it came to disclosure, using words such as forgetfulness rather than giving a definitive diagnosis. Among the reasons they gave for this was because of the stigma that was associated with the words Alzheimer's disease. They suggested that dementia was under-diagnosed by as much as 50%.

A research team based in Stirling and London devised a questionnaire based on the work of Brodaty et al (1994) and Fortinsky, Leighton and Wasson (1995) that was mentioned earlier in this section. Its research was based on the self-report questionnaire completed by a group of GPs and other health professionals prior to attendance at a series of educational seminars (Downs, et al. 2002, Downs, et al. 2000, Iliffe, et al. 1999, Illiffe, Manthorpe and Eden 2003). This work, originally piloted in Stirling and later rolled out across the UK to incorporate a much wider response, was incorporated as part of a package that included free training on different aspects of dementia and was expected to be completed as part of the contract for offering the training. This enabled an opportunistic sample of GPs and 278 completed the questionnaire. GPs who were motivated to attend training seminars in dementia would frequently be those already interested in the subject. And the questionnaire also revealed many other facets of GPs' practice.

Disclosure of a diagnosis was viewed as always difficult by 48% of GPs, and of those who did disclose the diagnosis 39% used euphemistic language. Younger GPs were more inclined to disclose a diagnosis and feel that early diagnosis was worthwhile. Disclosure was viewed as the task of the specialist rather than the GP. Professionals found it difficult to accept the diagnosis as they knew what the implications of the disease process would be. Resistance to disclosure occurred due to a desire to protect the patients and their families from the negative and stigmatising effects of such a diagnosis, with fears of patients becoming anxious and depressed.

In Nottingham there was a similar picture. Johnson, Bouman and Pinner (2000) conducted a pilot study using a postal questionnaire (self-report) sent out to 55 doctors working in Old Age Psychiatry and Geriatric Medicine, of which 40 were returned. They found that 40% of respondents regularly told patients their diagnosis, while 35% sometimes disclosed, 20% rarely disclosed, and 2% never disclosed the diagnosis. They cited factors influencing their decision to share the diagnosis as: certainty of diagnosis; degree of patient insight; and severity of dementia. Reasons given for reluctance to tell were: fear of causing distress; fear of destroying or reducing hope or motivation; but less concern was shown for fear of precipitating a depressive episode, suicide or catastrophic reaction. Terminology used was examined and only 25% used dementia or Alzheimer's disease with the remaining 75% using euphemistic language including words like brain failure, memory impairment and forgetfulness.

In the Netherlands, Van Hout et al (2000) conducted a study of 28 GPs using focus groups and found that the GPs saw disclosing the diagnosis as a very painful process, with 19% regarding disclosure more harmful than helpful. GPs felt embarrassed at using the term dementia and communicating the diagnosis. Following this study Van Hout, et al. (2001) utilised mixed methods of research in order to elicit information about what is told at a memory clinic and they targeted patients attending the clinic along with relatives and GPs making the referrals. Patients and their families were interviewed with structured questions from a standard questionnaire and a postal questionnaire was sent to GPs. 48% of patients were told all they wanted to know and this was the case for 61% of carers. 19% of patients thought they knew what to expect and for the carers this was 34%. There was a discrepancy in the views of the patients and carers compared to the GPs when it came to clarity of diagnosis with 95% of GPs feeling that the diagnosis was communicated clearly, while 26% of patients and 40% of carers felt that they received a very vague diagnosis. Carers felt less positive about the clinicians than patients who were generally positive about them.

A modified version of the Scottish questionnaire was used by Cody et al (2002) and sent out to 878 primary care physicians (PCPs). There was a return of 142 and analysis showed that PCPs found difficulty in giving the diagnosis and the prognosis, with uncertainty of diagnosis being seen as a barrier. However, if they were certain of the diagnosis, they were more likely to tell the patient. 46% said that they would tell because the patient had a ‘right to know’, with 12% citing it as the right thing to do, and 11% telling so that the patients would know what to expect. Only a small number, 4%, would not tell, because of potential emotional harm, with the same number not telling because they did not think the patient would understand. The language they used in the disclosure was a mixture of clinical terminology and euphemism.

In a survey of 58 memory clinics in the British Isles Lindesay et al (2002) found that 96% of clinics give feedback to patients about the outcome of their investigations, while 100% of families receive feedback. However, it was noted that only 55% have an explicit protocol or procedure for disclosing the diagnosis of dementia to a patient.

In a more recent study, Connel et al (2004) utilised a qualitative method. There were 39 physicians who participated in 8 focus group interviews that focused on the disclosure process including questions about what specific words were used or avoided, to whom was the diagnosis usually given, how do patients and family members usually react, and how do you respond. This study also included focus groups with 52 carers and results of both groups were compared. They found that physicians rarely disclose the diagnosis to the patient without a family member present, unless they are in the very early stages. At other times the physician chooses to tell the family before the patient is informed. Language avoided during disclosure included terms such as dementia, senility, Alzheimer's disease, while language used included memory problems and physicians said that they tended to hedge round it by suggesting that the patients would not be safe to be on their own. Others do use the terms dementia or Alzheimer's when they feel confident in their diagnosis. Physicians noted that families responded well to the diagnosis while caregivers reported their first reactions as shock, denial and frustration, although physicians felt that family members were never shocked by the diagnosis as it was only confirming what they had known. There was convergence and contradiction between the two groups on other points too. Caregivers felt more benefits of knowing the diagnosis and regretted not knowing earlier as it helped them be more patient and understanding. Physicians tended not to mention psychosocial advantages and they tended to focus on pragmatic planning and service provision. This qualitative study compared and contrasted the views of physicians and caregivers but did not include the people with dementia.

Using the same questionnaire as designed by Johnson, Bouman and Pinner (2000), a study of Flemish GPs was undertaken by De Lepeleire, Buntinx and Aertgeerts (2004). They sent the questionnaire to a random sample of 1000 Flemish GPs and their response rate was 647, although only 521 were then eligible for analysis. They found that 37% always or usually tell patients their diagnosis, while 37% do so rarely or never (which is higher than the previous study). Influencing factors included the insight of the patient, their personality, certainty of diagnosis, or the attitudes of the relatives of the patient. Factors likely to influence GPs to withhold the diagnosis included destroying patient hope, causing psychological distress, precipitating a depressive illness, or catastrophic reaction. The most important arguments in favour of telling is increased motivation to take medication, getting personal affairs in order and the promotion of a good doctor-patient relationship. The authors felt that the results showed that GPs "pay a great deal of attention to the patient's feelings, experiences and ability to cope and to the proper timing of their information" (De Lepeleire, Buntinx and Aertgeerts 2004, p. 426).

The most common method of data collection for this group was the survey questionnaire which was usually postal, although more recent studies did include qualitative methods with the introduction of focus groups. Only one study utilised interview methods with semi-structured questionnaires based on grounded theory methodology. Other interviews conducted were from structured questionnaires. Most studies concentrated on the medical profession with the Stirling based study incorporating a wider group of health care professionals, and some studies incorporating carers and only two studies included patients.

**Table 1 A summary of literature of doctors' disclosure of diagnosis**

| Researchers | Year | Country | Sample | Aims | Methods | Key findings – with regard to the 6 key questions noted |
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| | | | | | | |
| Brodaty et al. | 1994 | Australia | 1473 GPs | To find out difficulties GPs experience in the diagnosing and managing dementia | Postal questionnaire | 20% regarded disclosure as more harmful than helpful.<br>13% thought that there would be an initial denial of the diagnosis by patient and family alike. Despite being aware of diagnostic features GPs still reported difficulty in diagnosis |
| Rice and Warner | 1994 | UK | 245 UK doctors on Old Age section of Consultant membership | To discover what Psychiatrists tell patients with dementia about their illness | Postal questionnaire | Wide variation in practice. Disclosure was linked to severity of dementia with people with moderated degree of illness being most consistently told. People with mild dementia rarely told due to uncertainly of diagnosis while people with severe dementia were almost never told because of ability to process information. Many doctors thought that information giving should be patient led. Relatives were almost always told. Written information should also be patient led<br>The term dementia was frequently avoided when talking to patients. |
| Fortinsky et al. | 1995 | USA | 498 Primary Care Physicians (PCPs) | To find out the diagnostic, management and referral practices of Primary Care Physicians for people with dementia | Postal questionnaire based on vignette | 55% of PCPs would disclose diagnosis to people with early dementia while less experienced doctors were mort likely to give a diagnosis. 90% would disclose it to families<br>33% would separate patient and carer when diagnosis was being given.<br>Severity of dementia was an influencing factor of whether to tell or not with more likelihood of disclosing to people with a moderated degree of dementia than either the severe or mild group |
| Wolff et al. | 1995 | Scotland | 35 Old Age Psychiatrists<br>35 GPs | Seeks to elicit the differences in attitudes to dementia between Old Age Psychiatrists and GPs | Postal questionnaire<br>Standardised interview using same questionnaire | 33% of GPs and 20% of Consultants were unsure whether patients with early dementia ought to know their diagnosis. There was no real difference to attitude to disclosure although Old Age Psychiatrists were more likely to use the term dementia. |

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| Gilleard and Gwilliam | 1996 | UK | Consultant in charge of 16 memory clinics throughout Britain | To find out the practice of diagnosis sharing in memory clinics | Postal questionnaire | 56% told patient precise diagnosis and 81% shared information with patient while 100% informed carers. 25% would not discuss the information routinely but would respond honestly if patients asked. Only 12·5% shared the diagnosis with the patient before the carer while 19% shared the diagnosis with the carer only. Language avoided was precise terms like Alzheimer's disease. None of the clinics saw patients on their own |
| Rice et al. | 1997 | UK | 138 Geriatricians | To establish the difference in practice of psychiatrists and geriatricians to disclosing a diagnosis of dementia | Postal questionnaire | Disclosure linked with severity of dementia. 77% told ≤ 20% of patients with severe dementia, 29% told less than 20% with mild dementia while 41% told more than 80% of these patients Carers were more likely to be informed although Geriatricians seemed to tell people more commonly and carers less commonly than did psychiatrists. |
| Clafferty et al. | 1998 | Scotland | 246 Consultant Psychiatrists | To ascertain how many psychiatrists gave a diagnosis of dementia | Survey-postal questionnaire | 44% disclosed the diagnosis as their normal clinical practice which was lower than for most other psychiatric diagnoses apart from personality disorder when disclosure was only 42% |
| McWilliams | 1998 | England | 5 people with dementia<br>5 carers<br>5 old age psychiatrists | To examine how a diagnosis of dementia was given and received | Qualitative interview | Consultants avoided frank disclosure and only 20% used clinical terminology when disclosing to patients with carers agreeing that patients should not be told much. Carers were given more information than patients. Patients were distressed through lack of information and the manner of presentation was not always helpful. Little information was shared with each other. Factors influencing the diagnosis giving were fear of causing distress, uncertainty of diagnosis, lack of interventions and personal fears of dementia |
| Vassilas and Donaldson | 1998 | England | 281 GPs | To find out the extend of truth telling of GPs towards patients with the diagnosis of dementia compared to terminal cancer | Postal questionnaire | GPs more likely to disclose the diagnosis of cancer (95%) than dementia (39%) with 3 most important factors influencing diagnosis as diagnostic certainty; patients wish to know; patients' emotional stability. |

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| Boise et al. | 1999 | USA | 78 Primary Care Physicians (PCPs) | To explore how PCPs approach the diagnosis of dementia and identify barriers to diagnosis | Focus Groups | Difficulties were highlighted in making a diagnosis but once that was made doctors they were consistent in their responsibility to tell patients and families their findings. Difficulties in discussing the word dementia attributed to stigma. Doctors did not think patients or families would like them to diagnose dementia. Dementia was under diagnosed by as much as 50%. |
| Iliffe et al. | 1999 | UK | 558 GPs and nurses | To stimulate active debate on issues around the subject of early diagnosis of dementia | Postal questionnaire and workshops | 48% of GPs always found it difficult to give a diagnosis while only 28% found it difficult to tell families. Nurses found it more difficult than doctors to give a diagnosis |
| Downs et al. | 2000 | Scotland | 278 GPs | To assess GPs views and practices on dementia diagnosis | Survey-postal questionnaire | 41% had difficulty disclosing the diagnosis to the patient and 21% had difficulty disclosing to the patients family |
| Johnson et al. | 2000 | England | All doctors working in Old Age Psychiatry and Geriatric Medicine (40) | To examine the key areas in the process of truth telling in disclosure of diagnosis of dementia | Survey-postal questionnaire | 40% of doctors usually disclose the diagnosis. Factors influencing disclosure include certainty of diagnosis, insight, desire of patient to know, insight of patient. Influencing against disclosure include fear of destroying hope and fear of causing psychological distress. |
| Van Hout et al. | 2000 | Netherlands | 28 GPs | To identify the GPs perception of their tasks, practice and obstacles to diagnosing dementia | Focus groups and questionnaires | Disclosure regarded as painful, delicate task with 19% seeing disclosure as doing more harm than good. Doctors felt embarrassed by the term dementia and by communicating the diagnosis and found it a delicate and painful job. Barriers to early diagnosis were uncertainty, embarrassment at conducting cognitive testing, lack of time and non-consulting patients. |
| Van Hout et al. | 2001 | Netherlands | 31patients, 84 carers<br>101 GPs | To measure quality of care experienced at an outpatient memory clinic by patients, their families and GPs | Patients and families interviewed using a standard questionnaire while GPs completed a postal questionnaire | 48% of patients and 61% of carers were given as much information about the diagnosis as they wanted and following diagnosis 46% of patients and 58% of carers knew how serious the illness was<br>26% patients and 40% of relatives felt they received a very vague diagnosis while 95% doctors felt they gave clear diagnosis ;.<br>Patients more positive about doctors than carers |
| Cody et al. | 2002 | USA | 142 PCPs | To elicit the practices of PCPs in the diagnosis and management of dementia | Survey-postal questionnaire | 30% had difficulty disclosing a diagnosis to people with dementia although this was only 20% to the families. Terminology used was mainly clinical language like vascular dementia, multi-infarct dementia, confusion, dementia, and Alzheimer's disease and only 35% reported using words like memory problems |

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| Downs et al. | 2002 | Scotland | 114 GPs | To find out what GPs tell people with dementia and their families about the condition | Survey-postal questionnaire | 99% told the carer the diagnosis but only 55% told the patient. Among those GPs who disclosed 39% used euphemistic terms only when disclosing a diagnosis to patients but only 4% when disclosing to carers who receive much more medically oriented explanations. GPs who did disclose tended to be younger and more likely to consider early diagnosis important |
| Lindesay et al. | 2002 | UK | 58 Memory clinics | To determine the characteristics and functions of the memory clinics | Survey-postal questionnaire | 96% give feedback to patients following the results of tests and 100% give feedback to families and GPs.. Policy regarding disclosure is only held by 55% of the clinics/ |
| Iliffe et al | 2003 | UK | 990 GPs, community nurses, practice nurses, community mental health nurses and other workers in health care | To explore the perspectives of doctors and nurses on early diagnosis of dementia | Postal questionnaire | Disclosure seen as a specialist task. Professionals found dementia a difficult diagnosis to accept. Resistance to disclosure attributed to a wish to protect patients and families from the negative aspects of dementia |
| Connel et.al. | 2004 | USA | 39 PCPs<br>52 Caregivers | To examine attitudes of physicians and caregivers towards assessing and diagnosing dementia with special emphasis on how a diagnosis is disclosed | Focus groups | Doctors reported caregivers handled the disclosure well while caregivers reported a highly negative emotional response.<br>PCPs rarely disclose diagnosis without family member being present, sometimes telling family prior to patient. Many PCPs avoid clinical terminology such as dementia or Alzheimer's disease unless they are really certain of the diagnosis |
| De Lepeleire et al. | 2004 | Belgium | 521 GPs | To ascertain the practice of Flemish GPs of disclosing a diagnosis of dementia | Postal questionnaire | 37% usually tell patients the diagnosis while 37% do so rarely or never. Influencing factors to disclose include patient insight; personality; certainty of diagnosis; relatives of patient;<br>Influence to withhold diagnosis includes diminishing hope, causing psychological distress; precipitating depressive episode or catastrophic reaction. Reasons to tell include encouragement to taking medication; promotion of good doctor patient relationship; getting personal affairs in order. GPs pay a great deal of attention to patients' feelings, experience and ability to cope and time their disclosure accordingly. |

This review of research into medical attitudes and practices around the area of disclosure of diagnosis of dementia is still far from reaching a consensus as to what best practice should be. The summary of findings presented in Table 1 shows that there is a wide variation of practice in relation to the six questions identified at the outset of this section. There appears to be a general trend for higher rates of disclosure to be reported in recent studies, and lower rates in earlier studies. Research has shown that the proportion of doctors giving a diagnosis of dementia routinely to the patient ranges from 37% (De Lepeleire, Buntinx and Aertgeerts 2004) to 96% (Lindesay, et al. 2002). The diagnosis is always given to a higher proportion of carers and families rather than to patients from 48:61% (Van Hout, et al. 2001), 96:100%. Very few patients were told first (12.5%) (Gilleard and Gwilliam 1996), with patients rarely being told without family members being present (Connel, et al. 2004). Language used throughout the process of disclosure varied with some doctors only using euphemistic terms to patients (39%) compared to only 4% to carers (Downs, et al. 2002). The most common factor influencing whether a diagnosis is disclosed or not was the severity of dementia (Fortinsky, Leighton and Wasson 1995, Rice, et al. 1997) and the least common being the consultant's personal fear of dementia (McWilliams 1998), with others noted as uncertainty of early diagnosis, fear of causing distress and lack of interventions.

The perceptions of the impact were only mentioned in two studies and both noted that patient and carer experience differed greatly to the perception of the doctors, with Van Hout, et al. (2001) noting that 95% of doctors felt they gave a clear diagnosis with 26% of patients and 40% of carers feeling they received a vague diagnosis while Connel et al (2004) noted that doctors reported caregivers handled the disclosure well. Caregivers reported a highly negative emotional response. The challenges and difficulties reported in relation to the disclosure of the diagnosis ranged from doctors finding it a difficult diagnosis to accept (Illiffe, Manthorpe and Eden 2003) and to disclose (Downs, et al. 2002) to some doctors feeling embarrassed by the terminology (Van Hout, et al. (2000).

The diversity of medical practice in relation to the process of engaging with patients and their carers around the diagnosis of dementia and its disclosure reflects both the changing face of scientific knowledge and treatment in relation to this condition, and also to debates within the medical profession around the nature of 'person-centred' care. The review presented in this section was largely completed before the systematic review by Bamford et al (2004) was published. The thesis review includes some papers that were published since the Bamford et al (2004) review cut-off date (September 2003). However, the overall conclusions of both reviews are much the same. Bamford et al (2004) write that "existing evidence regarding diagnostic disclosure in dementia is both inconsistent and limited, with the perspectives of people with dementia being largely neglected" (p. 151). They add that "there has been an emphasis on quantifying attitudes and practice with little exploration of the meaning of diagnostic disclosure" (p. 167; emphasis added). I would wish to give my agreement and support to both of these statements.

#### *2.3.6.4 Research into the doctor's role in early diagnosis of dementia: conclusions*

A substantial amount of research has been carried out into different aspects of the role of the GP and Old Age Psychiatrist in the diagnosis and care of people with dementia. There are four main themes that emerge from this body of research. First, both GPs and consultants alike experience a number of dilemmas and areas of tension in relation to their work with this patient group. These tensions include personal stress, organisational stress (e.g. workload) and moral dilemmas. Second, at least some doctors hold negative attitudes toward this patient group, and do not believe that they have much to offer them. Third, the research into disclosure of a diagnosis of dementia suggests that there exists a wide variation in practice with some doctors believing that the patient has a right to receive the diagnosis, while others are willing to make decisions on behalf of patients. Finally, unlike other areas of medicine, the research on dementia has little to say about relationships between doctors and people with dementia, or the ways that doctor-patient interaction takes place.

#### *2.3.6.5 Research on disclosure of a diagnosis of dementia from the point of view of the patient*

> "Without a diagnosis there is no meaning to our illness...we need to see the diagnosis as the 'once-upon-a-time' of an illness; the start of a story...[it] gives this chapter of our lives a title and a meaning" (Cayton 2004, p. 10).

Literature concentrating on the patient perspective on disclosure is much less extensive (see table 2) than research on the medical stance. It is only over the past decade that there has been a move towards consulting people with dementia about whether they want to know their diagnosis. From a moral perspective, there is a strong argument that the right to know the diagnosis belongs to the person (Fearnley, McLennan and Weaks 1997). However, this position is not always respected by others as has been seen in the previous section. The imperative of an early diagnosis has already been stated in this thesis in relation to treatment and engagement in the task of adjustment.

In a recent systematic review of the literature on the disclosure of a diagnosis of dementia, Bamford et al (2004) cited eleven studies which included people with the diagnosis. Only six of those studies concentrated only on people with dementia themselves without involving others, although some of these studies seemed to be based around covert inclusion of carers, either enlisted to help interpret written material or to verify what the person was saying was correct. Five of these eleven studies have been reported elsewhere in the thesis (Husband 1999, Husband 2000, McWilliams 1998, Pearce, Clare and Pistrang 2002, Van Hout, et al. 2001), reflecting the fact that in these studies the main focus was on different aspects of the subjective experience, with the question of disclosure being supplementary. The majority of these studies utilised qualitative methods with interviews being carried out on an individual basis with carers or in focus groups, and data was collected by postal questionnaires in two studies.

The remainder of this section will concentrate on studies that were primarily oriented towards eliciting the person's view of the diagnostic process. Marzanski (2000) asked thirty consecutive patients whether they would want to know the truth about what was wrong with them, and found that only 47% knew their diagnosis, while 66% reported that their diagnosis had not been discussed with them. The majority (70%) of these patients wanted to know what was wrong with them or wanted more information than they had already, while only 30% did not want to know or did not want further information than they already had.

To find out if people with dementia would find it helpful to have a written report on their diagnosis, Jha, Tabet and Orrell (2001) used a postal questionnaire to elucidate this information. Over 75% were in favour of reading their diagnosis in a letter. This result suggests that verbal communication alone may not be enough for many patients. The report that was sent was a full copy of their assessment, which was a copy of the GP report and the medical terminology had not been modified. Some people were unable to understand what was written and it is not certain whether this was because of the language used or due to the extent of their dementia. Although this study set out to seek the opinion of the person with dementia it also encouraged the use of relatives' involvement and it was therefore unclear as to who actually responded to the questionnaire. It may be possible, therefore, that this study reflects carers' views as much as it does the views of people with dementia.

Smith and Beattie (2001) carried out an observational study in Canada on fourteen patients and their families who were attending an out-patient clinic for assessment and diagnosis. Only twelve of the fourteen patients attended the family conference where diagnosis was shared. It was the prerogative of the relative to decide whether the patient should attend this meeting. Diagnosis of probable dementia was given to three patients and while the probable diagnosis seemed to alleviate uncertainty, the diagnosis of possible dementia given to five patients was much less precise and led to both patients and families having difficulty in interpreting such an assessment result of the assessment. Six patients were informed that they did not have dementia but this was not regarded as a relief and invoked a minor crisis in two of the patients under investigation. This study provides useful information on the dynamics of diagnosis and on the patient's need for certainty.

The organisers of regular focus group meetings for people with dementia run by the Alzheimer's Association invited a researcher (Young 2002) to attend four consecutive meetings so that questions about their diagnosis could be explored. 24 people with dementia also completed a questionnaire to indicate their mood state in addition to attending the focus groups. Thematic analysis of that data revealed that people with dementia expressed shock and disbelief at the diagnosis, with 55% describing themselves as depressed and 22% as sad following disclosure, although none of them were referred to mental health services or received medication. The feeling of depression mostly abated over time, but 22%, however, were still describing themselves as depressed at a later date, although it is unclear how long this was following the diagnosis. Almost all the people with dementia felt frustrated and dissatisfied with the medical encounters they had had with their primary care physicians. They were dissatisfied with communication and interaction patterns and disappointed in the medical care they received. They described interactions with doctors as being strictly disease-oriented as opposed to person-oriented. They also felt that they did not get enough information, felt marginalised, and that doctors communicated directly to the family member, even in their presence. Families tended to react in two different ways, divisive or cohesive.

In a study focusing on the threats to self in early dementia, Clare (2003) found that some of the participants had been given very little information, with some reports of occasional false information being given if questioned by the patient. One person realised that she had Alzheimer's disease although the doctor told her that it was premature aging. It was unclear from this study exactly how many people knew their diagnosis or had been told their diagnosis as this was not the main thrust of the study but, as discussed earlier, was a supplementary finding of the study.

One study undoubtedly did set out to answer the question of what it had been like to receive a diagnosis of dementia and that was the study entitled 'Tell me the Truth' (Pratt and Wilkinson 2001). This study involved interviews with 24 people with dementia a short time after their diagnosis and it concentrated on how patients felt about the way they had been given the diagnosis and the opportunities or limitations that they had experienced since receiving their diagnosis, and elicited their views on how they would perceive best practice in the sharing of the diagnosis. Findings were reported under three main themes relating to the three main questions. The majority of participants were in favour of receiving their diagnosis as early as possible following diagnosis, but felt that this should be decided on an individual basis. Participants reported that they felt very emotional following diagnosis citing feelings of shock, anger, fear and depression. Participants also felt that the diagnostic process was lengthy with many investigations and health service personnel being involved. Having an explanation for the experienced changes was felt to be a validation and allowed the person to seek out appropriate help to deal with the diagnosis with both pragmatic planning and social support being foremost. Participants wanted to have the opportunity of accessing additional information about services and welfare benefits.

Timing was also felt to be an important component as well as the need to know about the prognosis. Support from family and a friend was strongly suggestive of better adjustment while the absence of support was likely to result in patients being less well adjusted to the diagnosis. Having positive family relationships was found to be particularly important and lack of support lead to a reduction in self confidence and a greater need for formal support. This study generated a number of suggestions around the process of best practice in disclosure – it should be patient led within a supportive environment, and done over a number of sessions. Follow up appointments were seen as crucial to allow exploration of questions, although it was acknowledged that this took time and was not necessarily the role of the doctor. It was felt that GPs needed to learn more about how best to share the diagnosis (Wilkinson and Milne 2003).

From the studies that have been reviewed in this section it would not seem unreasonable to conclude that people with dementia want to know their diagnosis. However, they have rarely been consulted directly about their preferences and needs. Much of the time it continues to be the prerogative of the family/supporter and/or the medical practitioner as to whether they are privy to this information or not.

**Table 2 A summary of literature of patients' disclosure of diagnosis**

| Researchers | Year | Country | Sample | Aims | Methods | Key findings |
|---|---|---|---|---|---|---|
| Keady | 1994 | UK | 38 carers | To understand the experience of dementia | Grounded Theory | Developed a nine stage model to describe the person's pathway through the illness; slipping; suspecting; covering up; revealing; confirming; surviving; disorganisation; decline and death. In a further study to test this theory surviving was changed to maximising as it was thought to be too negative. This gave an early framework of understanding the process of dementia from the carers' perspective. |
| Phinney | 1998 | USA | 5people with Alzheimer's disease and their spouses | To gain greater understanding of the perspective of the person with dementia and their experiences | Qualitative methods: Semi-structured interview and observation<br>Quantitative methods: two measurement scales used | Two main themes which were being unsure and trying to be normal. Being unsure reflects how people fluctuating awareness of symptoms cause the uncertainty in their world, while trying to be normal reflects people's active efforts to continue living the their lives as they have done in the past. Symptoms were not the most important issue but the broader issues in terms of it's meaning to them and their concerns |
| Snyder, L | 1999 | USA | 7 people with an early diagnosis | To increase understanding of the subjective experiences and hear the voice of the person with dementia | Qualitative semi-structured interviews | Themes emerging from the data included moment by moment encounters with memory loss; ambivalence of disclosing diagnosis to others; concern over burdening loved one; response of friends and family; struggle between dependency and autonomy; inability to continue with pleasurable activities; ability to laugh and find humour; the pervasive presence of hope. |
| Harris & Sterin | 1999 | USA | 17 people with dementia and 15 of their caregivers | To gain an understanding of how a diagnosed persons sense of self or personal identity | Qualitative interviews | The self was in a state of flux, influenced by losses of significant roles, respect, autonomy, self worth and competency. 5 different typologies of reaction to diagnosis were proposed. Three core values were identified which helped to define personal identity, meaningful productivity; autonomy and need for comfort and security. |
| Gillies | 2000 | Scotland | 20 people attending a day hospital with a diagnosis of dementia | To expand the knowledge of the perspective of people with dementia | Qualitative semi-structured interviews | Two key themes reported were how dementia is experienced and coping with a failing memory. There was no shared diagnosis participants contextualized their experiences in the normality of old age. However the effects of this were still unpleasant, humiliating and undermining leading to loss of confidence, lower self esteem, and inability to maintain interpersonal relationships. |

| | | | | | | |
|---|---|---|---|---|---|---|
| Werezak & Stewart | 2002 | Canada | 3 men and 3 women | To explore the process of learning to live with early dementia | Grounded Theory Participants interviewed x 2 within a three month period | Outline a five stage model includes antecedents and proceeds through stages of anticipation, appearance, assimilation and acceptance. A continuous process of adjustment was observed evolving in response to a self awareness together with changing views of the outer world. Supportive family and friends played a key role in enabling participants to come to terms with memory loss. Telling others was highlighted as part of the anticipation stage. Anticipation of how people would treat them was a consideration which made them anxious about revealing their diagnosis to others. |
| Menne, Kinney & Morhardt | 2002 | USA | 3 men and 3 women all members of an early diagnosis group | To explore the day to day experiences of dementia and capture the voices of people with dementia | Qualitative semi-structured interviews | 2 theoretical frameworks (Atchley's (1989) continuity and Park and Folkham's (1997) framework of meaning making) were utilised to explore the experiences of people with dementia.<br>Desire to maintain continuity with their previous way of life while coping with the changes necessitated by dementia. Each individual adapted in a way that was meaningful for them and they modified their activities in order to maintain continuity with their pre-dementia behaviour |
| Pearce, Clare & Pistrang | 2002 | UK | 20 men with Alzheimer's disease and their wives | To explore the appraisals and coping processes of men with dementia | Qualitative semi-structured interviews | Two main themes emerged--men involved in an ongoing process of attempting to manage a sense of self against the onset of Alzheimer's disease through a combination of reappraisal and reconstructing a sense of self and maintaining a sense of self. Sense of self a result of appraisal of and response to their difficulties, which had an influence on and were influenced by their relationships and social identities. Balancing act between the wish to maintain a prior sense of self and the need to reappraise and construct a new sense of self. This was a cyclical process |
| Phinney | 2002 | USA | 4 men and 5 women—members of early diagnosis group or geriatric research centre attendees | To examine what happened in the illness narrative in light of fluctuating experiences of symptoms of dementia | Interpretive phenomenological methods | Symptoms can be vague, inconspicuous or salient, they may be forgotten or absent from a person. It is difficult for the person with dementia to articulate a narrative understanding of their experience in light of these findings. The illness narrative of dementia becomes shared as others join in the telling although in the end it can become a narrative of chaos that is all but impossible to articulate |

| | | | | | | |
|---|---|---|---|---|---|---|
| Clare | 2003 | UK | 12 couples (9 women and 3 men with dementia) and their spouses | To explore the process of adjusting to a diagnosis of dementia | Qualitative interviews x 2 three months apart | People tried to adjust in two different groups on a continuum from self-protective to integrative responding with much fewer falling into the integrative category. Main themes were holding on; compensating; fighting; coming to terms with acceptance seen as likely to require continual renegotiation as circumstances changed. These responses have implications for his or her sense of identity |
| Dijkhuizen, Clare and Pearece | 2006 | UK | 9 women and their families | To capture the subjective account of women's experiences of early Alzheimer's disease and how they manage difficulties with memory | Qualitative semi-structured interviews with women being interviewed separately form their husbands | Three main themes emerged which was connectedness; protective strategies and adjustment. Connectedness relates to identity with different connections noted, connections with the past, with family relationships, friends and neighbours and social roles and family environments. Memory problems threatened connectedness. Protective strategies where they said memory was not a problem, and minimized and avoided difficulties. Adjustment portrayed by normalising difficulties and finding ways of problem solving and getting on with it. Central element was the degree of connectedness or disconnectedness affected their appraisals. |

## 2.4 A Review of Research into the Subjective Experience of People who have had a Diagnosis of Dementia

This major section of Chapter 2 focuses on what has become known as the subjective experience of dementia. The section starts by briefly outlining the history of calls for the voice of people with dementia to be heard. A critical review of empirical studies of different aspects of the experience of dementia is then presented. The section closes with a summary of the main themes emerging from this literature.

### *2.4.1 The beginnings of a change of focus*

Historically, the voice of the person with dementia has been presented on their behalf by their carer (lay or professional), with an accompanying belief that people with dementia had a lack of ability to understand their own problems and express their own point of view (Bond, et al. 2002). Whilst this approach was acceptable in the 1970s and 1980s, the 1990s heralded a new era in the representation of the person with dementia. A dramatic paradigm shift has occurred in research into dementia over the last decade. In the past, seeking the views of people with a diagnosis of dementia was unheard of, and to be addressing them directly to find out whether they wanted to be informed of their diagnosis or not, or to be consulting with them and inviting them to be working collaboratively with a researcher in the design phase of any research project would quite simply have been perceived by practitioners as fanciful notions. The most welcome development of research into the subjective experience of dementia has opened up a completely new understanding of what it is like for people to be living with dementia and to have been given a diagnosis of dementia. With this change in focus has come a new and different language. No longer is someone viewed as a 'sufferer', but they have actually become a 'person with dementia'. No longer are the spouses/significant others seen as 'victims' of dementia or carers, but as supporters. This movement and the language used to construct a new and different way of seeing the person with dementia owe much to the work of the late Tom Kitwood (1997). He was among the first to pose a strong challenge to the traditional world view, which had been informed by the dominant medical discourse or 'the standard paradigm' as Kitwood called it (1989).

That view had portrayed the person being diagnosed with dementia as being consigned to await the inevitable decline and devastating destruction of the disease process, with little to be done for them but basic care and perhaps medication to control their behaviour problems and their mood (Kitwood 1993).

Woods (1999) detailed how the experience of dementia used to be described as a 'living death' and this added to the perception of people with dementia not being fully alive and many viewed it as a state worse than death. He goes on to discuss how a focus on the disorder obscures the view of the person and espouses the belief that the person with dementia should be given a voice. It is not only interesting but encouraging therefore to note that this writing is from the same author who wrote a book entitled 'Alzheimer's Disease: *Coping with a Living Death'* [emphasis added] (Woods 1989) a decade prior to asserting the importance of the person, and this reflects very graphically the shift in thinking of some of the leading professionals in the field of dementia care.

During that same year, 1989, the first book was published by someone who had been given a diagnosis of dementia. Robert Davis (1989), an American Presbyterian minister, told his story of his struggles and fears of being diagnosed with Alzheimer's disease. Davis, in his fifties and at the pinnacle of a very positive and successful career in Christian ministry, and by drawing strength from his faith, believed that he had been given the task by God of informing people what it was like to journey into the unknown abyss that was Alzheimer's disease. This clearly articulated account gave new insight into the effect that the diagnosis had, not only on the man, but on his immediate family and wider social network.

Some years later another American, this time a young woman with dementia, shared her experience, which she described graphically in the title of her writings, *'Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's Disease'* (McGowin 1993). Like Davis, she too painted a vivid picture of the devastating effects this diagnosis had on both her and her family.

These first two books laid the foundation for many more writers to share their personal experience of a diagnosis of dementia, including Boden (1997) and Friedell (2000). Friedell, a retired professor of sociology, has been instrumental in setting up the international organisation the *Dementia Advocacy and Support Network* (DASNI 2000), which is based on the value of autonomy, knowledge as empowerment, strengths in supportive networking, and the importance of a voice for people with dementia. This important forum is one which encourages members to present their thoughts, feelings and experiences of their subjective experience to such important gatherings as major international conferences. Current research is a major feature of the website both in reporting research studies published in the media and in their members' regular contribution to research journals (Bryden 2002, Friedell 2002, Friedell 2002, Sterin 2002). Some of its members are actively involved as collaborators in research projects.

These developments reflect the desires and needs of people to be active agents in, rather than passive recipients of, the process of dementia. The voice of people with dementia is becoming more than a barely heard whisper. While much of this activity is centred on American and Australian citizens, the voice of dementia in Scotland has raised its volume too. In a publication highlighting some issues around research methods from the perspectives of people with dementia, Wilkinson (2002) encouraged two of the contributing authors to write from an insider perspective (McKillop 2002, Robinson 2002). More recently, in a collaborative venture, she formed a partnership between a person with dementia and researcher to better inform and advise the research community on the best practice of the processes of the research interview with someone with dementia (McKillop and Wilkinson 2004). It is to be hoped that this project will encourage others, both people with dementia and researchers alike, to form collaborative ventures in order to help counteract the dearth of empirical studies exploring the subjective experience of dementia in order to gain a deeper understanding of meaning it has for people who have been diagnosed.

### *2.4.2 The voice of the person experiencing early dementia*

One of the leading proponents of hearing the voice of people with dementia is author/researcher Lysa Snyder (1999), who points out that the personal meanings of having a diagnosis of Alzheimer's disease has been most elusive because they are the most private thoughts of individuals. She suggests that although it is common for us (as researchers) to ponder the questions of what it might be like to live with the diagnosis, it is much less often that we ask this direct question of the person who could inform us.

Her book gives a narrative account of the experience of seven different people who have been diagnosed with some form of dementia. It is the mapping of a conversational inquiry into the emotional, psychological and intellectual processes of people with Alzheimer's disease. These narrative accounts are part of a larger sample of people with dementia who have come into contact with the author, and have been selected for their ability to reflect a 'broad spectrum of humanity' with the common denominator of the experience of being diagnosed with Alzheimer's disease. Interviews with each participant were all recorded and transcribed. The data were then analysed into themes. She lists these as

> "the moment-by-moment encounters with memory loss; the ambivalence about disclosing the diagnosis to others; the concern about being a burden to loved ones; the responses of family, friends and strangers; the struggle between dependency and autonomy; the inability to do the things that you once enjoyed; the ability to laugh and find humour in such serious circumstances; the pervasive presence of hope." (p10).

The themes emerging from this project reflect something of the lived experience of Alzheimer's disease. Some of the participants were interviewed many times and followed up over many years. There are some methodological limitations to this study. For example, it is unclear how long after the initial diagnosis participants were first interviewed. The author also describes dual relationships, with participants being part of a support network where she and the participants met regularly, and at times it was difficult to distinguish between research and practitioner perspectives as the narrative oscillates between both positions. However, peppered throughout the narrative writings of these seven people whose experience she has chosen to share with us in this text there is also a reflexive quality to the writing that embodies the insights and impacts gained in her quest to explore their experience.

In light of the above, and despite the fact that it makes no claims to be purely a research project, I have chosen to include this book within the empirical findings of research into the subjective experience. It is a key text in enabling the voice of the person with dementia to be heard.

### *2.4.3 Stage models of the experience of dementia*

In an attempt to make sense of what was happening to people with a diagnosis of early dementia, some authors have tried to portray the process in different stages, akin to the work of Kubler-Ross (1989) in which she posited that grief was a process with discrete stages such as denial, anger, bargaining, depression and then acceptance. Keady (1994) proposed a nine stage model of understanding the experience of dementia, which he developed from a qualitative grounded theory research study carried out with a group of 38 carers. This conceptual framework describes the person's pathway through the complete process as comprising slipping, suspecting, covering up, revealing, confirming, surviving, disorganization, decline and death. There is no claim that this model is solely based on the subjective experience of people with dementia, but in subsequent papers (Keady and Nolan 1995b, Keady and Nolan 1995a, Keady, Nolan and Gilleard 1995) based on interviews with ten people who were diagnosed as having dementia, the authors tested out their conceptualisation in relation to subjective experience. They found it to be robust with the exception of one of the stages, which was perceived to be too negative, and thus 'surviving' became 'maximizing' in an effort to represent the person with dementia more fully.

Further development of a theoretical framework, based on a stage model, is offered by Werezak and Stewart (2002) following a study to explore the process of learning to live with early dementia. A grounded theory methodology was utilised in this study which was similar to that of Keady (1994). Six participants (three men and three women) were recruited to this study (five with Alzheimer's disease and one with vascular dementia) ranging from 61-79 years of age. Although these 6 participants had early stage dementia it was not stated how long they had had their diagnosis, nor how long it was after diagnosis that they were recruited into the study. Data were collected over a three month period and people were interviewed twice, once at initial meeting and once at three months. The grounded theory developed by Werezak and Stewart (2002) described a continuous process of adjusting to early stage dementia. They put forward a five stage process beginning with various antecedents and progressing through stages of anticipation, appearance, assimilation and acceptance. This process is viewed as evolving in response to the person's self awareness, together with changes in their view of their outer world. Their findings specifically highlight the anxiety of the anticipation of telling others as part of the process. Two factors were considered in the decision of whether to tell or not – how people might react if they knew, and how people had reacted when they had known of the participant's initial memory loss. The participants in this study also saw themselves as the same person since diagnosis and sought both to assimilate the disease into both their inner and outer worlds, and finally to accept that the disease had become an integral part of them (a similar finding is reported by Clare 2002).

Bender and Cheston (1997) have formulated a three stage model of the subjective response to dementia, drawing together ideas from clinical and social psychology. Their three stages are: the emotional component; the behavioural component; and the social nature of emotional behaviours. The emotional response to a diagnosis of dementia is portrayed as having four types of feeling: anxiety; depression; grief; and despair or terror. Anxiety was portrayed as a fear of the future and an unpredictability of what might happen, while it was pointed out that depression was a complex factor in dementia and the most frequently reported affective response.

Depression may mimic dementia while also being a risk factor in developing dementia, with there being higher levels of clinical depression in people with an early diagnosis. Bender and Cheston (1997) argue that grief can be seen as akin to depression with multiple losses often being experienced in dementia. They vividly describe the ways in which a feeling of emptiness and absence can be compounded by the neglect of others, such as professionals who administer lengthy assessment which highlights deficits in a situation where there is no provision of emotional support. The second phase or stage of the model involves adapting to the process of decline. A range of coping strategies may be created to deal with the emotional turmoil such as the defence mechanism of denial. Living in the past allows people to establish their identity; stories told within a group may add to the ability to establish a positive social identity and also allow people to explore the subjective experience of dementia and their experiences at an emotional level. Stage three of the model concentrates on the importance of the social context and suggests that the expression of emotions largely depends on the social system to which the person belongs. Bender and Cheston (1997) argue that good dementia care

> "involves the holding and containment of the emotional content of the action and its reflection back in a form that can be used by the patient. We need to be open both to the content of the stories we are told, and the despairing need for reassurance" (Bender and Cheston 1997, p. 525).

Their model is specifically intended to provide a framework for psychotherapeutic interventions with people who have been diagnosed with dementia and has not been tested by research.

How useful are 'stage' models of the response to a diagnosis of dementia? There are a number of difficulties associated with a rigid 'stage' model of the person's experience of dementia such as the one proposed by Keady. One of the difficulties of describing the process using a 'stages' approach is that people do not pass through these 'stages' in an orderly manner. There is also a danger that some practitioners or carers may take these stages quite literally and be expecting to experience all of the stages in a neat sequence. Whilst the stage approach represents a valuable form of early theorizing around the subjective experience of dementia, it is perhaps wise to keep in mind that the categories or 'stages' were initially developed following caregiver interviews and ratified with the data from ten people with a diagnosis of dementia and have not been generalised to other samples. Werezak and Stewart (2002) on the other hand, offer a different view of a stages model, describing it as more of a continuous process which suggests that with each new awareness experienced by the person with dementia the process of assimilation has to be repeated. This paints a picture of being and becoming. The Bender and Cheston (1997) model has a similar dynamic and flexible quality. Our need to revisit and re-evaluate early theories in light of contemporary knowledge is important, and while we acknowledge what we have learned from the early work of Keady, it seems likely that more fluid ways of understanding the experience of dementia may be of more relevance to us in the twenty-first century.

### *2.4.4 The experiences of people with dementia who have not been informed about the diagnosis*

In a qualitative study undertaken in Tayside, Gillies (1995, 2000) interviewed 20 people who had been diagnosed with dementia, all of whom were living in the community and were in receipt of formal support services, thus indicating a level of need where carers had already actively sought formal help and support. These interviews, while giving a 'glimpse of the here-and-now world' of people living through dementia, were unable to explore the meaning of being diagnosed with dementia as most had not been given, and were unaware of their diagnosis. Ethically, whilst described as being vetted by a four-tier hierarchy of access through ethics committees and gatekeepers, although participants are described as having given verbal consent it would be difficult to claim true informed consent, they are also described as 'dementia subjects', which implies that research was done <u>on</u> them rather than <u>with</u> them. Gillies reported the findings from this study as how dementia is experienced rather than the experience of dementia. The two main themes were how people experienced dementia and how they coped with what they experienced. They experienced dementia as an age related memory problem rather than a disease process, negatively compared their abilities with their former abilities, experienced humiliating effects of unreliable memory, and tried to minimise or normalise their experience. Coping with failing memory engaged two main coping strategies, practical coping and depending on carers, whilst coping at an emotional level produced euphemism to avoid facing the memory problem.

Because very few knew of their diagnosis, the experience of dementia for them had been perceived as an inevitable and normal part of the ageing process. Therefore, issues surrounding a diagnosis of dementia have been unacknowledged by the cohort, and one might argue that entitling the study the subjective experience of dementia is somewhat misleading.

In more recent enquiries, there has been an attempt to concentrate on the experience of people at an earlier point in the trajectory in seeking to understand how they cope with and make meaning of the onset of dementia. Many of these studies offer their findings as themes.

### *2.4.5 Living with early dementia*

A number of important studies have explored the experiences of people who have received an early diagnosis of dementia.

We learn much from an in-depth study by Phinney (1998) who interviewed and observed five people with Alzheimer' disease. The participants were interviewed twice within two weeks, three of their spouses were interviewed separately using the same interview schedule and three participants were observed for a total of six hours. These people, on average, had been living with dementia for five years and had been diagnosed 2½ years previously. Their mean Mini-Mental State Examination (MMSE) (Folstein, Folstein and McHugh 1975) was found to be 19 points from a total possible score of 30, consistent with mild to moderate degrees of dementia. She found that participants oscillated between two poles: that of 'being unsure', and 'trying to be normal'. Being unsure was related to the fluctuating awareness experienced and the inconsistent nature of this awareness led to feelings of uncertainty. However, the main concern shown by the participants was how to diminish the impact of early dementia in order to lead as normal a life as possible. These findings illuminate the early lived experience, and despite the knowledge of their diagnosis, and the acknowledgement of the disease process, the people involved in this study were struggling for a continuity of their normal life. The results of this study reflect characteristics of Sabat's self$^2$ and self$^3$, where new self$^2$ attributes such as having a diagnosis of dementia which are being integrated are at odds with the uncertainty of how other people are going to react to the knowledge of the diagnosis where self$^3$ is under threat and struggling to maintain 'the normal'.

Pearce, Clare and Pistrang (2002) provide evidence of the social construction of self and of the need for people diagnosed with early dementia to continually reconstrue a new sense of self. In a qualitative study based on semi-structured interviews with 20 men who were experiencing early Alzheimer's and their wives, they were able to demonstrate that the sense of self perceived by these men did not constitute a single construct. Rather it was a complex process with the person's sense of self

> "continually being constructed and reconstructed through social interaction. How men managed their sense of self ... was influenced by their partners' coping processes and the wider socio-political influences such as attitudes to being an ageing male" (p.187).

In order that this new identity of self could be reached, a 'delicate balancing act' between wishing to maintain an existing sense of self and the acknowledging of the need for reappraisal and reconstruction needed to be managed. This was described as a cyclical process of ongoing appraisal, experiencing new losses, and engaging coping strategies, with each of these three factors changing and fluctuating. The tensions alluded to in this study are in some ways similar to the tensions between the two themes of 'being unsure' and 'trying to be normal' in the earlier study of Phinney (1998). However, it develops further the insights offered by that earlier work by shifting focus from 'trying to be normal' to the acknowledgement of a need to define and construct a new sense of self, and in a way engaging participants in the defining and redefining of a new normal, albeit in many ways a transitory normal. To facilitate the new normal necessitates not only a reappraisal and reconstrual, but ability to become less protective of the old self in order to integrate these changes into the new self. Again this concept of social interaction being necessary for the construction of self is in keeping with Sabat's concepts of self[3]. In order to incorporate the diagnosis, a new attribute has to be added to the self[2].

Clare (2002, 2003) offers a conceptualization of the coping strategies identified in her study of twelve couples; one partner (nine men and three women) having been diagnosed with early Alzheimer's disease, aged between 57-83 years with an MMSE score ranging from 19-29. Each couple was interviewed separately twice, and data were analysed by thematic analysis utilising the method of Interpretive Phenomenological Analysis (IPA). Adjustment to the experience of dementia was viewed along a continuum ranging from self-protective to integrative responses. The self-protective group was perceived as making an attempt to maintain a sense of the 'old self' and hold on to normality as they had known it, whereas the integrative group was characterised by their ability to meet the threats to self as a challenge, which enabled them to come to an acceptance of what was happening, and integrate these changes within the self. The majority of people within this cohort were confined to the self-protective end of the continuum. Adaptation to change involved five interrelated processes. These were registering changes, reacting to them, finding ways of explaining them, experiencing the emotional aspect of them and attempts at adjusting to the changes. This study adds to the growing body of evidence that suggests that the self with dementia is socially constructed in accordance with Sabat's model. These processes, unlike the stages offered by (Keady 1994) appear to have the person with dementia being more active and agentic, rather than accepting, passive recipients of a disease process. These findings suggest that people are capable of adjusting to changes in their cognitive and linguistic functioning through adopting a stance that fits with their nature, situation and past preferences and experiences.

Taken together, the findings reported in these three studies suggest that the tension between developing a new sense of self and maintaining or protecting the previous self (leading a 'normal' life) is a crucial task for people in the weeks and months immediately following a diagnosis of dementia. This tension is experienced as a cyclical process involving movement back and forward between the new and old 'selves'. It is also a process that, for many of those who were interviewed, is associated with a strong emotional response. Beyond this, these studies indicate that the work of self-definition that takes place is consistent with the overall framework offered by Sabat, and is highly dependent on the quality of relationships that exist between the person and those with whom he or she is in contact.

### *2.4.6 The continuity of a known self*

The theme of 'leading a normal life' is explored in depth in a study by Menne, Kinney and Morhardt (2002), who found that all of the six participants in this study wished to continue with the previous lifestyle with which they were accustomed. As a way of sustaining continuity, taken-for-granted activities would be modified in order to still be achievable following the dementia diagnosis. Two activities, driving and helping others, have been chosen to illustrate how people adapted by using long-standing patterns that have helped them function as unique human beings up until this point in their lives. When the question of driving was raised, one respondent used considered thought and reason in the decision-making process, working through the alternatives and considering the costs and benefits of continuing to drive or risk hurting people. This was how he had always made decisions, while the other responded to the authority figure of the doctor and he was unwilling to challenge that authority. While there had been a change in the daily activities (driving), both had shown continuity in their decision making and their way of adapting had been maintained and continued to serve them well and they were able to make meaning out of their situation by contextualising it. In a similar way they were able to find ways of helping others despite the limitations that their diagnosis had bestowed upon them. Continuity theory (Atchley 2000) and a meaning-making framework (Park and Folkham 1997) were utilised in this study to interpret the early experience of people with Alzheimer's disease. Striving to continue 'being' in the same vein, while reporting it as a struggle, was of immense importance to the participants of this study, who perceived it as a challenge. By contrast, in the Clare (2002) study, maintaining continuity was seen as being self-protective and at the opposite end of the spectrum from challenge and integration. These two studies give an example of two types of continuity: the desire **to be** (Clare 2002) who they were prior to the diagnosis, and the desire **to do** (Menne, Kinney and Morhardt 2002) what they did prior to the study.

### *2.4.7 The self in flux*

In a quest to gain a more sensitive understanding of how a sense of self is defined by someone who has a diagnosis of dementia, Harris and Sterin (1999) embarked on a qualitative study interviewing 17 people with a diagnosis and 15 of their caregivers. These 17 people had all been diagnosed within the previous four years and were all involved with early stage programmes following diagnosis by physicians at local hospitals, therefore no further testing was carried out. This study was vastly different from any other and was of collaborative design. One of the researchers, Gloria Sterin, had been diagnosed with Alzheimer's disease so this truly was a study with an insider perspective. All participants were made aware of this prior to interview, and were all really eager to explore their experiences with the researcher, and acknowledgement has been made of how this might have affected the research project adversely. Conversely, the experience she had of being diagnosed, and also the great experience she had as a researcher, counteracted this. Key themes around the impact of a diagnosis on the concept of self were:

- *a changing sense of self,* which reflected the not knowing who you were or who you would become
- *losses,* which reflected loss of independence, self worth and respect, loss of relationships, loss of memory, loss of meaningful roles
- *emotional reactions,* with frustration, anger, embarrassment/humiliation, fear, disempowerment and uselessness with frustration being the most common. These emotions were linked to efforts to maintain sense of self
- *maintaining self-identity* through continuity of their past skills and experience.

Harris and Sterin (1999) also identified five different patterns of reaction to the diagnosis that they called typologies. These are summarised in table 3:

| Typology | Reactions |
|---|---|
| I'll live until I die | Fighters, people who actively engaged in living with dementia. Their independence helped preserve sense of self. Accepting of what life dealt them, learned ways to deal with it |
| I accept what I have | Surprised and upset by diagnosis, they faced facts but did not struggle against the disease. Could fit their new roles into personal identity without damaging the sense of self |
| There is nothing wrong with me | Denied diagnosis which was too devastating to contemplate and too harmful to the sense of self. Denial necessary way of maintaining self |
| I'm struggling to get through the day | Overwhelmed by diagnosis and tried to conceal it. Struggled to maintain previous activities. This group had great difficulty coming to terms with their diagnosis and struggled to try to understand the impact on the self |
| I'm giving up | Most aware of their dependence and resented it. Found no effective way of dealing with the disease. Could no longer continue their present self because it demanded too much energy. They felt despondent about the future |

**Table 3 A list of typology of different reactions to diagnosis**

These five different ways of responding to the diagnosis reflect how individuals embrace the knowledge of their diagnosis and try to make meaning of it. For some it is a challenge to be faced, a fight to be won, but for others it is a challenge too far and demanded too much energy to maintain a continuity of the self identity they once held. The core values of that self identity which emerged from the data were meaningful productivity, primacy of autonomy and the importance of comfort and security.

They also found that the social psychological milieu could have both an affirmative as well as a negative effect on the self-identity. In conclusion they advocate that by understanding what happens to the self following diagnosis the social milieu could be adapted in such a way as to enable the preservation of the person's dignity and self respect, and reflects the notion of Kitwood (1997: 20) who believed that "if identity is to be maintained it will be very largely on what others provide".

### *2.4.8 The self and the illness narrative: co-constructing the story*

In an effort to understand the meaning of illness, it is often through the telling of the illness story to others that it becomes meaningful to the person. According to Frank (1995), "ill people have to learn to think differently. They learn by hearing themselves tell their stories, absorbing others' reactions, and experience their stories being shared…the self is being *formed* in what is told" (p. 1 and 55).

Phinney (2002) challenges us to turn away from the notion of the self as primarily independent and to seek to understand how the self is constituted through a relational existence with others sharing in the telling of that story. When the illness happens to be dementia, it is not always possible to be the sole storyteller, since stories rely on memory and language and there may be some loss of capacity in each of these areas. In a study to examine what happens to the illness narrative when symptoms of dementia become more pronounced, Phinney (2002) interviewed nine community dwelling people, four men and five women with ages ranging from 64-88 years, who had been given a diagnosis of dementia just over two years prior to the study. They lived with a family member who was also interviewed. These people had all been involved with a research centre or been part of an early diagnosis support group. Each was interviewed three times over a period of 2-6 months and the data gathered were analysed using Interpretive Phenomenological Analysis. She found that the discussion of symptoms fluctuated and there was a changing awareness in people's stories of how they experienced these symptoms. Phinney (2002) concluded that there are two key aspects of the meaning of the Alzheimer's symptom story. First, it is a story that is impossible for the storyteller to give alone, the stories being jointly lived and jointly told, with others joining in the telling. The second key aspect of the dementia story is that it is "inherently and fundamentally unknowable and untellable" (p. 340). In the telling of the story sometimes the narrative itself breaks down, with the teller no longer able to remember who he has told, and what he has told himself and others of his story. As a result the story begins to become more difficult to follow. The story no longer holds its meaning. In order to make it more meaningful, others join in the telling of the illness narrative. Over the course of the illness, the story becomes more and more a "narrative of chaos" as the illness progresses and it becomes more difficult to give coherence to the co-constructed story.

In keeping with belief that we are interdependent beings reliant on others as well as our selves for the sense of understanding and making meaning of our situations, Van Dijkhuizen, Clare and Pearce (2006) offered a *Level of Connectedness Model* of the appraisal and coping strategies of 9 women who had been diagnosed with early Alzheimer's disease. Semi-structured narrative interviews were carried out with the women and their family member, who was also interviewed separately. Analysis of this study was by Interpretative Phenomenological Analysis and ten themes were identified which were then consolidated into three higher order themes: connectedness, protective strategies and adjustment. Connectedness meant a connection with the past social network of relationships including family, social roles and familiar environments, and was experienced on a continuum from connectedness to disconnectedness. The theme of protective strategies was found in those who conveyed a sense of the loss of memory as being no problem. Threats to connectedness with their past, their relationships and their environment were seen as possible reasons why this group tended to downplay their difficulties. However, it could also have been that these women were so secure in their relationships that it really did not appear to bother them. In the final theme, adjustment, the narrative accounts suggested that they saw their difficulties as a normal part of their lives and of just getting on with it which reflected evidence of a resilient nature.

The studies by Phinney (2002) and Van Dijkhuizen, Clare and Pearce (2006) highlight the importance of relationships with others and the dependence on others for the maintenance of the sense of self. In addition, Phinney (2002) draws attention to the way that the person with dementia and those around him or her act together to construct a coherent narrative account or illness story.

### *2.4.9 Changing relationships*

In all of the studies into the subjective experience of dementia that have been reviewed above, the theme of relationship emerges to a greater or lesser extent. There are a myriad of relationships which are affected by dementia, and the most common to be reported within a research context tended to be spousal relationships or, more rarely, relationships within a family context.

Families do not occur in a vacuum and both Dilworth-Anderson (2001) and Pearlin et al (2001) emphasise that the family is not a free standing institution and note that influences from a wider social context on the functioning of families include culture, values, and economics.

Although it is not the intention here to explore and expand social network theory it is worth mentioning a study by Fratiglioni et al (2000) in which it was found that “a poor or limited social network increased the risk of dementia by 60%...an extensive social network seems to protect against dementia.” (p. 1315).

Being in relationships seems to have some protective factors, however it does not insure against dementia and the impact this diagnosis has on relationships is reported in this section.

The following sections focus specifically on studies that have examined the impact of dementia on the spousal relationship; the importance of mutuality and reciprocity in the relationship; the concept of couple hood; and the ambivalence and ambiguity within relationships.

### *2. 4.9.1 The impact on the spousal relationship*

The earliest study that included the person with dementia within the relationship context was Wright (1993) who studied the interactions of 47 couples. In 30 of them one of the pair had a diagnosis of Alzheimer’s disease, and as a comparison, 17 couples who enjoyed relatively good health. She reported the marital relationship to be ‘profoundly different’ for each of the two groups. The ‘healthy’ group was characterised by enjoyed mutual companionship, high affectional and regular sexual expression, shared responsibilities, and low degree of tension. The ability of couples to take the attitude of the other was the hallmark of the relationship.

In comparison, marital relationships were a quite different experience for partners within the ‘Alzheimer’s group’. Previously shared household responsibility became the main responsibility of the caregiver spouse, tension was much higher, and there was a need for alternative companionship. Sexual expression too was changed, and either loss of sexual drive, or increased desire and demand, was experienced, which left the caregiver with mixed emotions. The attitude of the other was no longer reciprocal although the caregiver still retained the capacity to take the attitude of their spouse and had a commitment to stay in the marriage relationship. The caregiver’s stance was made more possible by retaining the image of their spouse as someone of value.

The view of the relationship from the perspective of the person with Alzheimer's disease did differ to that of the caregiver spouse. Household responsibilities were seen as unproblematic, there was a perception of low tension, and the need for a close, clinging companionship was portrayed. Sexual expression tended to be either lost, or in a few cases was exaggerated, while the expression of affection also reflected these trends of low or high need. The spouse with Alzheimer's disease showed different levels of ability to take the attitude of the other, and tended to withdraw if they felt they were being rejected. When social contacts were perceived as being too complex these were constrained. Their commitment to their marriage reflected their dependency on their spouse as their most significant other. Wright (1993) concluded that the developmental outcome of the Alzheimer group was expressed by the committed-dependent relationship which extends over the dimensions of adaptation and control along with distortion and disorder. It is clear from this study that Alzheimer's disease has a dramatic impact on the marital relationship.

Marital interactions were the subject of a study by Gallacher-Thompson, et al. (2001). They compared the interpersonal interactions of 27 caregiving wives and their husbands with Alzheimer's disease with 27 non-caregiving wives and their husbands. Each couple was videorecorded while performing two distinct tasks. Task one recorded interactions over a meal time while task two recorded the joint planning of a future event. They were also asked to complete questionnaires to assess depression, stress, relationship mutuality and perceived hope. The results of this study showed that caregiving wives reported higher levels of depression and stress, although they held similar shared values and feelings of closeness. Unsurprisingly, non caregiving couples appeared to be more interactive and supportive. Caregiving wives were most facilitative during the future planning task and husbands with Alzheimer's disease scored most highly on rapport building.

Pearlin, et al (2001) found that caregivers reported that there was a decline in shared activities, loss of emotional support from their spouse coupled with a reduction in the quality of verbal communication. She posits that these changes may have negative consequences on both morale and perceived changes in the intimacy and satisfaction of the marital relationship, and recommends that professionals working with people with dementia and their families undergo training in relationship counselling in order to address the consequences and issues arising from the changing relationship and the ensuing distress which is experienced as a result of these changes.

### *2.4.9.2 The importance of mutuality and reciprocity*

One of the most significant factors in the relationships of someone with dementia was mutuality. In a study by Baikie (2002), four distinct groups were defined: *high mutuality (internally reinforced)* which reflected the continuity of a strong loving relationship; *high mutuality (externally reinforced)* which indicated that both parties were gaining similarly, e.g. the mother may be cared for by a daughter who was dependent on her for housing; *low mutuality* which often signified the breakdown of family relationships; and *no mutuality,* which was when family members were resentful of the person with dementia and the destructive effect that it had on the rest of the family, and often thought that death was a preferred option. Mutuality had the strongest influence on the decision around entry into full time institutional care, more than any other factor, although another three were also significant influences on this decision: caregiver management ability, moral values and levels of tension. This study sample has comprised of two thirds spousal relationships and one third children caring for a parent.

### *2.4.9.3 Couplehood*

The issue of 'couplehood' formed the basis of a single case study reported by Hellstrom, Nolan and Lundh (2005), who contend that we should be studying people with dementia as social beings rather than monads with the emphasis on the person with dementia as a relational being. This single case was part of a larger constructivist study in which 20 spouse couples engaged in four interviews over a space of 18 months. The couple in this study, who had agreed to engage in the co-construction of their story and provide agreement for the researchers' account of this, were interviewed simultaneously by two different researchers. Each interview was analysed utilising constant comparison methods prior to the next interview taking place, in order that earlier themes emerging from the data could be explored. The wife had been diagnosed with dementia and the husband was her primary carer.

The study recounts, from the couples' narrative, ways in which both partners continued to 'seek involvement' through the shared activities in which the husband actively reinforced, rather than negated, his wife's sense of agency. The relationship was truly reciprocal and they responded as a couple to the many challenges posed by the diagnosis of dementia. Helping his wife provided the husband with a sense of purpose that had become part of his identity as he sensitively encouraged her to continue to do as much as she could with minimal, sensitive support, in order to avoid undermining his wife's self esteem. Doing things together was an extension or continuance as to how they had always managed their relationship and they were very involved in activities centred round their Christian faith and their church. One of the things that they found helpful in maintaining their involvement was to inform their church members of the wife's diagnosis, who now too help in an affirming way through being aware of the diagnosis by providing assistance. It was not clear from the study which of the couple informed the church members of the diagnosis. Although Hellstrom, Noland and Lundh (2005) have not yet reported on the full study, early analysis shows that despite this couple being unique there were similar features in others in the study that were seen as operating as a couple. The researchers call for a shift in focus from the person with dementia to 'the couple' in spousal relationships as they are actively involved in working together.

The notion of continuing couplehood was the basis for the study by Kaplan (2001) who explored to what degree couples still felt married when one spouse with Alzheimer's disease had been institutionalised. In this study, 68 people with spouses still living at home were interviewed and findings showed that there was boundary ambiguity, and five different categories emerged from the data. These were on a continuum from strongly feeling part of a 'we' to feeling strongly about being an 'I'. However, not all caregivers perceived themselves at the same starting point and while there is undoubtedly change occurring within the couplehood relationship, it is unclear as to how much each person has moved along the continuum.

A rather different method of studying the interaction of couples was instituted by Clare and Shakespeare (2004). They recruited ten couples from a memory clinic (one of the couple being recently diagnosed with dementia) with MMSE scores ranging from 20-29, and ages ranging from 52-83 years. They wanted to record conversations between the couples about their diagnoses. Although all of the partners had been given the diagnosis, only three of the ten participants had been told and it was therefore not possible to introduce the research subject as the experience of dementia, but it had to be changed to the experience of people attending a clinic for advice about their memory problems. They were then invited to hold a five minute conversation with each other and come up with a statement about their present situation. This conversation was recorded, although the researcher did not stay in the room with the participants during that time.

The approach utilised in the analysis of these recordings was informed conversational analysis. It was found that most of the participants with dementia were uncertain as to what their task was, which could have placed them at a disadvantage. Partners offered cues to enter the conversation and frequently took control of the conversation – with partners defining what should be discussed. It was interesting to note that partners avoided, or skirted round the emotional pain or concerns of the person with dementia, with partners insisting on normal responses, which led to the person with dementia being in danger of being silenced. Resisting this process required persistence and determination, or was overridden by the need to preserve the relationship.

In other couples, the partner defined them as being or having a problem. A central task of this participant was to resist malignant positioning. The balance of power was noted to have moved to the partner. The fear of the participants for their future went largely unheard, and very few addressed any of the issues of the impending decline, and often responses were dismissive in nature. Partners positioned the couple as helping each other although positioned themselves in various ways, such as collaborators and helpers, although this was sometimes difficult to sustain. Conversations also encompassed a societal component offering the ageing process as a reason for the memory deficit with only one couple drawing on medical discourse, referring to it as a disease, and in this way were able to engender hope of a cure for the future.

Resistance was a key finding of this study with participants struggling to retain their voice, express their fears and feelings, and also struggling to resist being positioned negatively. Partners also portrayed resistance but in full acknowledgement of the diagnosis, with a reluctance to facilitate the expression of their partners' feelings of fear, and they preferred to avoid stress. There was also a resistance to collude with their partner's face saving attempts or to engage in normalising and minimizing. It was concluded that these forms of resistance would lead to the person with dementia being placed at a disadvantage. The partners tried to position the couple in an acceptable way as working together but more detailed analysis belied this attempt and reflected the shift in power to the partner with the beginnings of malignant positioning evident.

The studies reviewed in this section provide powerful evidence of the significance of couple relationships as a means of mediating the effect of dementia. These studies have used intensive methods of qualitative analysis to identify a range of interaction patterns and language strategies that are used within couples to construct shared meanings around the experience of dementia. This research includes valuable indicators of the type of positive, supportive relationship that can enable a person with dementia to retain selfhood and agency to a maximum degree.

#### *2.4.9.4 Couples' reactions to diagnosis*

In an earlier section of this chapter (see 2.3.6.4) research into the role of the doctor in disclosing a diagnosis was discussed. That earlier section also reviewed research into patients' views of diagnostic practices. In the present section, studies that have looked at the impact of diagnosis on the 'couple' are considered to examine the meanings that couples have constructed from their early diagnosis.

Robinson, Clare and Evans (2005) recruited nine couples from four memory clinics in London, with one partner having a diagnosis of dementia; five women and four men ranging in age from 45-73 years, and with an average MMSE of 23/30. The time they had been diagnosed ranged from two months to two years. The study utilised semi-structured, single interviews to explore the experiences, understandings and shared constructions of their diagnosis and illness. Couples were offered a follow up counselling session although this was not taken up by any of the participants. Interpretive Phenomenological Analysis was the choice of method of analysis. Influenced by theories of loss and acceptance of chronic illness in the interpretation, a model of the process was offered as couples appeared to be in an ongoing process of 'making sense and adjusting to loss'.

Receiving a diagnosis had both positive and negative effects, although it did not always increase the couples' understanding or acceptance of what they were experiencing. For some it confirmed a problem, provided relief and understanding whilst making it more difficult to deny what was happening For others the converse experience was that it did not alleviate the uncertainties about their memory problems, with most looking for more information elsewhere. The lack of practical support to couples has a bearing on their feelings of isolation, together with the fact that nothing could be done. The process of adjustment to loss and making sense was akin to that found in models of grief.

The process of acknowledging loss was an important step in the overall process, with a loss of independence, memory loss, and loss of previous roles and lifestyle with feelings of depression and frustration that accompanied the losses. Changes in the relationship revealed an inequality in power, and changes in their role within the relationship were also reported. The findings of this study suggest that it may be useful to help couples make a joint construction that enables them to make sense of what is happening to them, find ways of adjusting to the changes experienced in their identity and their roles, and help to manage losses in the face of a diagnosis of early dementia.

#### *2.4.9.5 Ambivalence and ambiguity*

Some studies into the experiences of couples, in which one partner has been diagnosed with dementia, have identified high levels of ambiguity and ambivalence within the couple relationship following the event. In a recent study, de Vugt et al (2003) found that there was ambiguity from caregivers because they experienced deterioration in their relationship but at the same time they felt much closer to their partner than in the past. Behaviour problems were cited as the main contributory factor to the deterioration in relationship. Passive behaviour, such as apathy, seemed to be more destructive within the relationship than excessive behaviours. Apathy reflected a lack of reciprocity which was a key feature in the breakdown of the relationship.

Eloniemi-Sulkava et al (2002) reported that changes in the marital relationship reported by spouse caregivers showed a decline in happiness, in the equality of the relationship, and in expression of sexual needs since the onset of dementia. Smith et al (2002) found that the illness affected all areas of life, both for the patient and the caregiver, including spiritual, legal, financial, housing, medical and emotional needs and concerns.

Forbat (2003) examined the relationship of two women, a mother and daughter, one the carer and one the cared for, through the medium of talk utilising a discourse analysis approach. A single case study was presented to illustrate the identity constructions and longstanding relationship difficulties. This account is of one person with dementia who is in residential care and the other with her daughter; it is unclear as to the extent of the dementia. One event is constructed as two different stories that illustrate the tensions within the current relationship. This form of analysis brings a different dimension to the problems inherent in the relationship and examining an incident in the past projected this meaning into the current difficulties of the relationship and Forbat (2003) suggested that this approach had the potential to help understand, explore and deal with current difficulties with people who have long shared histories. The sensitivity to the language used was seen as a key to the understandings and meanings of the narrative which includes that of the person with dementia. Although this study suggests an ongoing process, she only conducted single interviews and did not trace the reactions over time.

### *2.4.9.6 The impact of dementia on relationships: summary of key themes*

The studies reviewed in this part of the thesis suggest that relationships play a major role in determining the trajectory and quality of life of people diagnosed with dementia. Research has identified the types of supportive and collaborative patterns that are associated with good outcomes, and the types of negative and malignant relationships that lead to poor outcomes. The studies that have been carried out have largely focused on relationships between intimate partners (usually husbands and wives) – there is clearly a need for research that explores wider sets of relationships, for example, the children and members of communities. Methodologically, many of the studies that have been reviewed have found it necessary to use a combination of interviewing and observation in order to collect sufficiently rich data on the phenomena being investigated.

### *2.4.10 Conclusions: research into the subjective experience of people with early dementia*

The studies that have been discussed add a great deal of understanding of the meaning of the subjective experience of an early diagnosis of dementia. From these we can glean that coming to terms with a diagnosis appears to be a continual, yet cyclical process, dependant upon the person's awareness and ability to respond and adjust to new and different internal and external changes. The process has been described as staged, moving through distinct stages one to the next. There is evidence of a struggle for continuity. In all of these studies the self-identity of the person is implicated, and is described as being in a state of flux told through the illness narrative and shaped by reactions of others in the relationship, who can contribute to either a positive or negative sense of self. These findings are the results of studies, all of which are qualitative in nature, but each designed differently, with sample sizes ranging from five to twenty participants, all at varying degrees of time following a diagnosis, and with participants having differing cognitive function.

Many of the studies were carried out with highly educated people, who may be more likely to seek early diagnosis or agree to enter research programmes, or perhaps both. It is common practice in these studies to record one or maybe two interviews, some with validation of spouse/carers, and with a few adding observation to their method of data gathering. Only one study spanned a 6 month period, and then it was an interview at the beginning and at the end of the 6 months with no observation of what happened in between. Missing from the literature to date are studies that follow people intensively, and in their own environment, over a prolonged course of time in the post-diagnostic period, and there are no reports that suggest the researcher become part of that lived experience in order to reach a deeper understanding of the post-diagnostic experience.

The material that has been reviewed reinforces recent calls to practitioners and therapists to see people with a diagnosis of dementia within a relationship context and not as people in isolation (Nolan, Keady and Aveyard 2001, Sheard 2004), with interventions being tailored to incorporate as wide a network as possible of family and friends (Van Dijkhuizen, Clare and Pearce 2006). In order for this to happen there is a need for an understanding of what happens in, and to the relationships of which the diagnosis of dementia is a factor.

Although there is a paucity of literature on relationships within the context of the person with dementia, much was learned from the studies reported above. The impact on the relationship was seen in terms of being both pragmatic and psychological in nature. Responsibilities and roles changed within the relationship and previously shared household tasks become the responsibility of the caregiver. Changes in the relationship were characterised by a lack of reciprocity and mutuality, sexual expression, increased tension, with diminished interaction and support. Shared activities were fewer, with a reduction in verbal communication. The loss of mutuality and reciprocity were the most likely indicators of whether someone with more advanced dementia would enter full time nursing/residential care.

Couplehood was explored, and issues around adjusting to change and how people continued with shared activities. It seemed that the person with the diagnosis provided love and companionship while the partner became more active as a helper, and sensitively encouraged continuity of previous activities by becoming more involved in a subtle way. One helpful element was sharing the diagnosis with friends and family who provided affirmative support. The shifting of the balance of power became obvious in relationships where people with dementia became less powerful and more dependent. Spouses avoided discussing strong emotional pain or feelings, and at times in conversation people with dementia were in danger of being silenced. Malignant positioning was difficult to resist as was the struggle to maintain a voice. Indeed, all aspects of life were affected.

The studies reported above are the beginnings of a body of literature starting to demand more of an understanding about how dementia is understood within the social milieu. Despite being described as a process, the majority of the research is undertaken utilising single episode qualitative interviews. Researchers have to date been reluctant to build relationships with families and become involved with them over time in order to gain a better understanding, and no ethnographic data has been collected during a lengthy post diagnostic period.

In order to gain new understandings of what happens in the post diagnostic process this present study was designed to engage with people living within a relationship context in order to fill this gap in the literature and gain a clearer understanding.

## 2.5 A Review of Research into the Role of Counselling in Early Dementia

Two of the main themes to emerge from the review of the literature so far are the importance of relationships in the post-diagnosis phase and the necessity of gradually developing a sense of self that integrates the reality of being diagnosed with dementia. Counselling is a form of help that is widely available in all Western industrialised societies, and which operates through a trusting and safe relationship to enable the person to engage in self-exploration and repair. However, the counselling world has been slow to respond to the needs of people with early dementia and as a result there is little empirical evidence to date that reflects the lack of engagement of counselling researchers in this field. A systematic review of counselling for older people revealed no studies of post-diagnostic counselling for people with dementia (Hill and Brettle 2004).

Literature pertaining to counselling is largely anecdotal or clinically based and a-theoretical (Bartlett 2003, 2003, Bender 1999, Cheston 1998, 2000, Gibson 1999, Kitwood 1990, Labarge 1981, Whitsed-Lipinska 1998). However, Woods (2003) acknowledges the difficulties of collecting research evidence and warns of the folly of embarking on premature "'gold standard' randomized controlled trials (RCTs)" (2003,

p. 5) which would be inappropriate at early developmental stages of new approaches. He suggests methodologies such as single case studies as a method that may be helpful in the process of developing interventions.

In a call to listen to the narrative accounts of people with dementia Sutton and Cheston (1997) warn of what we will hear

> "We are listening to people talking about a pain that may well one day be our own or that of our husbands, wives, fathers and mothers. We cannot make this future 'better' in the sense of taking this pain away: we can only try and listen and to help the person feel that they have been heard. ***This is as hard as it is necessary***" (emphasis added) (p. 162)

That counselling is necessary for a person with dementia is not a contentious issue within this thesis. Instead, there are two areas that require further inquiry. First, there is the question of how counselling can be most appropriately offered to people who have received a diagnosis of dementia. Some suggestions in relation to this question are offered in Chapter 7. The other area is concerned with the evidence base for counselling and dementia. The following sections of Chapter 2 consider the available studies of counselling people with dementia, with a focus on individual counselling as an intervention for early diagnosis.

### *2.5.1 Is therapy possible?*

A study by Greenwood and Loewenthal (1998) posed the question of whether or not therapy was possible with someone who has a diagnosis of dementia, and although no firm conclusion was reached, interesting observations about the research process, a single case study, was openly discussed. Difficulties were noted because the therapist was also the researcher and evidence suggested that the research design had influenced therapy. There was no indication of the severity of the dementia that this man experienced, and although he is described as being in a 'home' it is unclear if this was because of his dementia or other reasons. The conclusion reached was that it was impossible to know if the client had benefited from the meetings with the therapist/researcher but they had been of great interest to the researcher.

### *2.5.2 Opportunities for early intervention*

The study into the emotional responses to a diagnosis of dementia illustrates the area in which counselling may be effective. The most common worry of people with a diagnosis of dementia is related to the fear, which includes fear of others finding out, fear of being judged, fear of future dependence, and not being listened to, according to Husband (2000). A sample of ten people, seven women and three men, agreed to take part in the study and were recruited from people who had been referred for neuropsychological assessment and who were subsequently given a diagnosis of dementia. Their average MMSE was 23.4/30. They were asked two questions about whether they had been worrying a lot about their memory problems and what thoughts had they had regarding what might be causing the memory problems. Having then received their diagnosis from the Consultant Psychiatrist of Clinical Psychologist, they were invited to return in 6 months to take part in the second part of the study. This also comprised of two open ended questions which were, "what are you most worried about in relation to your diagnosis?" and "what effects has the diagnosis had on you?" (p. 545)

Mode of analysis was content analysis and frequency counts of the handwritten notes at interview. The foremost issue to which participants made reference was the social stigma of having dementia and they felt ashamed and humiliated. They were greatly concerned about others finding out and lived in fear of this because they felt that others would treat them differently. They also held negative beliefs of the future presentation of the self, feeling they may become stupid or incompetent. This led to the adoption of unhelpful coping strategies that resulted in an increased anxiety and lowering of access to gaining a valued social identity thus lowering self-esteem. Fears of the future were based on images held of their previous, negative experiences of dementia within their social network, with fears of not being listened to or consulted about anything, holding a view that people with dementia did not count, especially with health care professionals. The effects of personhood and self-esteem were of paramount importance to this cohort.

These are all worries which could possibly be diminished with appropriate psychotherapeutic interventions. Such interventions could also serve to enhance self-esteem and facilitate continued engagement within their social milieu with the maintenance of a narrative self identity being a possible target for therapy. Whilst it was recognised that this study had a fairly small sample it was equally of import to note that 100% of people voiced similar fears, worries and concerns. The findings of this study gave a greater understanding of the thoughts and feelings that people experience following an early diagnosis and served as a good basis on which to begin designing appropriate therapeutic interventions.

### *2.5.3 Post-diagnostic counselling*

One very early pilot study conducted in America by Labarge et al (1988) with people with mild dementia showed that no effect was evident after the study. In light of the design of the study and the expectations of the counselling session, it is hardly surprising that this was so. Two groups were enrolled in the study, one experimental and one control group Each was randomly assigned eleven people with eight people completing the experimental group study. This group received two individual sessions of 50 minutes each, with the first session taken up with psychometric tests. Session two was designed around the following structure: building rapport; gathering information about patients' feelings regarding their experience of memory loss; exploring alternatives and ways to deal with loss; confronting incongruities; and giving information about the disease process. The aim of the session was to alleviate stress, frustration and anxiety, maintain self-determination, and help deal with memory loss. These seemed to be unrealistic expectations of one counselling session. While it was observed that both groups benefited emotionally from the interactions of the pre- and post-counselling testing, they concluded that there was no significant difference between the two groups because both essentially received treatment. However, observations made suggest that people wanted talking sessions to work through issues in a cognitive way, that they requested more written information and wanted something to help with their losses. There was no detail of the theoretical model utilised during these sessions, neither was there detail about what happened (if anything) with the control group.

Counselling for people in the post-diagnostic period has been incorporated into a study of effects of early intervention within the context of a memory clinic (Moniz-Cook et al 1998). The sample in this study was divided into two groups; the first fifteen people diagnosed were referred to their local Community Mental Health Team (which would be normal standard practice) and they became the control group. The next fifteen people diagnosed became the early intervention experimental group. Counselling was incorporated as part of the early intervention package, which was delivered by a clinical psychologist. Along with the giving of the diagnosis, the intervention package included crisis prevention advice and psycho-educational input about wellbeing of the person with dementia and their family over a 4-14 week period. This cohort was then referred on to their local Community Mental Health Team for continued support. Whilst acknowledging the methodological limitations of this pilot study the researchers claim that fewer people in the experimental group had been institutionalised at the end of 18 months and cite early counselling as one possible reason for this, "experimental families were particularly enthusiastic about the early counselling aspect of the intervention" (Moniz-Cook, et al., 1998, p. 209, Moniz-Cook 1998).

Within a Cognitive-Behaviour Therapy (CBT) paradigm, Husband (1999) described the post-diagnostic intervention of three people following their diagnosis of dementia. The standard approach to therapy had to be modified in order to accommodate the cognitive decline in three main areas and by slowing the pace, and no formal homework or written records were requested. This study did not employ standardized outcome measures but the subjective experience of the participants was invited, and the subjective view of the therapist noted. Participants reported that anxiety was much lower at the end of therapy, and all three participants had benefited. The sample in this research study was part of a larger cohort, however it is not stated what the outcome of the other participants were and clearly this needs to be more fully reported, although early subjective evidence is encouraging.

There does not seem to be one psychological model that has primacy over others as far as early intervention is concerned, and the work of Brierly (2003) within a Psychodynamic Interpersonal paradigm gives insights into how this model has also been adapted to engage people with a diagnosis of early dementia. This particular therapy was chosen as it concentrates on feelings and relationships, and was adapted to suit the needs of people with early dementia in order to evaluate its usefulness prior to a larger study. There was no indication of where the researchers accessed the group of 20 for their pilot study, nor does it give details of their diagnosis or cognitive abilities; it does make reference to participants attending day hospital and this would indicate a cohort of recently diagnosed people rather than being early on in the trajectory of the disease process. It gives details of the model of therapy, which they implied was more agreeable than a model which focuses on cognitive work. While there were no claims made about outcomes of this pilot study, the experience of participants was described as positive in most cases.

The three studies reported above were all pilot studies and this reflects the dearth of research based evidence for psychotherapeutic interventions following a diagnosis of early dementia.

There were a number of psychotherapeutically based post-diagnostic support groups reported in the literature, which are acknowledged here, but it is beyond the scope of this literature review to include them in this study. In a review of whether people with dementia were likely to benefit from Group Psychological Interventions (Scott and Clare 2003), it was found that relatively little evaluation had taken place, therefore no firm conclusions could be drawn although there were recommendations that further research is required in order to discern the usefulness of psychotherapy groups. They did, however, find in their own study that the majority of potential group members were reluctant to attend psychotherapy groups and preferred one to one therapy, although they were enthusiastic for groups focusing on social meetings.

### *2.5.4 Insider perspective*

An account of how counselling could help has been authored by Christine Bryden (2002), who was diagnosed with fronto-temporal dementia in 1995 and who completed a post-graduate diploma in counselling in 2000. Bryden's article offers a unique insight into both theory and practice of counselling in relation to early dementia. She was an insider on two counts, both personal and professional, and was therefore doubly qualified to suggest effective counselling interventions. Bryden (2002) offered an informed view of the different types of counselling and psychotherapeutic support that could be considered to be useful to people with dementia and whilst it did not constitute a research study, it gives a unique subjective view. She based her views on the work of Kitwood (1993), but acknowledges the need to place more emphasis on biography and personality, with the social context being that of the person's own home as opposed to Kitwood's work, which mainly focused on institutional care. Details of the different types of therapy which could be useful were listed and discussed alongside goals and obstacles of psychotherapy. She considered how therapy may need to be adapted while acknowledging the uniqueness of the individual and their coping mechanisms that have developed over a lifetime.

She concluded by discussing the inadequacies of the medical model to embrace the complex needs. Indeed, there was little mention made of the medical practitioners who made the diagnosis of early dementia within the psychotherapy literature.

Whilst doctors are often seen as the gatekeepers of such services, we know little of how they view the concept of post-diagnostic counselling, and this clearly needs to be addressed. We know from other fields of healthcare such as cancer and AIDS that post-diagnostic counselling is not a new concept within the health service; however, it is fairly new within dementia care. This is, in part, due to the recent developments around the practice of early diagnosis, and at this point in time very few services have access to post-diagnostic counselling.

### *2.5.5 Summary*

The concept of counselling as a choice of post-diagnostic intervention has not yet become widely available in Scotland despite the recommendation in the policy document, HDL 44 (2004). Perhaps this inertia is due to a lack of empirical evidence or perhaps there is a lack of willingness by counsellors to become involved in the field of dementia. Counselling research has done little more than dip its toe in the water, with very few studies reported, and with the majority of these being pilot studies. However, there is no lack of evidence that being diagnosed with dementia frequently leaves the person with psychological and emotional trauma for which some form of counselling would be beneficial. There has not, up until the present, been any in-depth study which observes the emotional processes over a significant period of time following a diagnosis, nor has there been any recognition that existing models of counselling may not in themselves be appropriately or adequately developed, and this study will begin to address some of these issues.

## 2.6 Chapter Overview: Key Themes and Emerging Research Questions

In this chapter, I have set out to provide a broad overview of the different discourses of dementia that operate within our culture. I have also sought to provide an outline of a social constructionist understanding of dementia. Finally, research into the role of the doctor, the subjective experience of the person receiving a diagnosis, and the potential value of counselling, has been critically reviewed. This is a long chapter reflecting the multiple perspectives on dementia that the thesis aims to encompass. But are there common themes that run across these broad areas of literature? While the conclusions of each section have been highlighted at the appropriate juncture, what, if any, are the over-arching questions and research challenges that have emerged?

In my view, there are four main themes that arise again and again within the literature. First, the sense of self of the person with dementia plays a pivotal role in the process of coming to terms with a diagnosis. Second, at least in early dementia, the factors that make a difference to the sense of self are social and interpersonal, rather than biological. It is through relationships, interactions and conversations with doctors, spouses and others that a positive or negative sense of self is co-constructed and maintained. Third, there is a lack of integration of theory and empirical research – with a few notable exceptions, the majority of research studies provide a fragmented view, rather than contributing to an overall theoretical model. Finally, fourthly, the task of learning about these processes requires painstaking, in-depth, qualitative analysis. Over and over again in the literature, researchers and reviewers have commented that the complexity of what happens in the lives of people who have received a diagnosis of early dementia can only be properly understood by doing research that respects the voices and experience of all who are involved. In this respect, it is notable that even researchers into the role of doctors have called for qualitative approaches to be employed more extensively.

In the light of these conclusions, the study that forms the basis for this thesis has been designed to address the following questions:

1. How do doctors (GPs and Old Age Psychiatrists) construct the meaning of early dementia? What are the linguistic and cultural resources and practices that they utilise in making sense of this illness?

2. How do doctors (GPs and Old Age Psychiatrists) understand their role in relation to the management and approach of patients presenting with probable early dementia?

3. What is the patient's pathway into and through an early diagnosis of dementia?

4. How do people who have received a diagnosis of dementia integrate this knowledge into their lives and relationships? What are the issues that face people who have received a diagnosis, and what strategies do they use to address these issues?

These four questions provide the basis for the study. Methodological choices (explained in the following chapter) were made in accordance to how these questions could best be answered.

The overall aims of this study were to:

1. Reach a different understanding of the medical perspective and how the diagnosis of early dementia affects the medical profession both personally and professionally

2. Develop a better understanding of how people experiencing early dementia co-construct the meaning of how a diagnosis of early dementia affects different aspects of their lives, and to advance our knowledge of the process over time.

3. Consider the potential role of counselling as a means of enhancing the process of coming to terms with a diagnosis of early dementia.

The following chapter will focus on methodological issues and methods which were chosen to guide the exploration of these questions and fulfil the aims of the study.

# Chapter 3

# Methodology and Method: Issues and Choices

## 3.0 Introduction

The purpose of this chapter is to discuss the methodological issues that have arisen and the choices that have been made during the process of planning and conducting this study, and to clarify my rationale employed in making these choices.

In chapter two, a review of the literature that represented the theoretical and research context for the study was presented. This review highlighted the need for research to understand the experience of people being given a new diagnosis of early dementia, and specifically called for research that would:

- be grounded in the experience of people who had been given a new diagnosis
- examine those experiences in relation to their social contexts with particular attention to their relationships
- seek a renewed understanding of the medical perspective in this process
- include people with dementia in the research process

It is my intention that the choices made in this chapter reflect the spirit of these statements.

### *3.0.1 An overview of the chapter*

This chapter has two main sections. First, methodological issues and choices are discussed and made transparent. This section also addresses theoretical and ethical tensions and debates within the domain of health research. The second section deals with the methods and procedures adopted to undertake this study. This second section is also divided into two parts, and describes the methods utilised in each of the two studies that were carried out.

The aims of the study, as stated in Chapter 2, Section 2.11, are "to explore the meaning that early dementia has for the medical profession, and how it affects them personally and professionally," and to "reach a deeper understanding of how people living within a family context with a new diagnosis of early dementia integrate that diagnosis into their daily lives and learn to live with dementia." In order for these aims to be realised, many methodological choices had to be made and difficult issues negotiated. The following section seeks to illuminate these issues, and the choices that were made.

## 3.1 Key methodological issues underpinning the study

### *3.1.1 Introduction and overview*

The key methodological choice that was made was that the aims of this study would be best achieved by using a qualitative methodology. Further, in order to fulfil the aims of this study of coming to a better understanding of different groups of people, in subscribing to the notion that there is no single truth or reality, it was decided that the most appropriate theoretical framework to guide this study would be that of Social Constructionism.

Two empirical studies were undertaken, employing different methods. In the first study, which focused on the experiences of doctors, semi-structured interviews were chosen. In the second study, which focused on the experiences of people diagnosed with dementia, ethnographic participant observation, along with interviews, were felt to be the most suitable method. Analysis of each data set was informed by different methods, but was mainly based on a Grounded Theory approach (Auerbach and Silverstein, 2003; Strauss and Corbin, 1998).

The methodological principles on which this study was based included a collaborative inclusive approach, with participants and researcher having a reciprocal, mutual relationship based on trustworthiness and openness. The study also sought to give primacy to the voice of the person with dementia.

Behind these methodological choices and values lies a complex decision-making process, in which I engaged current debates within the field of health research. The following sections are intended to reflect the nature of these debates, and the positions that have been adopted in relation to them.

### *3.1.2 Methodological tensions and debates in contemporary health research*

The main research question to which I wanted answers was borne out of, and informed by a combination of reading the literature, participating in professional practice in the field of dementia care, and in the observation of practitioners from other disciplines also working in this area. It would be true to say that it was also informed by assumptions I made in light of this experience. ***I wanted to know how people who had been given a medical diagnosis of early dementia integrated this knowledge into their day-to-day lives.***

I had observed and experienced people with early dementia while in practice and was aware of many of the different facets which their world encompassed, and how the impact of a medical diagnosis such as 'early dementia' had affected them and those who shared their world. This perspective can be regarded as representing a 'relativist' stance, in which different individuals and groups are understood as constructing different 'realities' in relation to an aspect of social life. At the same time, there is no doubt that the medical model of construing dementia has dominated the worlds of both practice and research (Harding and Palfrey, 1997; Adams and Clarke, 1999). In taking cognisance of this dominant stance, rooted in the assumptions of positivistic, scientific thinking, and taking account of my own observations, it seemed important to carry out research that did justice to both relativist and positivist ways of developing knowledge. My goal has been to create ways of finding a means of understanding that embrace what Mason (2002) describes as the 'intellectual puzzle' of resolving the tension between relativism and realism/positivism.

Mason (2002) posits that any approach to studying the social world is determined by the world view or theory held by the inquirer with respect to 'what is the nature of reality' (ontological perspective), and "how we come to know that social reality" (epistemological perspective). The importance of having an ontology and epistemology consistent with a methodology that answers the question of how the researcher goes about finding out what they think can be known is also emphasised by Mason (2002). The importance of this factor has led me to examine the epistemological and ontological tenets of both positivist and relativist methodologies.

Positivist methodologies are characterised by the ontological assumptions that there is an ordered universe which comprises distinct and discernible events that can be quantified, measured and tested: "social reality is viewed as consisting of a complex of causal relations between events ... the causes of human behaviour are regarded as being external to the individual." (Blaikie 2000, p.102). A positivist perspective makes a supposition of a knowable world with an objective reality, holding truths, waiting to be discovered or uncovered by scientific methods, with 'taken for granted' assumptions not being questioned. It also implies no agency at all.

Within this kind of approach, epistemological assumptions conform to the belief that 'objective' data can be obtained through experimental techniques or observations. The findings can be presented as 'truth' claims where reality can be recorded and reported accurately, in a value free manner. Hypotheses can be tested and generalizability can be achieved by increasing the sample number in each experiment, and can be reported as 'facts'.

Bryman (1988), suggests that the positivistic researcher uses a language similar to that utilised in the field of science, with terminology such as experiments, variables, controls and trials, in order to construct a world view. Other descriptions applied to such research include hard science, fixed, logical, structured and mechanistic (Silverman 2000). These claims have been held up as a 'gold standard' and to some extent this method is still seen as the preferred mode of research today, especially within the world of medicine and healthcare. However, within the field of health research, in recent years there has been the beginnings of a critique as to the legitimacy of the claims of the positivistic, scientific paradigm that questions the epistemological position, with increased cognisance taken of the social constructionist viewpoint that 'reality' is co-constructed between the researcher and the researched (Murray 1999).

The move towards relativist research within the health care domain began much earlier and includes classic studies by people like Goffman (1961), focusing on life in asylums, and Glaser and Strauss (1965), highlighting the awareness of patients dying. Today, the relativist paradigm is much more extensively utilised and accepted within healthcare research although it continues to be the less favoured methodology.

On reviewing the ontological stance of the relativist paradigm I find that it assumes that reality is socially constructed by social actors (people), and is concerned with the understandings and meanings made of that reality

> "These meanings and interpretations both facilitate and structure social relationships...in contrast to physical reality, which has to be interpreted by scientists, social reality is pre-interpreted; it has already been interpreted before social scientists begin their task of interpretation" (Blaikie, 2000 p. 116).

The scientific perception that there is only one true and fixed reality then gives way to the notion that there is the possibility of multiple social realities which are shifting. Each social reality is unique and real to those who construct it and it is *their* truth that is important, rather than any claimed 'objective truth'. Indeed there are "many alternative or complimentary definitions or understandings of reality, reflecting the backgrounds and interests of those involved" (McLeod 2001, p. 7). The epistemological assumptions of a relativist paradigm accept that social scientific knowledge is socially constructed can only be valid for that particular time, place and persons, and is shaped by the cultural context in which it occurs. All knowledge is subjective, in the sense of being influenced by the interests and worldview of the researcher, and his or her values, beliefs and biases.

Despite the view of Clough and Nutbrown (2002) that the wheel would continue to be re-invented if we (students) have to elaborate our ontological and epistemological positions in every PhD study that is undertaken, these issues nevertheless need careful consideration before embarking on the selection of the paradigm that will most appropriately answer the research question. In the context of a study that aims to **explore** the subjective experience of people who had newly been given a diagnosis of early dementia, to **understand** the subjective views of their support needs, and to **understand, analyse and interpret** how GPs and Consultants in Old Age Psychiatry construe their role, it seemed that the most appropriate choice for me to make was to design the research project around the relativist position. According to Robinson (2002)

> "People, unlike the objects of the natural world, are conscious, purposive actors who have ideas about their world and attach meaning to what is going on around them. In particular, their behaviour depends crucially on these ideas and meanings. This central characteristic of humans has implications for doing research involving them. Their behaviour, what they actually do, has to be interpreted" (Robinson 2002, p. 24)

This flexibility of a relativist approach also allows for alterations in the design of the study, and changes in the people involved in it, as the researcher finds different ways, not always obvious at the outset, to answer the research questions.

These are my justifications for selecting a relativist stance, within the constructionist/interpretive tradition, for this study. These factors also highlight the reasons for my rejection of the positivist stance, which is that it would not allow me to gain a fresh understanding and new knowledge of the different experience of participants, but would only have allowed the voice of the researcher, rather than multiple voices, to be heard. A positivist stance would by definition omit motives, reasons and intentions.

#### *3.1.2.1 The role of qualitative methods in health research*

In the Health Service there are ever increasing demands for evidence based practice and the majority of research carried out within the Health Service is based on quantitative methods. However, there are many questions that cannot be answered by the quantitative methods which have traditionally dominated research into health care issues (Dowell, Huby and Smith 1995). Qualitative research has an important role to play in understanding the experiences of users of health services, and in descriptive studies, and has been accepted as having a place in the exploration of complex interventions undertaken within the Health Service (Medical Research Council 2000). Qualitative methods are seen as particularly valuable for accessing the subjective worlds of people who are users of the Health Service. Despite their value, qualitative methods have come in for much criticism by people used to working within a quantitative paradigm because of their apparent lack of rigour and small number of participants in comparison to quantitative studies (Dowell, Huby and Smith 1995).

Qualitative research within the field of psychology and health psychology is still at an early stage according to Murray and Chamberlain (1999). This type of inquiry has the potential to extend the "understanding of clients and improve clinical practice on the basis of evidence from patients and colleagues" (Holloway 2005, p. xvii). With the potential to influence clinical practice, qualitative research in health care settings can be seen as being not in direct competition with quantitative methods, but as taking a place on a continuum of methods, with different questions being answered by different methods.

### *3.1.3 Social Constructionism as an underpinning theory for this research*

This study seeks to understand the subjective experiences and social relationships of people with a new diagnosis of early dementia of the Alzheimer's type, in the six months following diagnosis. It also seeks to understand how medical practitioners understand their role in the diagnosis of early dementia in that subsequent period. In order for me to reach a clearer understanding of how each of the main stakeholders constructed their involvement in this process, it seemed to me that the best choice of theory to aid that understanding would be social constructionism. I will now elaborate on why that is the case.

For over a decade, researchers within the field of dementia have been utilising the theoretical approach of social constructionism to glean new understandings of how people experience dementia within a social context (a comprehensive review of social constructionist literature within this field has already been cited in the previous chapter in section 2.2). In deciding that a social constructionist approach was the most appropriate theoretical stance that could elucidate new meanings and understandings, the key assumptions and beliefs of that approach were considered in the decision making process. According to Burr (2003), there is no single definition of the theory of social construction, indeed there is no single theory that is social construction. The term, although based on many sociological assumptions, is actually rarely utilised by anyone other than psychologists. It is suggested by Burr (2003), that any piece of social constructionist inquiry encompasses at least one or more of the tenets posited by Gergen (1985) as central to the work of the social constructionist.

First, there is an assertion that a *critical stance* needs to be adopted towards 'taken for granted' ways of understanding the world, which includes our own understanding of ourselves and of the knowledge that we and others perceive to be 'truth' that we base on unbiased, objective observations, such as scientific positivism. Within this present study the adoption of a critical stance calls into question the dominant discourse of medicine and challenges the 'taken for granted' assumptions associated with this way of understanding the process that leads to the label of dementia. It also calls for me, the researcher, to question my own understanding of how I understand the process.

Second, there is a requirement for the social constructionist to acknowledge their way of *understanding is bound by both culture and history*; therefore it is dependent on particular social and economic factors prevalent within societal culture at that specific time. Cultures vary widely in their concept of dementia, but western culture highly values the cognitively intact and devalues the cognitively impaired (Helman 2000). Indeed, there are many cultures where dementia is regarded as much less of a threat to health and more of a normal part of ageing. Even within our own society, for example, the term "Alzheimer's disease" has taken on a different meaning to that which was originally ascribed in 1907. At that particular time and up until the late 1970s, the term was very specifically utilised to describe a younger person's experience, while the presence of a similar set of symptoms seen in older people was known as senile dementia.

In 1906, Dr Alois Alzheimer described a single case of 'early onset' dementia in a 55 year-old woman named Frau Auguste D— that Kraepelin published in 1907, naming it Alzheimer's disease. Between the First World War and the late 1970s there was little research into Alzheimer's disease (Cheston and Bender 1999), and it was suggested by an American neurologist named Robert Katzman in 1975 that the term 'senile dementia' should be dropped and subsumed by the name Alzheimer's disease. This resonates with the social constructionist view that social 'facts' are culturally and historically based.

The third assumption which Burr (2003) posits is that *knowledge is produced by the co-constructions of people interacting together* and is sustained by continuing social processes. Therefore, our truth is our current way of understanding the world. From this perspective, dementia can be understood as a phenomenon that is co-created between someone having difficulties with cognitive function, or perhaps their ability to perform tasks of daily living as well as they used to, and another person, perhaps a General Practitioner or Psychiatrist, offering diagnostic testing and interpretation of the results of these tests and giving an explanation to the person. As a result, the meaning of dementia for that person can be regarded as being co-constructed between these participants within those social processes.

The final assumption offered by Burr (2003) is that *knowledge and social action are inextricably linked.* There are endless forms of co-constructions of our understandings of the world. However, each of these different constructions can also have a great many social actions associated with it. For example, if someone has been diagnosed by the medical profession as having a particular type of dementia they may be offered pharmacological treatment or offered psychological support. By contrast, however, in other societies 'demented old women' can be perceived as being witches and put to death (Helman 2000). Constructions of the world, therefore, espouse some forms of social action and reject others.

The man credited with introducing social constuctionism to a much wider field of psychology was Kenneth Gergen in 1985 (Liebrucks 2001). Although Burr (2003) credits Gergen with an earlier influential paper in 1973, the origins of the theory in fact stretch back much further than the 1980s. Social constructionism has no single intellectual root, but is based on numerous theories influenced by both sociological and psychological perspectives, including philosophers such as Kant, who held the view that human thought (and human action) was more responsible for the construction of knowledge than the previously held belief that there was an external reality waiting to be discovered.

Early psychologists of the twentieth century developed this theme with the major contribution coming from the Symbolic Interactionist school which was founded by Mead (1934), who was a member of the 'Chicago School' of sociologists, which believed that social action was the starting point from which the mind, self and society were examined, and how as people, through social interactions, we construct our own identities and each others (Burr 2003). The publication by Berger and Luckmann (1966) of *The Social Construction of Reality* marked a key moment in the development of social constructionist ideas. This book was probably one of the most important texts in the development of social constructionism, and set the scene for the later writings of Gergen (1994, 1999, 2001).

The main question that a social constructionist perspective poses in any cultural/social practice according to McLeod (2004), is "how do people act together?" (p. 351). In acting together, people jointly construct, and make meaning from, these actions and interactions. He posits that this main question leads to many other questions opening up different aspects of how action can be accomplished. McLeod (2004) identifies a range of questions based on the use of power, language, and cultural resources, which become salient when working within this philosophical stance.

The core values of social constructionism have been summed up in the following terms

> "Social Constructionism rests on the ontological assumption that reality or what can be known is constructed by persons as they interact within a social context ...Social Constructionism epistemologically assumes that reality exists within the conversation between the knower and the known. The relationship between knower and known is characterised by interdependence, reciprocity and mutuality" (Jankowski, Clark and Ivey 2000, p. 242)

The values of interdependence, reciprocity and mutuality expressed in this passage resonate with those to which I aspire in relationships, and this was an important factor in my choice of theoretical stance. In addition, it seemed to me that social constructionism would provide a conceptual framework within which it would be possible to engage in a process of inquiry that would honour the different understandings of dementia held by different stakeholders.

### *3.1.4 The practitioner as researcher: the importance of researcher reflexivity*

Having made the decision to employ social constructionism as an overarching conceptual framework, it was at this juncture that the first methodological issue was encountered. If I chose to employ a relativist paradigm, and subscribed to the notion that reality was socially constructed, how could I reconcile that with the scientific world-view that had such on influence on my professional practice? Working as a community psychiatric nurse within a specialist dementia team, much of the formative teaching that I had received was from a positivistic, scientific viewpoint, with a strong emphasis on the disease process.

A significant influence on working practice came from medical colleagues with whom a close working relationship (and at times, reliance) had been formed, in which they assumed ultimate responsibility for directing patient care. To question that scientific view of a physical disease process would be to negate much of how I had operated as a practitioner in the past and also to refute the knowledge claims of my medical colleagues. I felt that to do this would be disrespectful, and could be perceived as a betrayal by my colleagues. Nevertheless, I felt that the need to challenge my 'taken for granted' assumptions was indeed a necessity.

My own understanding of dementia had to be deconstructed before I could take a 'not knowing' stance in order to address concerns of validity, minimise the power differential between participant and researcher, and address hierarchical issues that arose throughout the research process (Jankowski, Clark and Ivey 2000). By asking these questions reflexively, reading more extensively and discussing these issues with supervisors and peers, I was able to manage the tensions within myself, and to continue to be able to respect the way that fellow professionals construct their 'truth', whilst acknowledging that it was only one 'truth'.

To address such issues within a social constructionist perspective on inquiry requires attention to the question of researcher reflexivity. Within social and health research, reflexivity has many meanings (Burr 2003). It has been argued that reflexivity underscores the significance of personal involvement as a central aspect of all qualitative research (McLeod 2001). Social constructionism acknowledges the researcher as a central figure who is involved in the active construction of the many steps of the research process (Findlay and Gough 2003).

Reflexivity is one of the processes by which researchers can engage in an examination and exploration of the meanings which situations and relationships have for them, and attempt to identify the cultural and historical context in which such meanings are generated. The main meaning of reflexivity, according to Brewar (2000), is that the researcher is part of the culture, context and research setting and the experience and identity of the researcher will constantly influence the 'findings' produced in any research endeavour (Hammersley and Atkinson 1995), while the idea that researchers can be neutral observers unaffected by their social world and their own social processes is challenged.

Whilst for some ethnographers, reflexivity is seen as a problem, for others it is an opportunity or solution (Brewer 2000, Findlay and Gough 2003), and can be viewed as part of the principles of good research practice. For the purpose of this thesis I will adopt a reflexive stance that will attempt to embrace the three key principles of reflexivity as offered by McLeod (2001), which sees reflexivity as implying an

> "awareness of the moral dimension of research...invites consideration of the processes through which text is co-constructed...opens up the necessity for new approaches to writing and communicating research findings" (p.196).

By engaging in this way, the intention is to portray a transparency within the research process. Reflexive commentary will be peppered throughout this thesis with an acknowledgement that this is only one construction of the events of this study, and should the same study have been done by someone else, the impact of that researcher on the process would be different from my experience and understanding.

#### *3.1.4.1 Reflexivity in practice: many hats but only one head*

One of the issues that has occurred has been the difficulty in separating the different identities of self for me in the research context and having to resist the temptation of acting as if I am the dementia care practitioner or family counsellor. An excerpt from my field notes of the first person with whom I was working reads thus: 'When I was with them, the difficulty that I had not being a therapist was incredible. I was unsure at times of my role and wanted to be the therapist without a doubt, so much so that I am not just exactly sure where the research questions were, and because of their pain I wanted very much be the family counsellor. It was very difficult'. This was the first encounter of such difficulty, which came very early on in the research process and being able to name it and write about it in my field notes enabled me to deal with this dilemma in a much more constructive way. Acknowledging these dilemmas and bringing them into a conscious awareness has helped to reduce the likelihood of this happening, or more realistically, has lessened the feelings of surprise when it did occur. Consequently, role conflict has been lessened by continually clarifying the purpose, and duration of my presence with the people participating in the study, and making clear boundary distinctions around what constitutes research and practice.

There have been times throughout this process when people with dementia and their families have been emotionally upset, asking for advice or information, especially around issues that I would normally have addressed as a practitioner. These issues needed to be dealt with in a professional manner and also needed to be credible with the participants, and the management of a tension between practitioner and researcher was again prominent. This was managed using as guiding principles a combination of the ethical code, a common humanity, and a knowledge of who was available locally to deal with their situations without participants feeling that they were being "dumped in the dementia wilderness", a phrase coined by one of the GPs in Study 1.

## 3.2 Implementing a Social Constructionist programme of inquiry – constituent methods

The aim of this section is to introduce the specific methods that were adopted in the context of carrying out this study. As described above, the study comprised two main aspects, reflecting the involvement of different stakeholders in the diagnostic phase of the illness. In Study 1, the views of medical practitioners were examined, while Study 2 focused on the experiences of those diagnosed with dementia. Contrasting methods were employed in these studies – ethnography using participant observation and interviews (Study 2), and a grounded theory approach based on interview data (Study 1). The rationale for employing these methods is provided in the following sub-sections.

### *3.2.1 Using ethnographic methods*

In keeping with a social constructionist stance, which embraces multiple knowledges and realities within a cultural and societal context, it was felt that the most appropriate approach to ensure that different voices would be heard and different knowledges co-constructed would be ethnographic. Ethnography is utilised as a means of understanding the social worlds of both groups and individuals through prolonged commitment of the researcher to being part of those social worlds. Hammersley and Atkinson (1995) posit that "ethnographers portray people as constructing the social world" (p11) through their own interpretations of that social world and through their actions based on their interpretations and, therefore different people create different social worlds. "Ethnographic approaches encompass such a range of perspectives and activities that the idea of adhering to *an* ethnographic position, as though there were only one, is faintly ridiculous." (Mason 2002, p.55).

Ethnography has its origins in social anthropology, and traditional ethnography embraces the study of a culture, specific group or tribe of people, concentrating mainly on primitive cultures and of the way they live every aspect of their lives (Cresswell 1998). Brewer (2000), suggests that there are two kinds of ethnography which he describes as big and little, describing big as being qualitative research as a whole, and little as fieldwork, where data is gathered over a lengthy period, sometimes lasting many years

> "Ethnography is the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally" (Brewer 2000, p.10).

Social researchers of the Chicago school, during the 1920s and 1930s, encouraged the development of the ethnographic method and in particular participant observation as a mode of study, moving from the 'primitive tribal cultures' to studying different cultural groups in the USA (Brewer 2000, May 2001). Since then, there has been an increasing use and development of ethnographic styles and different adaptations are now frequently used in health related research. Boyle (1994) posits that whichever way the ethnography is presented, it offers both an insight and understanding of a group of people that otherwise would not be gained. She puts forward the claim that there is now a shift in the focus on contemporary ethnography, with different commonalities being considered in comparison to the traditional.

Within the field of health research, ethnography is seen as yielding rich 'local knowledge' which is acknowledged as being of significant use in the development of health care services (Muecke 1994). However, traditional ethnography is viewed as an extremely lengthy method that is not compatible with limited research budgets and short term project initiatives. Ethnographically based pragmatic methods have consequently been developed to address the timescale issue, which have become known by several names: rapid ethnographic appraisal, mini-ethnography, or focused ethnography (Boyle 1994). Through utilising a focused ethnography, the researcher comes to understand the meanings of the participants within a cultural context and this method has been widely used to understand the illness experiences of select patient populations (Morse 1987). Focused, or mini-ethnography, is the style of ethnography which seems to be most appropriate for the purposes of the present research study. The core characteristics of focused ethnographies comprise

> "Time limited exploratory studies within a fairly discrete community organization. They gather data primarily through selected episodes of participant observation, combined with unstructured and partially structured interviews. The number of key informants is limited; they are usually persons with a store of knowledge and experience relative to the problem or phenomenon of the study, rather than persons with whom the ethnographer has developed a close, trusting relationship over time" (Muecke 1994, p. 199)

The characteristics described by Muecke (1994) reflect the key features of the present study (i.e. time limited, discrete community, data gathering by selected episodes of participant observation and unstructured interviews with a limited number of relevant key informants), arising from the aims of the study and the limited resources that were available. However, I would argue that 'mini-ethnography' does not imply research that is necessarily superficial: over a six month period it is entirely possible and highly probable that a close, trusting relationship could be developed between researcher and researched.

#### *3.2.1.1 Participant Observation*

Hammersley and Atkinson (1995) put forward the view that they see all social researchers as participant observers and interpret the term 'ethnography' as suggesting a set of methods characteristically involving

> "The ethnographer participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact, collecting whatever data are available to throw light on the issues that are the focus of the research" (p.1)

They acknowledge that their interpretation is broad, with unclear boundaries, but it is a definition that is consistent with their perception that participant observation is in some ways the most basic form of social research.

The section of the study that employed participant observation skills was time spent with people with an early diagnosis of dementia, and their families. The rationale for adopting this approach was to gain understanding and make meaning of what it felt like having to return home, to a familiar social setting, and build a new reality in the light of information gained in having had an early diagnosis of dementia. Rather than rely on interview only, it seemed much more logical and compassionate to spend time with the people who were research participants, to try to understand the changes that were happening in their lives in a contemporaneous fashion. While interviews (audio-recorded with participants' consent) were also used, I would argue that spending time with someone who has early dementia was necessary in order to form a trusting relationship. Once that relationship was formed, it gave a much better opportunity to witness the multiple realities of this field (Brewer 2000), and gave access to deeper knowledge of the situation than would ever have been possible in a one-off interview.

The study utilised what was described by Brewer (2000) as an 'observer-as-participant' stance, which involved the researcher in limited participation, with their role being seen mainly as the researcher. In this study the researcher/participant role was played out in the person's home, helping the participants prepare meals, being part of their normal every day conversations while 'hanging out' with them, and through being part of social outings to restaurants and cafés, or by accompanying them to clinics.

The first part of a participant observation type of study is usually spent learning the basics of the situation, such as the language of the culture. In this study, a specific geographical and cultural context was shared by all participants (they were all situated within a 25 mile radius of each other). In one sense I am fortunate to have belonged to that culture for many years and to possess privileged 'insider' knowledge, which has enabled me to understand much of the language. Conversely, I come to the situation shackled with many pre-existing notions, assumptions, ideas, feelings, knowledge and skills of an experienced practitioner in the field, and from this perspective it has been difficult to become the 'professional stranger' (Agar 1980), or indeed to 'make the familiar strange' (Clough and Nutbrown 2002).

#### *3.2.1.1.1 The insider/outsider perspective – or confused researcher?*

One of the central areas of my reflexive struggle during the research was around the question of whether I was operating from an 'insider' or 'outsider' perspective. In many ways I am both and neither at the same time. Would I have to have dementia myself to be classed as an insider? Or am I seen as an insider because of my previous knowledge and experience? Am I an insider in Study 1, being a professional among fellow health professionals or as a nurse practitioner would I be seen as an outsider among the medical profession who made up the sample? These are some of the many different constructions that could be applied to me within this research project. I see myself as having a privileged position in both camps.

Within Study 1 I had to be a bit of an insider to gain access to interview the medical profession and for them to enable me to have access to the participants in Study 2. With the participants in Study 2 I was able to utilise my previous knowledge and skills to set up a trusting relationship which enabled me to engage people in a meaningful way and empower them to disclose their innermost thoughts and feelings, and there were comments from some of the participants that by the end of the study they viewed me as part of the family – they had become so used to me being around. But, from both perspectives, I was taking an outsider view of what was their social reality. Insider and outsider, or *emic* and *etic* perspectives are common terminology in ethnography.

*Emic* relates to the insider's view and is situated at the heart of good ethnographic research (Boyle 1994, Fetterman 1998). The *emic* view of reality is imperative to the understanding and description of the insider's perceptions. This perspective requires that multiple realities are acclaimed, acknowledged and accepted, and in the case of this study, the realities of people who have an early diagnosis of dementia and their social networks which included their family, friends, pastor, Community Nurses, and Consultants in Old Age Psychiatry will all present with different realities in Study 2.

In order to understand these and make meaning from them, a researcher has to look at these realities through an *etic* perspective. The *etic* perspective represents the external reality of the social science researcher. The majority of ethnographers see these perspectives along a continuum of different levels of analysis or styles. Typically, data are collected initially from the *emic* perspective and sense is made of it using the insiders and the analyst's views: "good ethnography requires both emic and etic perspectives" (Fetterman 1998).

#### *3.2.1.2 Using interviews*

Research interviews can be seen as data that are gathered in a specific research conversation occurring at a particular time and place (Wengraf 2001). Based upon the conversations of daily life, the research interview is a professional conversation (Kvale

1996). There are various forms of this conversation and Burgess (1984) defines the qualitative research interview as "a conversation with a purpose" (p. 102).

The interview style adopted for this study was a semi-structured interview with the purpose of listening to people as they describe their understanding of the worlds in which they work and live, to explore the insider perspective, and capture their experiences, thoughts, perceptions and feelings (Rubin and Rubin 1995, Taylor 2005). This method is congruent with the qualitative design of the study, and its ontological position of human beings co-constructing meaning together and the epistemological stance as the source of knowledge located within the individual experience of the participants. This provides the means for exploration and clarification of the complexities of the topic, and their flexibility allowed the emergent information to evolve

The key tasks of interviewing have been well documented by McLeod (1999), whose text was extremely useful in the preparation for undertaking interviews. Although the interviewer can be seen as controlling the interview process (Silverman 1997), the interview method itself is seen not as a tool for obtaining objective, factual, information but rather as a method utilised for the generation of socially constructed knowledge (McEvoy 2002).

The ethnographic approach to interviewing is of a less formal nature than that of other types of qualitative interview. While researchers will have a loose structure to their interview questions, there is no specific order in which they will be asked, questions can be designed as prompts in order to open up an area of discussion. Fetterman (1998), refers to the 'grand tour question' which is intended to gain a broad insight into the participants' social world. This question would typically ask in this study, "how would you describe the changes in your life since receiving the diagnosis of dementia?" This is a broad sweep question and reflects the nature of what the research is attempting to understand. This interview is much more of a shared conversation within ethnography as opposed to a set of structured or semi-structured questions.

A feminist influence on the interview technique has also been adopted. Oakley (1981), describes the typical interview of the qualitative paradigm as a one way process which sees the interviewer glean information from the informant, but gives nothing in return. The product of this method is the creation of the researcher's meaning as opposed to a co-creation of shared meaning which is desirable in this study. The relationship between interviewee and interviewer was much more of a collaborative venture. For this collaborative relationship to develop, Arksey and Knight (1999) believe that there are a set of strategies which are useful, some of which have been utilised in this study. These include high levels of trust being built, close and continual attention to ethical issues, a reciprocal relationship, self disclosure and personal involvement and request for feedback from the data analysis when possible. Whilst a participant observation method of data collection with people with dementia and their families was employed in addition to interviews, the only method chosen for the professionals in the study was interview. This was, first, to fulfil the criterion of 'people with a store of knowledge' that is relevant to the area being studied, and would set in context the professionals' social reality. Second, it was for pragmatic reasons of time management and issues of access, although an opportunity of including three Consultants in Old Age Psychiatry in the participant observer segment of the study did arise when I accompanied some of the participants to the clinic.

Interviews in both studies were recorded by the use of an audio-tape machine. In Study 1 the complete interviews with the doctors were recorded. These interviews lasted from 35-90 minutes. In Study 2 only selected segments of our conversations were recorded and tended to be around a 90 minute discussion when we would sit and discuss the changes that dementia had brought, whilst field notes recorded other interactions. These recordings were transcribed by an experienced transcriber before being entered into the NVivo data management system.

### *3.2.2 A grounded theory approach– the basis for a multi-faceted analytic toolbox*

This study has been strongly influenced by the notion of a grounded theory approach of data analysis although it makes no claims to be purely a grounded theory study. Rather, I have viewed this theory, based on the writings of Strauss and Corbin (1998), as an important foundation for my qualitative research toolbox. Grounded theory was co-constructed by Barney Glaser and Anslem Strauss in the late 1960s and has been developed and described by authors such as Charmaz (1990), and more recently Auerbach and Silverstein (2003), who give a clear account of 'doing grounded theory' with the assistance of the NVivo software programme. Described by McLeod (2001) as the current 'market leader' in qualitative research, he attributes its popularity to the clear set of guidelines and expanding number of publications perceived as exemplars.

Central to the beliefs of Strauss and Corbin (1998) is that theory is fundamentally constructed from the data, which have been systematically amassed and analysed by way of the research process. Method, collection of data analysis, and emerging theory are inextricably linked. They advocate that evaluation is embraced in both art and science. The art lies in the creativity of the researcher to recognise and label categories appropriately, have the ability to contrast and compare, question the data, and distil, then extract from it, without losing the essence, and somehow make sense and meaning from the mountain of raw data that is relevant to the study. The science is seen in the ability to be rigorous in the task and of being able to create the theory from collected data, a theory which is arrived at by systematic process of analysis that identifies and connects categories arising from the data. A more detailed account of the data analysis follows in the Methods section of this chapter at 3.3.3.5 and 3.3.4.7.

### *3.2.3 Researching sensitive topics and vulnerable informants*

Including people with dementia in the study, even today, is still fairly novel within the realms of the research world, and the debate surrounding the ethical dilemmas in this process, especially around the area of informed consent, have been ongoing for some years now (Agarwal, et al. 1996). More recently the debate has been around the inclusion and involvement in the research process (Bartlett and Martin 2002, Wilkinson 2002).

People who have been given a diagnosis of dementia have been the subject of research for many years, mainly within a medically oriented, scientific, positivistic paradigm, and almost always as passive subjects rather than collaborative partners. In other words, research was something done to them, rather than with them. A gradual change has been witnessed in recent years where people with dementia have been encouraged and empowered to become both active participants in research in the social sciences (Robinson, 2002b, McKillop, 2002), and in contributing to research journals (Friedell 2002, Bryden 2002, McKillop 2002, Sterin 2002). Two earlier writers have become more well known as authors of their own stories (McGowin 1993, Davis 1989), by giving detailed narrative accounts of their journey through dementia. This has given the public the opportunity to share extremely valuable insights into the subjective experience of dementia. However, much work remains to be done in order to gain a greater understanding of this experience.

People with dementia need to be afforded the opportunity of being part of the research process and given options as well as opportunities of being included actively rather than continue as passive subjects throughout the trajectory of their dementia. Elaine Robinson (2002), in reporting her thoughts on being someone with a diagnosis of dementia, who was involved in research, has this very important message for us (the research community)

> "Who else knows what it's like to have the disease? No doctor, no matter how eminent, could ever truly appreciate how we perceive the horrors … unless he or she suffers from it too … What a hugely missed opportunity it would be if people with Alzheimer's were excluded from the very thing that could be used to gain a fuller understanding of their disease" (p.104).

This message, written so clearly, was indeed received and taken on board. If I wanted to understand the initial experience of someone being given an early diagnosis of dementia and how they incorporated that diagnosis into their day to day lives over a subsequent six month period, then who else should I ask but someone who is experiencing this situation. Whilst I acknowledge and respect the crucial role of family, friends and supporters, their experience of living with someone with dementia is perhaps a very different experience, and they can only report their own socially constructed subjective experience and observations. Their views of what it is like to experience dementia from the diagnosed person's point of view, however well motivated, are given by proxy. They used to be the accepted focus of most of the research efforts up until the mid-1990s.

This is now viewed as inadequate and there has been a call, not only for people with dementia to be included in research, but to become collaborators in the research endeavour (Sabat 2003, Wilkinson 2002). The voice of the person with dementia needs to resonate throughout the research process, and not only in the findings. When voice is mentioned in this research it is in an attempt to give primacy to "people whose stories are not often documented, publicised, listened to and afforded significance" (Goodley (2004) and while the stories of the participants is articulated through me, it is the voices of the participants that need to be heard.

If we are to truly subscribe to the idea of people with dementia as research collaborators, we need to seriously consider this from the design and planning stage of any project. By engaging people with dementia as active collaborators in research we

> "can come to understand more deeply the reasons behind certain reactions, certain behaviours …The discourse, the narrative, which is encouraged and revealed in such a relationship provides information that cannot be captured by rating scales or questions to which the answer is 'yes' or 'no', for we want to

> know not just 'that' someone feels one or another way, but 'why' as well" (Sabat 2003).

Many benefits can be experienced by the person with dementia who becomes a collaborator in research: feelings of enhancing self-worth, by co-constructing a valued social identity; feelings of contributing to the body of knowledge; and the realization of being able to influence future services for people with dementia. By encouraging this form of research partnership, we are not only enhancing the opportunity of co-constructing valued social identities as collaborators in research, but we are ensuring that they will have some impact on the future of services for people with dementia. (Sabat 2003, Whitlach 2001).

### *3.2.4 Systematic case study research*

The case study method can encompass both qualitative and quantitative data within its sphere of operation (Yin 2003). While, according to Yin (2003), ethnographic research does not always produce case studies, Brewer (2000) argues that all ethnographic research does involve the production of case studies. Hammersley (1992) proposes a more narrow definition for case study than has been traditional and sees it basically as a 'case selection' strategy of which he recounts three definitions Along with the case study, these are the survey and experiment forms of case selection. According to Hammersley (1992), in contrast to the survey the case study involves greater detail, depth and accuracy and is less likely to afford credible generalisations to the wider population with findings largely unrepresentative. This does not mean that there are no bases in case studies for generalisation, and evidence need not always be seen as statistical.

If we think of the case of Alzheimer's disease, the claim for this nosological entity was made from a single case which was published by Kraeplin (see page 28 of literature review). Since that single case, a growing body of evidence has been reported of the disease entity built on that first reported single case in 1907. Similar contentions can be made about the experiment with less convincing conclusions being reached by case study about the existence of causal relationships, and although it can be argued that it is less likely in case study it has nevertheless been reported that there is the likelihood that this can be observed. Stake (1995) contends that the real business of case study research is not 'generalisation' but 'particularisation' and the case selected is emphasised by its uniqueness, that each case is different; however, primacy must be given to the understanding of the case itself rather than the contention of how similar or different it is from others.

However, for the purposes of this research study the main utilisation of the case study method is in the management and presentation of data and will be employed to assist in the understanding of each 'case' which comprises the person with the diagnosis of dementia and the part of their social network that they wished to make known to the researcher and invited to be part of their research experience.

### *3.2.5 Quality in qualitative research – achieving credibility and practical utility*

Striving for quality and credibility within the qualitative paradigm are important issues, indeed Kvale (1996) refers to the concepts of generalizability, reliability and validity as having reached the status of a scientific 'holy trinity'. There has been a long debate over which terms should be utilised in qualitative research that would reflect the researchers' acknowledgement of the requirement for quality without compromising their underpinning philosophical stance that reflects the "image of the person as a reflexive agent, an image of the researcher as involved" (McLeod 2001, p. 190) Different terminology has been suggested and the most common terms in qualitative research are those of trustworthiness and authenticity (Lincoln and Guba 1985).

Whatever the choice of term, the authors of research reports are called to "show the truth-value of their research in the write up" (Holloway 2005, p. 276). The truth value is demonstrated in this thesis by a variety of procedures including member checking, peer debriefing, keeping a reflexive journal and making decisions made on procedures open and trustworthy in their reporting within this chapter, and later in the descriptive accounts of the findings in chapters 4, 5, and 6. An influence in all of the quality seeking procedures was the general model for good practice for research design described by Stiles (1993).

According to Lincoln and Guba (1985) member checking (or respondent validation) is the most important of all of these, and which consists of participants reading, discussing and passing comment on the findings of the study.

The procedures used for member checking and ordering of data analysis are described below in section 3.3.3.4. Methods of peer debriefing were also utilised and described in this section.

### *3.2.6 Summary of key methodological principles and values*

The key methodological principles adopted and employed within this study have their origins in different schools. The influence of the feminist movement is reflected in my commitment to collaboration where the researcher and the researched work together to develop a co-constructed account of the meaning of the data. Whilst I do not claim to be a feminist, I subscribe to their beliefs that a researcher should aim to create relationships with participants that are characterised by mutuality, reciprocity and equality. These are not merely feminist characteristics but are also embraced by the social constructionist perspective.

Another principle that informs the work reported in this thesis is the primacy of voice of the participants – this is reflected in their many quotes reported in Chapters 4, 5, and 6. According to Coffey (1999), we never truly represent others since it is the author who is choosing and editing the quotes presented. While acknowledging Coffey's (1999) position, my approach has been to follow Holloway's (2005) contention that to adequately represent a participant's social world, the "writer has to be committed to them and not see them as inanimate objects that are either passive or can be manipulated, but as active members of that world who are involved in the construction and re-construction of knowledge" (p. 282). Another of the guiding principles is that of *inclusion* of people with dementia at all stages of the research endeavour and that is reflected throughout this thesis.

Finally, my commitment to transparency and ownership of decisions made can be traced to the reflexive stance which has been adopted, both in the writing of this thesis and more apparently in my field notes and journal, and gives a demonstration of how I was involved in the research project rather than being merely a neutral observer. The methods utilised in this thesis will now be explained in more detail.

## 3.3 Method

This study uses an overall ethnographic, inclusive, constructionist methodology to explore how an early diagnosis of dementia affects the lives both of those diagnosed and those who diagnose (members of the medical profession). The earlier sections of this chapter clarified the methodological choices that were made in relation to the design of this study. The following sections describe the practical implementation of the study, and deals with issues of data collection and analysis, procedures, and ethical issues. First it will focus on Study 1 (the 'doctors' study') which utilised interviews and grounded theory analysis, before moving to Study 2 (people who had received an early diagnosis of dementia), which employed a more intensive, participative, ethnographic approach. As mentioned earlier, the reasons for the research project being carried out in two distinct studies were essentially pragmatic ones. Although the two studies are reported separately, it cannot be stressed strongly enough that they were both component parts of the one larger study. For the purpose of this chapter I deal with the methods of each study separately.

### *3.3.1 Introduction*

In this section I present an overview of the whole research design and then report separately on the methods of the two studies within this research project. Study 1 will give details of the sample, procedures, ethical considerations and data analysis, including a section on the use of the NVivo qualitative software package. Study 2 will then be introduced utilising a similar format but with the added section on how the inclusive approach to this part of the study evolved.

### *3.3.2 Overview of the research design*

This research project involved undertaking two separate studies. These studies, although separate, were interconnected in several ways. First the connection was that each of the three key groups of people who were involved in the diagnostic process, namely the Consultants, the GPs and the people with the diagnosis, were all included in the overall study. Second, three of the Consultants from Study 1 also participated in Study 2, by dint of referring people into the study, and then being part of the observational data of Study 2 as I, the researcher, accompanied all of the participants to the Consultants' clinics. None of the GPs who took part in Study 1 were involved in Study 2. Third, comparisons were made of the findings, where appropriate.

| DESIGN | STUDY 1 | STUDY 2 |
|---|---|---|
| Methodology | Qualitative – Interview | Qualitative—Ethnography |
| Method of Data Collection | In Depth Audio Recorded Interviews | Participant Observation<br>In depth Audio Recorded Interviews<br>Field Notes |
| Sample | 7 Consultants in Old Age Psychiatry and 12 Principals in General Practice | 5 People with a new diagnosis of dementia living within a family context |
| Method Data Analysis | Mixed methods mainly informed by a Grounded theory approach utilising constant comparison to elicit emergent themes | Mixed methods mainly informed by a Grounded theory approach utilising constant comparison to elicit emergent themes |
| Tools Used in Data Storage/Analysis | NVivo Computer Software Package | NVivo Computer Software Package |

**Table 4 A summary of methodology and methods from Study 1 and Study 2**

### 3.3.3 Study 1: Doctors' experiences of involvement in early diagnosis of dementia

The focus of this study is members of the two groups of doctors who are most frequently involved in the diagnosis and treatment of early dementia, namely GPs and the Consultants in Old Age Psychiatry. The main aim was to gain an insight into how medical practitioners engaged with early diagnosis of dementia and to construct a grounded theory model which would go some way to understanding how they make meaning of this area of their professional work.

#### *3.3.3.1 Sample*

The sample for Study 1 consisted of the entire population of Old Age Psychiatrists, seven in total, employed by the Health Board in the study area. This was the sole inclusion criterion. There were five males and two females with length of employment as a Consultant ranging from two years to 18 years, all of whom worked full time in Old Age Psychiatry, six of whom were Scottish and one originated from Spain. They were aged from 36-48 years. Each Consultant was randomly allocated a code number between one and seven for reporting purposes. To respect anonymity there has been no table made of their characteristics as it would make them easily identifiable.

The inclusion criteria for General Practitioners (GPs) were that they had to be a principal in General Practice for at least five years and to be practicing within the same Area Health Board as the Old Age Psychiatrists. This sample consisted of twelve GPs (six males and six females). Their time in practice ranged from six years to 31 years. Their countries of origin were as follows: seven from Scotland, three from England, one from Northern Ireland and one from Germany.

| Participants | Gender | Age | Number of years in practice | Urban | Rural | Relative with dementia |
|---|---|---|---|---|---|---|
| 1 | M | 40 | 8 | X | | YES |
| 2 | M | 45 | 17 | X | | NO |
| 3 | F | 42 | 15 | | X | NO |
| 4 | F | 51 | 23 | X | | YES |
| 5 | M | 53 | 24 | | X | NO |
| 6 | M | 58 | 31 | | X | YES |
| 7 | M | 42 | 13 | X | | YES |
| 8 | F | 57 | 23 | | X | YES |
| 9 | M | 36 | 6 | | X | NO |
| 10 | F | 49 | 14 | | X | NO |
| 11 | F | 35 | 6 | X | | YES |
| 12 | F | 48 | 15 | X | | NO |

**Table 5 A summary of GP participants in Study 1**

Whilst the entire sample of Consultants was chosen because of their location and profession, they also represented a wide range of practice experience both in years and in geographic spread, with both urban and rural areas being represented. GPs were chosen using the Grounded Theory principal of theoretical sampling (Strauss and Corbin, 1998), choosing interesting informants on the basis of an emerging analysis, and who were recommended by colleagues as being people with relevant knowledge and experience. Following 17 interviews it was decided that there were no new categories or themes emerging following the interview of the tenth GP participant. However, two more were interviewed in order to be sure that saturation had definitely been reached. The group of GPs recruited to the study reflected a good mix of age and experience (See Table 3.2).

### *3.3.3.2 Procedures*

Two pilot interviews were carried out. The first interview was with a GP with whom I had worked who was aware of the research project and understood the process. This GP was happy to be involved in testing the interview schedule and was prepared to give feedback. The second interview was carried out with a GP whom I did not know to allow me to experience interviewing 'a stranger'. Both of these GPs had been sent an information leaflet (see appendix D) prior to our meeting. Interviews took place in the GPs' surgeries. The procedure was explained, confidentiality was assured and the consent form signed by participants prior to the commencement of the interview. Following the first interview some adjustment to the questions were required, and again following the second interview. During the second interview the GP was asked to read a passage referring to people with dementia as 'heartsink' patients and to make comment about this piece, as a means of eliciting attitudes. This was done because it was often reported as being the views of some GPs; it did not work and it felt like I was testing the participant's reading ability. This was not really commented on and so was removed from the schedule as it did not add anything to it. The schedule was then used for the other ten GP interviews and minor adjustments were made to it prior to starting the Consultant interviews. The interview schedule used with both GP and Consultant participants can be found in Appendix G. My approach in interviews was to use these questions as a starting point for further exploration, and to encourage participants as much as possible to tell their own 'story' in relation to their involvement with patients diagnosed with early dementia. Interviews lasted 30-90 minutes, were recorded on an audio-tape and were then transcribed by an experienced transcriber.

#### *3.3.3.3 Ethical issues and consent*

Ethical approval was received from both the Local Research Ethics Committee (LREC) of the Health Board and the School of Health and Social Sciences, University of Abertay Dundee Ethics Committee. Submission of information about the study being issued to the participating doctors and patients and their families had to conform to the standards of LREC.

#### *3.3.3.4 Data analysis*

Management of the data for this study was facilitated by the use of the NVivo Qualitative Data Analysis programme (Richards, 2005). Recordings of interviews were transcribed by a senior medical secretary who had experience in transcribing research interviews and who was also bound by the same code of confidentiality as the researcher. Prior to the audio tapes being handed over for transcription, I listened to them to start formulating some ideas and to get a sense of what was being said within the story of each of the doctors. Following transcriptions, I listened again, going over the tapes slowly and following the text on the transcribed documents to immerse myself in the data. The data was then entered into the NVivo programme. Although the computer programme assists in the management of the data it does not do the analysis which has still to be done in a very similar way that Grounded Theory analysis (Strauss and Corbin 1998) was done prior to the use of computer programmes. Documents were colour coded to make it clear whether the document was pertaining to a General Practitioner or a Consultant in Old Age Psychiatry. Memos and comments were added to the transcripts throughout the process of analysis using the 'data bites' feature. The transcriptions were then coded using the 'free nodes' allowing for themes to emerge from the data and a separate document was created to record thoughts. Repeating ideas were grouped together utilising the 'tree nodes' facility with themes then being organised into coherent categories. A process of constant comparison between the transcripts was incorporated into this process. Theory was developed from the grouping of themes into main categories. The above procedure was truly an iterative process moving back and forth between the raw data, the theory developing from the themes and ideas that were forming.

Member checking was carried out in both studies. However, due to the time constraints on the participants and the author, it was decided that one GP and one Consultant should read and comment on Chapter 4, which was the findings of Study 1. Verbal feedback was given from both. The GP was amazed at the detail in the study and found some of the concepts difficult to grasp while the Consultant discussed some changes required regarding some of the terminology used and also expressed surprise at some of the findings especially the notion of GPs wishing to give the diagnosis to the patients. In Study 2, on the fourth visit to each case study participant, I shared the analysis that had been completed and the early formation of categories and concepts and discussion ensued and changes made accordingly although general consensus was achieved. One participant wanted to read and have his own copy of the thesis and this will be delivered in due course, although he has read and commented on chapters 4, 5 and 6 to date.

Something which I valued greatly was peer debriefing. This technique can be described as the use of an informed colleague as a sounding board for the researcher to verbalise ideas and concerns, to share emerging findings and test out possible concepts. I was fortunate to have a colleague who was working with people diagnosed with early dementia. We discussed regularly the new ideas and concepts emerging from the data and she was able to test them out either by observation or intervention. This was both validating and affirming. Other fellow students and both supervisors also acted in this capacity. My supervisors also audited selected segments of my analysis, by generating their own categorisation of passages of transcript material, which was then discussed together to identify and resolve areas of divergence. These were among the strategies employed in this study in the quest for quality and validity.

The analysis and writing up of Study 1 was complex and sensitive. Not only did I know many of the participants but in my naivety I had assumed that there would be a clear set of protocols that each practitioner would adhere to and use the same criteria for diagnosis, treatment and referral to other services. This was not the case, and the moral uncertainties and ethical dilemmas that I then faced in this task were numerous and often onerous. This burden of anxiety about the consequences this thesis would have on the profession when published should not be underestimated, and for a lengthy period of time throughout the analysis I frequently became stuck. In order to represent the medical practitioners in a meaningful and honest way I had to return again to a social constructionist perspective, which emphasises that this kind of inquiry is not about making truth claims but instead aims to elucidate the co-construction of knowledge that is "provisional and contestable and...historically/culturally specific." (Burr 2003). My anxiety then stemmed from what I can now see as the tension between the realist and relativist stance, projecting the scientists' (medical practitioners') need for validity and reliability onto my text and the questions that this would engender and my ability to justify my chosen methodology and methods. This tension continued throughout the process of Study 1.

#### *3.3.3.4.1 The NVivo qualitative analysis software programme*

This computer software programme has many different functions. I received an introductory one day course and found that very useful. I was then able to attend a further two day training course which built on the previous course to allow me to learn more about the functions of the programme which were pertinent to my study. I used it primarily as a data management tool which also assisted in the process of analysis. Data storage and retrieval was efficient with colour coding facility, and also it had the ability to search whole sets of documents for specific data. It can automatically record the location of the text, the file reference and other information noted about the text. It is essentially a very efficient filing system. The process of data analysis is made much more manageable with selected text being assigned codes, and categories. It also has the facility to record memos and other comments and thoughts about the data. It can allow ready access to all previously assigned data. It allows codes to be amalgamated with other codes, to form categories and higher order categories. It also has the function of testing out concepts and reorganising them in different ways. I also used it to store my field notes and journal, and it kept documents neatly together in one study. What this programme cannot do is break the data down into bits or indeed put these bits together again, only the researcher can do that. Whilst it is a superbly helpful tool it does have its limitations and can only be as efficient as its operator. During analysis, my main use of it was to break down the data and assign it to codes and categories and I tended to resort to a paper flipchart when I was grouping categories together and creating concepts. It is a very efficient tool and can be used in different ways. For me, an amalgamation of computer and paper and pen were essential components of the data analysis.

## 3.3.4 Study 2: An ethnographic study of the experiences of people who have received a diagnosis of early dementia

This study concentrated on the lived experience of the person with a new diagnosis of dementia, within a family context, over the subsequent six months. The advantages of an ethnographic approach have been reported in Chapter 3, section 2.1. Adopting an ethnographic approach allowed me to have much more time with participants, therefore becoming part of their everyday experience, rather than being a distanced observer. The aim of this study was to find new ways of understanding the emotional, relational and psychological process that enfolds at, and following, a diagnosis of early dementia.

### *3.3.4.1 Overview*

In this section of the thesis, the methods employed and developed in Study 2 will be reported. This includes the study sample and how that sample was chosen, a summary of the data collection within each of the cases, along with the procedures employed, ethical issues and consent, the evolving of an inclusive approach and analysis of the data.

#### *3.3.4.2 Sample*

This group of people selected for invitation into the study were people who have been given an early diagnosis of dementia and who were living within a family context. The criteria for inclusion in the study were that participants:

- had been given a diagnosis of early dementia by a Consultant in Old Age Psychiatry no more than six weeks prior to the first meeting with the researcher;
- had been informed of their diagnosis;
- had sufficient cognitive capacity and memory to contribute verbally to a conversation and be able to discuss issues of daily living;
- should have an absence of other mental disorders;
- agreed to be included in the study and were capable of giving informed consent;
- were living within a family context and had a close (spouse, parent, sibling, child, nephew or niece) family relationship with the person with whom they were living.

It was decided in negotiation with my supervisors that there should be five case study participants and their family/social networks in the study. Any fewer seemed at the time of decision not to be sufficient to gain a rich variety of different types of the experiences of patients. In retrospect, however, given the time and resources available for the study, two or three cases would probably have been the ideal number from the point of view of data collection and management.

All participants were invited to participate in the study by the Consultant who diagnosed them.

The participants were:

**James**, a 68 year old man, was the first person referred into the study by Consultant 2. James had been married for 45 years, with three children, now all adults and living geographically distant from their parents. James and his wife had five grandchildren. James had run his own successful pharmacy business until retiral at 60 years of age. He had many hobbies and interests and was a devout Christian. He lives in a village near the major county town.

**Beth,** a 74 year old woman, was referred into the study by Consultant 2. Beth had been married for 54 years, with two adult children both within travelling distance of one hour, and four grandchildren. She was a school secretary until she retired at 60 years of age. She also has many hobbies and interests. She lives with her husband in a quiet residential area of a major city.

**Ian,** a 79 year old man, was referred into the study by Consultant 1. Ian had been married for 51 years, with two adult children who were both within travelling distance of one hour, and had four grandchildren. Ian was a GP until he retired 18 years earlier. He had few hobbies that he was able to participate in because of his poor physical health. He had moved to a rural village on retiral.

**Maggie,** a 69 year old woman, was referred into the study by Consultant 2. She had been widowed four years earlier. She had three adult children, one of whom lived with her, and the other two within a short distance. She had seven grandchildren. Prior to her retiral at age 65 years she was a chef in a local hotel. She had few hobbies. She lived in a small rural town.

**Jenny,** a 77 year old woman, was referred to the study by Consultant 3. She had been married to her husband twice. They had divorced once, but they had never lost touch over the years and remarried two years ago. They had three adult children, two within travelling distance and one in South Africa. She was a secretary to a university Professor prior to her retiral at 65 years of age. She had few hobbies that she was able to engage in, because of physical disability. She lives in a small hamlet within two miles of the nearest city.

All of the participants had been diagnosed with early Alzheimer's disease, each was prescribed one of the cholinesterase inhibitor drugs, and all were in contact with the research project within 15 days of their diagnosis.

#### *3.3.4.2.1 The issue of recruitment*

The recruitment of participants into Study 2 relied on Consultants in Old Age Psychiatry introducing the topic of research to their patients. Although the inclusion criteria had been discussed with all of the consultants, it was their choice as to who was invited into the study while the researcher and the people with dementia had little or no control over this. A delay in participant entry to this study had more to do with long waiting times for scan results with knock on effects of delaying diagnosis which also then meant a delay in referral to the research project. Although the criteria for entry included all types of early dementia, it was five people with Alzheimer's disease who were referred to the study.

It is not only practitioners who can act as gatekeepers or filters (Manthorpe 2001) for dementia research, but families who may feel very protective to someone whom they see as vulnerable, and responsible for, and whilst this may be frustrating for the researcher, it is indeed an understandable stance for them to take. In all there were six people referred into the study. Following agreement with the consultant to participate, and having discussed it at length with me by telephone and having read the information literature available, one family member decided that he did not want to be involved despite the fact that his wife (who had been given the diagnosis) did. The desire for people with dementia to be autonomous in making the decision of whether to enter a research project or not is desirable, but it should also be acknowledged that gatekeepers do have a valid protective role to play (Pratt 2002).

#### *3.3.4.3 Procedures*

Once the Consultants had referred the people into the study, I contacted them by telephone to arrange a suitable meeting time. I answered any immediate questions they had and following that telephone conversation sent them an information leaflet about the study. I also informed them that should they want to withdraw from the study after reading the information that their current or future treatment would not be affected. I then contacted them the day before I was due to visit to check they were still happy to be in the study.

At the first meeting I introduced myself as the researcher, spoke about the aims of the study, answered questions that they raised and also discussed consent to be in the study. It was at this point that they were invited to sign the consent form and although they only had to sign that once, I continued on each subsequent visit to check that they were still happy to be in the study and recorded their agreement on tape when we started to audio-record the interviews. The length of the project was also discussed and the participants were all in agreement to being part of the research for a six month period.

In chapter 5 Section 1.1, I explain in detail how James (the first participant to enter the study) became a collaborator in the research design. He and I worked out during our time together how the data should be collected.

Both recorded and unrecorded data were collected at each meeting. Recorded interviews followed a conversation around the experience of receiving the diagnosis and the subsequent feelings, thoughts, beliefs and changes which occurred that participants had observed and experienced. I was trying to capture 'their diagnosis story'. My period of observation and unrecorded interview were also trying to capture a different dimension of their story, about how they interacted with their spouse/supporter and how other relationships were affected. The opportunity I was given to observe participants in different social settings allowed me to observe how they interacted with people other than family and also how they interacted in a different environment.

As soon as my time with the participants was over I drove my car into the next street and recorded my observations, thoughts and feelings into a Dictaphone so that I would capture as much as I could while it was still fresh in my memory. I then transcribed this into my field notes on returning home. I did not make notes while I was with participants. I delivered the audio-taped interviews to the senior medical secretary and she transcribed them very efficiently. I then read them as I listened to them on the tape to make sure that the transcriptions were a true record and it also allowed me another opportunity to familiarise myself with the data.

In Chapter 5 at Section 1.1 it can be seen that James suggested that I interview people with whom he had close relationships and to whom he had told his diagnosis. He had asked them if they would mind being interviewed by me, then contacted me to tell me they had agreed and gave me their details. I then contacted them by telephone and arranged a suitable meeting time. I also sent them an information leaflet and went through a similar routine to gain informed consent. They were only interviewed once. This was the routine utilised for all other contacts.

In order to demonstrate an openness and transparency within the research project and to adhere to the social constructionist principles to which I subscribed, it was agreed between the participants and I that I would take my laptop. This was to share with them where and how I stored the data gathered and to discuss with them early category formations within the data analysis. Most participants agreed with the early analysis, and were intrigued as to the part played by the computer. James told me that I had missed the great part love had played in his life, which I then added. Jenny felt relieved that although everyone was different, there were similar themes running throughout the five participants' stories. At this point I also showed them the relationship maps that I had drawn primarily to have a visual representation of their lives, relationships, and important interests and hobbies. This again was something for correction, and I had missed a really important relationship in Ian's life, that of his sister, whose husband also had Alzheimer's disease. That was a catalyst for him to discuss his worst fears of ending up like his brother-in-law. These visual representations viewed by the participants enriched the data and the validity of the study. It also aided in the co-construction of knowledge as we discussed together the analysis.

Further validation was pursued towards the end of the study when James read Chapters 5 and 6 and commented on them. James was able to recall clearly that he had chosen the pseudonym James in the project because that had been the name of his father. He recognised this when he read the chapters. I also discussed my new theory formation with him because it was primarily based on his encounter with his pastor. He remembered clearly the exchange he had with him and how meaningful that had been. He agreed with the sequence of events and the theory created but asked me to make sure that I did not underestimate the courage it took for him to tell his pastor that he had Alzheimer's disease (this is reported in Chapter 7 Section 2.6).

There have been calls to continue developing inclusive methods in dementia oriented research for some time now (Sabat 2003, Wilkinson 2002) in order for the voice of the person with dementia to be heard. As a practitioner of many years experience of working with people with dementia and as a trained counsellor, I was able to exploit the skills I had developed. These skills included forming meaningful relationships, interviewing skills, observational skills, communication skills and being able to put people at their ease, being used to being with people who were experiencing emotional turmoil – and the knowledge gleaned about dementia both from literature and subjective experience was invaluable in developing this method. Building up a rapport with each person in the study was a very important part of the data collection and this happened at a different pace for each individual and their spouses/families. This was something that I was familiar with in my previous work and recognised the importance of a trusting relationship (Brewer 2000) in order for people to feel comfortable enough to confide their deepest fears and anxieties about their diagnosis. This was done by taking each session I spent with families gently, and respecting the timing of the information that they wanted to give and being able to recognise when they did not want to give answers to some of the more intrusive questions just at that time. Once the relationship was well established people were very open and due to the emotive subject the research questions at times evoked strong emotional responses. I made sure that I checked with them about answering such questions and reassured them that it was perfectly fine not to answer anything that they did not want to. I also checked whether they were still happy for me to collect the data and record it at each meeting and this process of consent (Dewing 2002) continued until the end of our contact time together.

### *3.3.4.4 Summary of data collected within each case*

As can be seen from table 3.6 below each of the contacts was different and unique to each participant and although they followed a similar pattern everyone responded in different ways to requests for access to others within their network. Some relationships developed more deeply than others with some of the participants more reserved than others about giving information. It is still uncommon for people with dementia to be invited into a research study and elsewhere in this thesis I have highlighted some of the issues around inclusion and how this project developed to be inclusive not only of people with dementia as active participants who were in control of their input into the project but also how the methods for gathering data were developed in collaboration with them.

| NAME | HOURS of CONTACT | VENUE | INTERVIEWS RECORDED | SOCIAL NETWORK INTERVIEWS | ATTENDED CLINIC |
|---|---|---|---|---|---|
| James | 39 | Participant's home, cafes, clinic, restaurants | 6 with participant and wife | Minister<br>Friends | Twice |
| Beth | 33 | Participant's home, cafes, clinic, restaurants | 6 with participant and husband | Son and daughter-in-law<br>Daughter and grand-daughter | Twice |
| Ian | 30 | Participant's home, GP's surgery, clinic, restaurant | 6 with participant and wife | Community Psychiatric Nurse<br>Daughter<br>Grand-daughter | Once |
| Maggie | 17 | Participant's home, clinic, restaurant | 4 with participant and 2 with daughter | Community Psychiatric Nurse | Once |
| Jenny | 31 | Participant's home, clinic, restaurant | 6 with participant and husband | Daughter<br>Community Psychiatric Nurse | Once |

**Table 6 A Summary of contact details with participants in Study 2**

### *3.3.4.5 Ethical issues and consent*

The issues around cognitive capacity address whether a person with a diagnosis of dementia has continued ability and responsibility for making their own decisions always have to be considered. One of these issues is focused on informed consent. Within this study informed consent was gained by explaining the purposes of the research, providing participants with information about the study and giving an opportunity to ask questions and highlight any anxieties that were present. Although a consent form was signed by each person being interviewed at the beginning of their involvement in the study, on each occasion that time was spent in the presence of the participants, further verbal permission was sought for recording both written and audio-taped data, as an indication of the researcher's commitment to ethical practice.

Within dementia research, there remain some contentious issues around taken for granted assumptions concerning ethical issues. In a discussion about data collection, Clarke and Keady (2002) state the importance of the duration and pace of interview in order to avoid tiredness and anxiety. They continue to assert that "For people with dementia, it is reasonable to assume that an interview would be of shorter duration than for someone who is not cognitively disabled" (p. 37). I would argue that the people in this study, while dictating the pace, were never observed to become tired, although some did become emotional with the content of the discussion rather than with the anxiety of being part of the research process and because of the ethnographic nature of this study the participants were extremely tolerant of this researcher both interviewing them and spending time 'hanging out' with them for long periods of time.

It is difficult at the outset of any research project to anticipate whether there will be benefit to the individual participants although Berghmans and Ter Meulen (1995) argue that in dementia care research there is seldom of direct benefit to the individual. However, Sabat (2003) contends that there are many prospective benefits to participants such as the maintenance and enhancement of self-worth, especially if the person is informed by the researcher as to the valuable contribution that they can make to society by becoming a research collaborator and by showing them they still have much to give. Situated within this tension was the idea that James and I shared about finding out what it had been like for the people involved in this research project and a report of this can be found in Chapter 7 Section 4.1.

Due to the clear inclusion criteria set out in this project, the individuals recruited to this study had minimal cognitive impairment, with the result that cognitive capacity and ability to participate, while important, was less of an issue than they would have been if this study was concentrating on people with more severe levels of cognitive impairment. This study nevertheless did adhere to following general ethical principles (Bartlett, 2002).

#### *3.3.4.7 Data Analysis*

The process of analysis begins whenever the person is referred to the study, from the first verbal interaction during the introductory telephone conversation until the final compilation of the thesis (Stake 1995). This process has a story to tell (Becker 2000). It is not just about coding transcripts, but writing impressions in field notes and reflections in a journal. All of these actions have an element of analysis incorporated. Data analysis of the case study individuals was both different and similar to the data analysis already reported on in Study 1. In Study 2 there was much more data to manage and analyse. Although I adhered to the principles of grounded theory, it was decided that initially I would present a narrative summary for each case study which was checked against the transcripts by both supervisors. Analysis was mainly influenced by what people said and searching for and discerning the codable moment (Boyatzis 1998).

The first case study (which lasted for 6 months) was analysed fully prior to the second case being recruited to the study. From the findings of the first case it was clear there were certain themes, for instance telling friends and family their diagnosis, which needed to be explored more fully in subsequent cases. This pattern of analysing cases and then exploring themes and issues from one to the next, followed with the subsequent case study individuals who became part of this project. The cases were analysed separately and compared case by case. They were also compared across all cases. This analysis, while being richly informed by the grounded theory method of analysis, was more driven by emergent themes from the data, and it was a continuing iterative process, back and forth between transcriptions, notes and listening again to tape recordings to revisit the actual spoken word. Initially, I had thought of presenting each case as a separate analysis within the thesis, but this was unworkable because of the constraints of space. I had also thought about utilising the themes emerging from study 1 to inform the analysis of Study 2. However, most of the themes from Study 1 were not relevant to Study 2 with the exception of ‘the telling’ theme which was salient to both. This left me to re-engage with the ethnographic data utilising the grounded theory approach and allowing categories to emerge from the data. This took quite some time although slowly, analytical concepts and new understandings were evident as the analysis of the data was reconstituted. This reworking of the old into something new, as well as an account of the evolving of collaborative methods used in Study 2, is presented in Chapters 5 and 6.

# Chapter 4

# The Doctors' Stories

## 4.0 An Overview

This chapter reports the findings of Study 1, which tells the story of the experience of 19 members of the medical profession as they reflect on their thoughts, feelings, attitudes and actions around the topic of the early diagnosis of dementia and what it means to them both personally and professionally. Doctors have rarely had, or taken the opportunity in a research context to discuss the issues that arise for them in this field.

The results of the analysis of this study highlight six main themes: how doctors come to understand early dementia; their perception of themselves as part of a fragmented healthcare system; how they evaluate [this area of work diagnosing early dementia] as being difficult and complex; their views of patients' needs; their experiences of 'telling' patients the diagnosis. It also addresses many other issues that surrounded this area of doctors' work.

It was never the intention of this study to separate the analysis of the data into two distinctive sets of Consultant and General Practitioner (GP) experiences. The aim instead was to try to understand what early dementia meant to them as doctors because, as one Consultant was quick to point out, being Consultants had never stopped them from being doctors. Despite this, there were times throughout each 'story' that they did separate into generalists and specialists although this did not happen all of the time – and there were times when some GPs had more in common with some Consultants than with fellow GPs. Therefore, it stands as 'The Doctors' Stories'.

## 4.1 Understandings of early dementia

The understandings that the medical profession had of early dementia was influenced and informed by many different spheres, including knowledge gained by both personal and professional experience. These understandings were dominated by scientific knowledge and by a reductionist approach to the diagnosis of early dementia. They also incorporated the historical perspective and changes in practice, observed changes over time with people that practitioners had known prior to their diagnosis, and also through years of experience as clinicians.

The ways in which an understanding was reached were also informed by personal experience and by clinicians putting themselves in the place of the patient. And although there were many elements common to many of the clinicians interviewed, each had an individual interpretation of what early dementia meant.

### *4.1.1 The meaning of early dementia*

The meaning of early dementia for doctors in this study was characterised by the lack of uniformity in a definition or consensus that was borne out by comments such as, "when people are talking about it [*early dementia*] people are meaning quite different things in their heads." (Consultant 6: 32). Or, "that means different things to different people." (Consultant 7: 23). There was also a temporal element to this understanding of how long changes had been present prior to a diagnosis being sought, with the added imperative to diagnose as early as possible in the illness since "the advent of treatments for dementia." (Consultant 1: 20).

Within the group of GPs there was uncertainty and discomfort and that was based on the premise that they only saw two or three people per year with early dementia and there was a consequent anxiety about whether the signs would be recognisable. "I have to say it is an area where I do feel uncomfortable because I am not sure that I would spot somebody with early dementia." (GP4: 13). Another found the concept "quite confusing, and I wouldn't say at the moment that we are particularly well geared up for looking for early diagnosis of dementia and that is possibly to our detriment. The question [*about the meaning of early dementia*] is really quite hard." (GP7: 19).

Although some practitioners found it difficult to articulate the meaning of early dementia, the dominant themes that they did discuss fell into four broad areas: biological changes in the brain; intellectual and cognitive decline; behavioural changes; and changes in functional ability. They made very few references to the patient's subjective experience. It was interesting to note that there was no singular definitive meaning assigned to the phenomenon of early dementia that was shared by all the participants, or even shared by the groups who made up the sample.

### *4.1.2 The need for scientific evidence*

That there is a need for scientific evidence is not in contention here and it would be injudicious to dispute its value within the context of this thesis. The part it played in a diagnosis of dementia is one of immense importance to the medical profession, to the patient and their supporters. Great significance was also placed on different tests such as blood tests and various forms of neuro-radiological scans, and these were highlighted in the conversation with Consultant 3 who told how explaining to the patient what investigations would be requested was essential

> "further investigation is required and that some physical investigations such as blood test is necessary and that a scan of the brain is necessary to look at the blood supply and the memory areas of the brain, and conclude that interview by telling them that we really need the evidence from the scan. In other words a note of the blood supply, a note of the memory area of the brain and intellectual tests, and history, to give us a reasonable certainty about the diagnosis" (Consultant 3: 27)

For some clinicians it increased their degree of confidence in the diagnostic process and outcome while for others it was a means of excluding other diagnostic possibilities such as tumours. Science does not always provide clear evidence or answer the clinician's questions. This was the case with Consultant 5 who found that "if a CT scan comes back with a report along the lines of cerebral atrophy, no evidence of vascular, no space occupying lesions I am then presented with a dilemma as to what to do next." (Consultant 5: 71).

The range of tools used to measure different levels of change or deficit listed in this study as being of value include: blood tests; cognitive tests such as Mini-Mental State Examination; more extensive testing by Neurophysiologists; and neuro-imaging scans and consultation with the Neuro-radiologist.

All of the above increased the level of understanding through scientific knowledge, and helped clinicians reach a definitive diagnosis.

### *4.1.3 A diagnosis of exclusion*

Whilst the scientific testing could sometimes leave the diagnostician with a lack of clarity, the importance of being able to come to a differential diagnosis was very important. However, this diagnosis was normally one of exclusion as highlighted by

GP1, "if I suspect that it might be dementia that's afoot, I would still check out thoroughly in terms of history and examination, and also investigation to determine the diagnosis looking for other physical problems that might be afoot, only establishing the diagnosis of dementia after we have excluded all else." (GP1: 12). The signs and symptoms of dementia frequently mimic those of several other illnesses and conditions and it was therefore important to have the facility to differentiate and GP6 pointed out it could "sometimes be a difficult picture to differentiate, for example, a depressive illness from a dementing process because sometimes the features will be very similar when they are presented." (GP6: 87).

It was not only scientific testing that assisted the doctor in coming to the definitive diagnosis. Along with the tests and specialist knowledge, clinicians relied on their own experience of practice and powers of observation as well as listening to the history given by the patient and/or their supporter. Another reason for requiring as clear a diagnosis as possible was the implications of different drug treatments for different types of dementia. Alzheimer's disease now has three specific anti-cholinestarase drugs while some other dementias may react badly to certain types of drugs. For example, people with Lewy Body dementia have an adverse reaction to some anti-psychotic medications. It was therefore very important to have as accurate a diagnosis as possible which was not always straightforward as one GP commented, "I am not sure I would have the skills to say right I think this is this type of dementia versus this type of dementia." (GP4: 346).

The diagnosis of an early dementia was frequently requested from Consultants in Old Age Psychiatry because they were seen to be more practiced and skilled. This was borne out by the feelings of GP11, who commented, "it's not my area of expertise, it's too new, it's changing all the time. I just feel it's something that's more appropriate for psychiatrists to keep up with and to be able to assess." (GP11: 150). However, even with all of the scientific tests, knowledge and experience of the practitioner and experience of the patient, it is still a diagnosis that can only be confirmed at post mortem. The problem of coming to a diagnosis was reflected in the words of GP2: "I think that the sorts of problems in people who have dementia much of what we do is the question of diagnosis. I mean there is no specific diagnostic test for dementia so we don't have a strong protocol to follow for that" (GP2: 75).

Diagnosing dementia was seen as a complex and difficult area of work and, without doubt, one of the major challenges faced by the medical profession.

### *4.1.4 Change in knowledge and practice*

Practice has changed greatly over the years with more recent emphasis on earlier diagnosis and pharmacological treatment of Alzheimer's disease. Society is now much more informed about dementia through campaigns to raise awareness by voluntary organisations like Alzheimer Scotland Action on Dementia and the Alzheimer's Society, which organise and publicise a Dementia Awareness Week every year which is extensively covered in the media. This raises both awareness and heightens expectations.

The opportunities for gaining knowledge within the public domain have also increased as people have more and more access to sources of information such as the internet, and because dementia is being increasingly portrayed in television programmes. It is much more acceptable now to discuss dementia and some practitioners likened it to the cancer movement campaigns around twenty years ago to raise awareness of the condition and make the use of the word more acceptable. Society is now much more open and willing to address contentious issues. Whereas families used to be expected to "look after the person until they could not stand it any more then the institution took them in," (Consultant 3: 15), people were now perceived as being much less likely to wait until they hit crisis point and, "the number of folk being referred earlier by all routes has increased." (Consultant 4: 147).

Another explanation why people were being referred earlier was that they were now taking more responsibility for their own health, with a greater degree of partnership and collaboration with their GP. "I think more and more people are being involved in their care and their own problems and I think they have a right to." (GP6: 145). And there is much more sense of ownership and autonomy in the discussion and decision making processes as highlighted by GP1. "We are doing this in a partnership and working together, and all I am doing is guiding them [*the patients*] and letting them know what's available." (GP1: 28).

Within the medical profession attitudes and practice had also changed over time and patients were being viewed as being much less dependant and more proactive. GPs were referring people much earlier than before for diagnosis and treatment and "sometimes GPs' letters can be quite helpful actually. I do think they are improving." (Consultant 6: 53). And while it has taken years for such practice to change, the business of late referrals prompting admission had fallen. Gone are the days about which Consultant 6 recalls, "I only got referrals when people thought they really needed whisked to the asylum. You know, please see and take away." (Consultant 6: 61). The emphasis now was much more on assessing and treating in the community.

This shift in practice had been due in part to changes in practice and current knowledge, but it was also being driven by policy that started in the early nineteen-nineties when Community Care became a reality, and subsequent government policy (see introduction Chapter 1 Section 2 for detail) also became a driver for change. Awareness of change in practice was also gleaned through personal experience and one Consultant recalled conversations with their parent about the care of their grandmother who explained, "my mother was just about cracking up trying to look after her, but in those days a nice man came from the hospital and wrote out a bit of paper and your problem disappeared." (Consultant 2: 236). Changes in practice seemed to have been influenced and recognised by society, policy, new developments in treatment, increased and updated knowledge, and personal experience.

It is to the personal experience that we now turn.

### *4.1.5 Increased understanding through personal experience*

Nine out of the nineteen doctors interviewed had close relatives who had received a diagnosis of dementia but none of them were living with the person with dementia at the time of the interview. Having this personal experience had a fairly dramatic effect on the understanding they had of how dementia affected the lives of the family carers and evoked empathic responses from some of the doctors who have had this experience. Such experiential knowledge "adds a different dimension. I'm not saying that you are any worse a health professional if you don't have that personal experience, but it does add something … it was an enlightening experience." (Consultant 5: 306). It also had the added value of helping professionals learn more about dementia from personal situations and to aid their ability to use that experience in encounters with patients. One Consultant expressed the view that there are times in clinical situations when "it is no longer my clinical experience but what I have learned through my parent being ill," (Consultant 7: 277), that informs practice.

The experience of being interviewed prompted one GP to verbalise, for the first time, the fears and anxieties about a parent who was suspected of displaying the first signs of early dementia: "I've probably got a relative that might be developing dementia at the moment, my Mum, her memory is just not quite as good as it used to be and I find it unbelievably sad." (GP4: 464).

Therefore, as stated by one of the Consultants, having a relative with dementia did undoubtedly bring a different dimension to the clinician's perspective, but that understanding was not available to all, and for those who have had that experience it does influence practice. However, even without personal familial experience, clinicians were able to access empathic ways of understanding and responding to patients by 'thinking themselves' into the place of the patient.

### *4.1.6 Putting themselves in the patient's place*

A different way of understanding was experienced through some of the doctors having the ability to think of what it would be like for them if they were the patient. This ability also influenced practice and raised opposing views of methods of breaking bad news. One was that they would want to know, and the other was not so sure, as illustrated by two of the Consultants in the study. "I would be upset, but I wouldn't not want to know about it because I wouldn't be able to do anything about it if I didn't know." (Consultant 1: 78). And the opposing view

> "if somebody was going to tell me today that I was going to develop an illness and that I was going to die in ten years and it would not be a particularly pleasant way to die, I am not sure that I would particularly want to know." (Consultant 3: 95).

An empathic understanding is perhaps more akin to one of the GPs in the study who demonstrates reflective practice in a more robust way, "I really try to think often, if I suffered from this condition, what would it be like for me and make sure that I am treating the patient in that way, so it is not just another patient...so I offer the patients the best." (GP1: 121).

In putting her/himself in the place of the patient one GP thought of what the reaction to having dementia would be and upon doing so immediately thought of what the treatment options would be, and commented, "I would be depressed so you would have to treat it and I think you have to treat each of these things as it comes up." (GP5: 180).

The influence of a personal encounter with dementia, whether it is through a relative or through the thought processes of clinicians thinking themselves into what it would be like for them to have dementia, undoubtedly had an impact on the way they treated patients who came to their surgery or clinic, allied with the scientific knowledge mentioned before. Another addition to the modes of understanding was the way that people perceived dementia and carried fantasies or stereotypical pictures in their mind.

### *4.1.7. Stereotypical images and fantasies*

The stereotypical images that doctors had to deal with mostly came from their perception of the patients' construction, usually taken from a worst case scenario and many doctors had to spend time exploring these fantasies and refuting the negative images that were conjured up in association with the words dementia and Alzheimer's disease. There always seemed to be a need to be "fighting against a very negative image of dementia," (Consultant 6: 307), while trying to balance that with being honest and open, although at times "you get the feeling that you are not being entirely truthful as to what may lie ahead." (Consultant 3: 95). And so there seemed to be a tension around the need for truth and the need to give hope. Some of the negativity was blamed on society that felt it was "not very socially acceptable to say that you are demented." (GP12: 67). Doctors realised that there were many misunderstandings and prejudices out in the general community, and others blamed the negativity on the distortions of the media. Some of these negative images were also part of the doctors' constructions, some of which could be offered to the patient in an attempt to quell their anxieties, as Consultant 1 explained

> "when I say Alzheimer's disease I usually say to people now normally when people think of Alzheimer's disease they think of older people usually women who need lots of help and assistance with this, that and the next thing and have lots of memory problems, but that's not the case with you" (Consultant 1: 56)

Images of people "rapidly losing their marbles" (GP2: 39), or, "just simply shells of incontinence" (GP5: 59), or, "creating a monster using one word" (Consultant 3: 107), were some of the more negative pictures painted in association with the word dementia. Some of these images like the following from GP8 had their origins within the family system

> "we have all seen the old people with no memory and we have said to our families, don't ever let that happen to me. My own mother wanted me to promise I would put her down, although I didn't have to, but people absolutely hate the idea of being like that" (GP8: 219)

This illustrated yet another source of how an understanding of dementia could be constructed despite the professional knowledge and understanding gleaned through training and practice.

## 4.2 Working within a fragmented system

Clinicians saw themselves as a part of a very wide ranging and fragmented health care system and were sometimes unsure of how they fitted into the world of early dementia. Within the region of the study the range of services provided by the health care system was also fragmented and inconsistent, sometimes from practitioner to practitioner as well as from area to area, with different emphases placed on the different pathways trod by people with early dementia. Among these anomalies was the lack of consistency of how referrals were made into specialist services from primary care services. Each of the different areas had its own particular ways of dealing with the process of early dementia, and each area within the region had a different emphasis on early detection of dementia as well as variations of who were the groups of workers involved. There was at times a lack of clarity and an ambiguity as to the role and function of some of the professionals and together they added to the fragmentation of the service offered and were seen to impede the progress of the patient's journey. In the absence of local protocols for early dementia, much of how the service functioned relied on the doctors' relationships with, and access to, fellow professionals. This was compounded by the understanding or misunderstanding of the role of the professional and the vagaries of the referral systems.

### *4.2.1 Roles, relationships, responsibilities and referrals*

The roles, responsibilities and referrals did appear at times to depend on the relationship that different professionals had with each other. Again, there was no uniformity amongst the doctors as to how it would be decided who should be referred to whom, when this should happen, and how exactly each perceived their role in relation to each other and to the patient. The diagnosis, referral, treatment and subsequent interventions over the first six months following diagnosis seemed to be the individual choice of doctors, whether Consultant or GP, according to how they saw their role in conjunction with the patient and how it corresponded with the roles and availability of their colleagues.

Once more the fragmentation of the system was made evident by the different spread of services throughout the regions and the professionals and other agencies that were available to take referrals for people with a new diagnosis of dementia. This fragmentation reflected the lack of local protocols and care pathways.

#### *4.2.1.1 Roles*

The perceptions of individuals of their own role and of others varied widely. One Consultant saw that they "play a very small part in it because I actually am responsible for clarifying the best diagnosis at the time," and seeing their role as "a relatively minor part in the management of the whole illness." (Consultant 1: 38). And although this may be a minor role, the Consultants frequently see themselves as being the gatekeepers of scarce resources and the gateway to the wider team, although some GPs similarly see themselves as gatekeepers, and this can depend on whether the Community Mental Health Team accepts referrals from Primary as well as Secondary care.

Consultants saw their role mainly as providing assessment and diagnosis together with an interest in the longer term management of the patient, although this was usually seen to be more appropriate for other members of the team and Consultants did not consequently regard themselves as the natural person to follow the patient up. Some GPs see their role as "quite clearly to make early referral, quite clearly to support the spouse enormously ... assess how they are coping, see what their needs are and it's about mobilising other members of the support team." (GP5: 22).

One Consultant saw the GPs' role as being just as important in the six months leading up to the diagnosis as the subsequent six months when more people were usually involved. Many GPs saw that they had a very significant role in the lead up to diagnosis and thereafter "we have to be involved in talking to people about it because whatever happens with the psychiatrist we are the main stay of long terms support." (GP8). For others, it seemed that the role of the secondary services were clearly of paramount importance and the only way to access specialist investigations. The only way we can access things like CT scans and MRI scans is via Secondary Care so I will always refer. I would like to do this but I can't do it here so we need somebody else's expertise." (GP4: 140).

There was a mixed response from some GPs who felt that they could do most things themselves but the system did not allow for them to access some services, while for others there was relief that Secondary Care, mainly Community Mental Health Teams, took over the management of people with an early diagnosis of dementia.

### *4.2.1.2 Relationships*

The relationships between professionals were influential with regard to how they saw each other functioning within the Health Care Service. The relationships were described as being along a spectrum ranging from superficial to excellent and one of the Consultants voiced the concern, "as the service gets more stretched that relationship is always in danger of getting more tense. You know, when they have a problem and you can't solve it because you haven't got a bed." (Consultant 2: 165), and saw the relationship depending on the ability to help other colleagues.

In many ways the relationship was a direct result of the service that people provided and where the relationships were described as strong or good, there were comments like "we've got a good relationship with the Old Age Psychiatrist... provides a very efficient service, communicates well, assesses the patients well and I mean we do have a great deal of respect for [*person's name*] and I wouldn't fault our relationship or their personal service." (GP8: 191).

Others were less pleased with the service and found it difficult to communicate, complaining that there was a lack of dialogue, few face to face meetings, and that sometimes it was almost impossible to reach Consultants. Some had to make do with leaving messages for their secretaries and one GP found a way to circumvent that by using e-mail, which was always found to be successful. In most cases what characterised the relationship between GPs and Consultants was a mutual respect based on the level of service request and provision.

### *4.2.1.3 Responsibilities*

Responsibilities were not always seen as being role specific, especially when it was felt that it was a joint responsibility to work together for the benefit of the patient. One GP pointed out, "I think we are in the same boat and we have the same goal of keeping these patients fine and good as possible" (GP9: 89), and a Consultant of the same opinion thought that GPs, "by doing their best, together with us, to keep people where they are for as long as possible," (Consultant 7: 197), was an important responsibility which identified that both of these sets of medical practitioners were sharing a common aim.

Consultants and GPs both shared the notion that Consultants were principally responsible for diagnosing and prescribing appropriate medication. Sometimes members of the same group saw their responsibilities differently. One GP felt that "it's my responsibility to keep up to date with the latest treatments, medication and non-medication, the latest support...continuing to be up to date with what's available, what I need to offer the patient and what is the best evidence for that," (GP1: 117), which was in direct contrast to another GP who thought "it's not my area of expertise, it's too new, it's changing all the time. I just feel it's something that's more appropriate for psychiatrists to keep up with." (GP11: 150).

Most felt that since the introduction of medication there was a new responsibility to refer people as early as possible although this was contrary to the thoughts of one Consultant who questioned the ethos of early referral

> "I have a certain discomfort about rushing to all this early referral because you know there is a lot of like, holding up your hands and saying well it is mild cognitive impairment, come back and see me in six months, and you know, if everybody is rushing around, referring everybody early and you are not doing anything, you know, maybe we are on a bit of a bandwagon here that is just adding to anxieties" (Consultant 2: 140)

However, a colleague claimed "an early diagnosis in dementia to me means what we should be doing day in, day out," (Consultant 1: 20), pointing to yet another fragmented notion that everyone is committed to early diagnosis of dementia. Some GPs were thankful that it was the Consultants' decision to prescribe medication or not and saw refusing a patient drugs as easier for Consultants than for GPs, because such decisions could affect ongoing doctor-patient relationships.

The ultimate responsibility was a focus on helping and supporting people to increase their quality of life by enabling people to lead a more fulfilling life. However, there was a question around who was the best person to do this. One GP reflected, "I'm not sure that in General Practice we are making a very good job of this either because we are still very illness focussed but by the nature of our job we are...it possibly does have to be delegated or devolved to someone with a specialist knowledge and interest" (GP8: 219). Whilst the thrust of early referral would appear to have increased since the introduction of anti-cholinesterase drugs, it has been acknowledged that illness focus is not always the best, or only, way of enhancing the quality of life.

Referrals to others who had the ability to facilitate a more fulfilling life seemed fraught with uncertainty, and that again suggested a fragmented system.

#### *4.2.1.4 Referrals*

The majority of referrals to Consultants came from GPs. Referrals were now mostly appropriate for an early diagnosis and had consistently improved over the years although it was felt that more in-depth information was more forthcoming when there was a telephone conversation between the referrer and recipient. Most of these referrals were for confirmation of a diagnosis that sometimes had already been tentatively made prior to the consultation, in conjunction with the person with possible dementia, their family or supporters and the doctor involved. Other reasons for referral were to institute investigations that GPs in the Primary Care Setting did not have access to.

Prescribing anti-cholinesterase medication was also something only Consultants had access to. This was thought to be for purely fiscal reasons, although it did sometimes upset GPs that they had to refer into the Secondary Care Sector when some of them felt very competent to prescribe medication. "That is disappointing that we have to, unnecessarily as I see it, involve secondary care not for clinical reasons but to get permission to use a particular drug, so that's how I feel about it and when it is in that category and some are, then it disappoints me because I think it is an unnecessary extra place for the patient to have to go" (GP1: 49). This not only pointed to the financial constraints on prescribing but also to the added burden and anxiety placed on people by having to attend a hospital clinic.

Waiting times at one particular diagnostic clinic were so long that local GPs had discovered a route that would circumvent it and directed early referrals to clinics run by Old Age Psychiatrists, although this did highlight a clinical governance issue of best practice. Many of the GPs felt that there was not adequate support for practices, and although some of them could make direct referral to other professionals, it was felt, at times, that this was not addressing patient need but was a service delivered on the professionals' terms. For instance

> "I've arranged to admit this patient to my caseload and I will see them again at 11 a.m. on the 2nd October 2003 when I will speak to them for 30 minutes and then I'll write another letter... it's precise and professional, but it's not relating to the actual needs of the patient when it comes down to the bit."(GP2: 134-135).

Others felt that while Community Psychiatric Nurses were largely appreciated by the families, they would rarely take direct referrals and, with the advent of Community Mental Health Teams, the service was even more remote from the practices and GPs rarely had face to face contact with them with the exception of those who continued to attend practice meetings – but they were now in the minority. Consultants seemed to follow up referrals that were diagnosed as having Alzheimer's disease and that were commenced on medication, but if they had a vascular dementia they were referred back to their GP for treatment and "often they feel that they have just been dumped in the dementia wilderness." (GP4: 198). Doctors only discussed Alzheimer's disease and vascular dementia.

The fragmented Health Care System around the subject of early diagnosis of dementia, whilst succeeding at times in establishing a diagnosis, instituting treatment and referring to other agencies, both statutory and voluntary, was found to be disjointed and lacking the equity of resource and consistent commitment across the region to recognise early dementia.

This phenomenon was, however, frequently described as complex and difficult to grasp.

## 4.3 The difficulty of the work

The evaluation of the area of work associated with an early diagnosis of dementia has been deemed both difficult and complex by each of the nineteen participants in Study 1. From the time that the possibility of such a diagnosis first crossed the mind of the doctor, through firming up that diagnosis, giving the diagnosis and prescribing treatment and follow up over the subsequent six months, the period that this study embraced, there did not seem to be one step of the journey, for doctors as well as patients, that did not embody the challenging and harrowing nature of the disease. Areas rated as difficult included the lack of resources, disappointment at slowness of scientific advances in achieving a cure, the emotional impact the work engendered, the lack of support and supervision for doctors, the difficult decisions that had to be made, and having to work within the confines of the system.

### *4.3.1 Lack of Resources*

The lack of resources seemed to impede the work of the doctors involved with early dementia. Some mainstream services were seen as 'luxury' and there was an awareness of finite services not meeting ever growing demand. The growing demand on society by people with dementia was portrayed as some kind of societal burden by a GP who feared, "our culture is going to become increasingly heavy with demented patients so it's many people, many shells walking around looking for bodily care. Quite a prospect isn't it?" (GP5: 217).

This kind of doomsday scenario was echoed by one Consultant who also saw it as a national situation and believed that we were in "the middle of a cognitive impairment epidemic and all aspects of the service are getting saturated, whether it be beds, nursing home places, CPN time, or Consultant time, it is all at saturation point." (Consultant 2: 55). Another felt that it was a government issue that gave such a low priority to older people in general and kept them short of much needed resources, which in turn caused great frustration among professionals and patients alike, and made a difficult job even more so because of the lack of resources.

It was felt that early diagnosis services had been resourced out of existing services, with no extra provision being made, and there was a fear that they could be a casualty in the cutback as new Consultant contracts come into being, at a time when the service might have to be dealing with crisis intervention rather than crisis prevention. The lack of resources for people with dementia within the Psychological Therapies specialty was regretful, especially within the new set up of Community Mental Health Teams. Although access was sometimes available for neuropsychology and psychology, there was less opportunity for referral to a counsellor as there were very few trained therapists within the teams. The acknowledgment of need for psychological therapies was seen as a key aspect, but little hope was seen of recruiting specialists of this nature through lack of funds or therapists finding it to be an area of little interest, and because those available had fairly lengthy waiting times. One of the scarce resources that people need is professional time and it is very difficult to give what is needed, especially within the short ten minute consultation of the GP. "We are quite time restricted, spending time with a patient to really explore their understanding and to help move things forward and advise them best is time well spent." (GP1: 109). Other staff groups are also affected by time. There exists a desire for more of a CPN service but with the realisation that "the CPNs are really busy and they can't go into see everybody all of the time." (GP12: 55).

Resourcing services was also a difficult task. One way of trying to attract funding for services for people with dementia was to explain to funding bodies "how awful it [dementia] is and it is awful." (Consultant 6: 317). Another difficulty was that dementia never seemed to gain high priority. "Often poor old dementia gets left near the bottom of the list ... right at the bottom of the ashes." (GP10: 192). "A Cinderella in some ways." (GP2: 119). "Mental health takes low priority to most things and dementia takes lower priority than all the others." (GP7: 243). And some of the services offered are seen as very basic with little specialist training for staff or volunteers.

Competing for resources was also an issue and both national and local health care providers had to prioritise to meet government targets, "which have to be interesting and acceptable to the general population and obviously things like looking after young ill children is something which generates much more enthusiasm than looking after granny who is a bit dottled." (GP2: 119). In practice this meant that a lot of the service seemed to concentrate on being reactive rather than proactive, and one GP observed that the service, especially for people with an early diagnosis, was underdeveloped, "I suspect because it is very badly under funded." (GP11: 160). Lack of resources was a major issue with both Consultants and GPs. This made a difficult area of practice more difficult because of the constant struggle to attract both funding and workers to an area that was not seen as being particularly attractive. The constant battle for resources and recognition of the value of the service also compounded the emotional impact felt by doctors who had to face the trauma of dealing with patients receiving a diagnosis of early dementia with scant resources to offer them. This emotional impact was acknowledged by doctors as something that they were expected to deal with, albeit with little resources.

### *4.3.2 The emotional impact of an early diagnosis*

The emotional impact of working with people with an early diagnosis of dementia has rarely been explored within the medical profession. Emotionally, doctors were affected in two different ways: feelings that they had for their patients who were experiencing the diagnostic process, and personal feelings triggered by these encounters related to dealing with the diagnosis of early dementia.

#### *4.3.2.1 Feelings for patients*

The feelings doctors had for patients were mainly centred on a feeling of sadness – sadness for patients who had not been referred into the system early enough to benefit from early interventions, whether medication or advice. "It makes me feel sadder, unhappier when they have missed that opportunity." (Consultant 3: 95). Such feelings were compounded for doctors by having to tell people at the start of the trajectory that they may have ten years or more in which they will deteriorate. Sadness was also expressed for the missed opportunities that society fails to provide for people with early dementia, opportunities that they are still capable of enjoying, and that is coupled with sadness that medication does not help everyone. Only some people will have a little benefit with no knowledge of longitudinal outcomes.

GPs found it especially painful to watch patients, with whom they had a doctor-patient relationship with for many years, begin to develop dementia and then have to watch them deteriorate. "It can affect you quite significantly and you feel feelings of sadness that this has happened to somebody that you've known and someone that has been perhaps a very able individual because you know where things are going and their abilities are going to diminish." (GP6: 224). And sadness was felt quite acutely at the time of breaking the bad news of the diagnosis, described by another GP who felt, "it is quite difficult and usually these are patients you've known for quite a lot of years so it is sad really to see them, their functioning decline, but you just have to try and go into professional mode." (GP12: 134).

The acknowledgement that a diagnosis of dementia would change the doctor-patient relationship was highlighted as "it means that my relationship with the patient is essentially and inevitably going to change as their dementing process gets worse." (GP5: 5). And this GP felt a sense of loss when this was being discussed.

#### *4.3.2.2 Feelings for self*

The effect of working with dementia much of the time was described by one Consultant as akin to "a bombardment of insoluble problems" (Consultant 2: 169), and whilst there was little effect with 'each individual bite', there was a cumulative effect that sapped the morale over time in dealing with a disease that had such a poor prognosis and which left doctors feeling jaded and stressed at times. Conversely, the majority of the Consultants reported feeling positive about the input that could be offered, although this was admittedly linked sometimes to a feeling of deception if there had been a more positive spin applied to the effect of the medication than it merited.

Other feelings identified were fearfulness of how the professional should respond when faced with a patient who had early dementia and who had come to the doctor expecting to be 'made better', and the doctor was left with a feeling of impotence because of an inability to greatly influence the situation. The feelings that doctors were experiencing were overwhelmingly negative whilst there was feeling that as professionals they made a positive contribution to patient care. There was an awareness of the need for these feelings to be processed and managed and the support available for this was found to be limited.

### *4.3.3 Support through supervision*

One area in which feelings and emotions arising from different work situations can be explored, processed and resolved, is in clinical supervision. Clinical supervision and management support for health care professionals is a well established practice in many different sectors of the Health Service. This was not found to be the case for Consultants in Old Age Psychiatry and Principals in General Practice who were seen as very senior practitioners within the medical profession. They had no formal opportunities for access to supervision despite a realisation that this could be beneficial to them both personally and professionally.

The only avenue available to Consultants was their Peer Group meetings, and although GPs did not have this formal type of forum they had practice meetings with their partners. The Consultant Peer Group discussed situations in general and raised anxieties about different issues although "it never gets too personal." (Consultant 1: 113). The majority of the time is spent focusing on educational issues, the frustrations brought about by poor management systems, and lack of resources. (Consultants 3 and 4). It was felt that it was not an entirely safe environment to bring personal issues regarding work related problems. "The peer group we have is good ...but it is certainly not a forum to come in the door on your hands and knees and say help me, I've had enough" (Consultant 2: 172), and consequently, doctors had to develop their own modes of coping with the stresses that dealing with early dementia brings to their lives.

The need for supervision was felt quite strongly in discussion with the majority of doctors but one GP wondered if the reason it was not available was because it was discouraged by a profession which perceived itself as being at a career pinnacle and supervision was therefore seen as surplus to requirements, adopting an attitude of "I am a consultant and who can supervise me and to a lesser extent GPs probably feel the same but we desperately need it." (GP10: 218).

Different practitioners had different needs as far as support systems were concerned and many had to look for other forms of dealing with stress and not always rely on colleagues – as one Consultant pointed out, "medical training is not about supporting your colleagues." (Consultant 1: 107).

#### *4.3.3.1 Support through other channels*

Whilst the comment that medical training is not about supporting your colleagues may be true among some practitioners, many GPs were able to discuss areas of anxiety within the multidisciplinary team and seemed to have more ready access to a supportive environment than their Consultant colleagues who were more isolated in this respect. Consultants felt that it was not something that they could go home and discuss with their partners because of the confidentiality aspect of their work. One Consultant told of the isolation, "I can remember being upset about it and being aware of being upset but not really having anybody that I could to speak to anyone about it." (Consultant 1: 96). Another expressed the stressful nature of having to cope regularly with matters that could make "grown men cry." (Consultant 6: 154).

Many of the doctors had developed their own personal way of surviving by trying to shut off personally from each patient, and by metaphorically putting them in boxes to avoid personalising feelings. Because of the way that surgeries and clinics were designed and operated there was never the time or space to adequately process thoughts and feelings between patient consultations as GPs are expected to see patients every ten minutes, and Consultants every thirty to forty-five minutes. Some tried to leave their thoughts and feelings about work in the work environment and immersed themselves in their own hobbies and interests and spending time with their families away from the work environment.

The lack of support and supervision and the perceived need for them has highlighted yet another 'difficult area' with which the doctors in this study had to deal. With little in the way of formal support, doctors faced many complex issues and made very difficult decisions concerning people with an early diagnosis of dementia.

### *4.3.4 Difficult decisions and dilemmas*

Throughout the assessment process difficult decisions had to be made and doctors sometimes were faced with dilemmas as to what they believed was best for the patient. At times there was a conflict of ideas between family members and doctors, with a question as to who really was the patient. This created a tension between the needs of the family carer and the needs of the patient. As one GP reported, "once the diagnosis is made the relatives very often wrap this person in cotton wool and won't let them go anywhere alone and that's very frustrating for somebody who most of the time is reasonably okay and suddenly their whole life you know they've got a minder and they are minded and they don't like it." (GP 8: 64). Sometimes the tension happened when families did not want the patient to know that they had spoken to the doctor about their concerns and that could be very uncomfortable and quite dramatic. "It's all this cloak and dagger stuff and often I feel that a lot of it is that they want you to sort things out" (GP12: 127).

Further dilemmas revolved around the giving of the diagnosis and that will be addressed in more depth in section 4.6 of this chapter. Decisions to be made included whether the word dementia should be used or not, whether the patient was told their diagnosis or not, if a family asked for it to be kept hidden to try to protect the person, and what information and how much information should be given. As doctors monitored their practice and reflected on their intervention Consultant 5 summed up very succinctly the feelings of the group, "I have a question, am I actually doing the right thing for the patients?" (Consultant 5: 107).

One dilemma that GPs faced which did not occur with the Consultants was how to approach the subject of a possible diagnosis of dementia with a patient who had consulted them about something completely different, or, perhaps they had observed signs of dementia developing in that patient over a period of time. Some felt that it had been enough to document concerns and 'keep an eye' on the situation, while others struggled to know how best to tackle such a sensitive subject. Another dilemma occurred when the rationing of available services had to be apportioned. Both Consultants and GPs had to make judgements as to who got what, usually not based on patient need but on what services were available, thereby often designating services such as CPNs and Counsellors for people with an early diagnosis as luxury items.

These were some of the difficulties that doctors faced when dealing with someone who had been diagnosed with, or whom they suspected of having, early dementia. Working within the confines of the Health Service brought many different challenges and frustrations and somehow it seemed that these practitioners were doing what they could within the confines of the system of which they were part. The needs of the patient were not only in conflict with the family/supporters but sometimes with the needs of the organisation and its demands on the practitioner. Yet the organisation was there primarily to meet the needs of the patient. The doctors' view of the needs of the patient will now be explored.

## 4.4 Views of patients' needs

Doctors saw the needs of the patient to be split into many different tasks that had to be performed either by themselves or by colleagues, and thus adopted a task oriented approach to patients. Four core tasks were identified in this study: assessment, diagnosis, treatment and referral; along with lesser tasks incorporated within these central areas with scant emphasis on post diagnostic follow up. Both sets of participants had the same core tasks to carry out although the emphasis on each was weighted differently. Tasks were seen as important to doctors and by identifying their tasks they were in some way creating an identity of the doctor as a purposeful, agentic self. Without the patient this would not be a self that could be fulfilled. One GP described the approach taken,

> "We break it down medically, and we deal with the tasks because we are the ultimate task orientated people. GPs are the ultimate task orientated people and we identify ourselves, we define ourselves by our abilities to deal with tasks, we are ultimately definable by our work and if you strip away the work you wonder what you have left." (GP5: 63).

### *4.4.1 The task of assessment*

Patients were assessed first of all by their GPs. They would consult the GP looking for reasons for the changes that they were experiencing in memory and functioning. This was sometimes a subjective experience, but frequently these changes had been brought to the attention of the patient by friends or family, or would be identified by their GP when other problems were being investigated. GP assessment consisted of taking a history of the presenting issue, undertaking basic cognitive testing, checking out some physical systems including blood pressure and taking various blood samples. This sometimes took a few visits because of the constriction of appointment times for GPs, who were only assigned ten minutes per patient. "We have ten minute appointments to assess them; psychiatrists have about half an hour if not more." (GP11: 150).

Following initial assessment by GPs a tentative diagnosis would be offered or at least discussed, sometimes a range of alternatives of what might be the cause of the changes was given, and it was usually at this point that discussion took place between GP and patient about further specialist assessment. Consultants would sometimes see patients in their own homes at the request of the GPs, but the normal procedure for people with an early diagnosis in this study followed a path similar to that described as

> "The usual routine for outpatients would be to do some very, very basic cognitive testing such as the Clifton Assessment Schedule survey version, Mini Mental State Examination, which is pretty rudimentary and the Geriatric Depression Scale, to take a brief history from the presenting patient, simply an overview of their life as they recall it and describe it, to then particularly check aspects of that with the accompanying family with the permission of the patient and then to meet at the end of the clinic with a view to discussing diagnosis if appropriate" (Consultant 4: 50)

The feedback received by GPs from these Consultant assessments was on the whole very positive and helpful. However, one GP felt that much of what they did was a waste of time

> "Usually I get a great long letter about four pages which tells me all about the patient's upbringing and which school they went to and you know all the family history and one thing and another, most of which is of little relevance and takes me a long time to read and at the end of the day there's usually little practical input other than the question nowadays and more recently as to whether they are going to use medication" (GP 2: 235)

This doctor seemed to question the value of what was being offered in light of the scarce resources of doctors' time. This was not a view shared by the majority of GPs.

Most Consultants would also request further neuro-imaging radiological investigations depending on which region they were practising in and what was available. These investigations and tests lead to a more informed differential diagnosis.

### *4.4.2 The task of diagnosis*

Doctors often felt that a diagnosis had been reached, prior to a visit to either the GP or the Consultant, by the patient and/or their supporter who would have most likely tentatively discussed the alternatives and would perhaps be looking for confirmation or disconfirmation of their assumptions. Reaching a diagnosis of early dementia was a diagnosis of exclusion, which would explain the need for such a thorough assessment, and was frequently done in tandem with GP and Consultant working together. "The main basic thing I would be looking for would be specialist help to firm up the diagnosis by helping to firm up the exclusion of other diagnoses so that we agree that this is it." (GP1: 24). Although GPs felt comfortable making the diagnosis, for the most part they felt that the patients needed to see a specialist for confirmation: "I think actually the patients want to see a specialist because they want to know they have had specialised skills and expertise to say yes." (GP4: 144).

The task of making a diagnosis was shared between the patient, the supporter, the GP and the Consultant, but the task of giving the diagnosis was frequently left up to the Consultant. Most GPs felt that it was up to the specialist to give the diagnosis when the results of the scans and tests were being given although one GP disagreed and wanted to give the patient the diagnosis. However, this opportunity was rarely afforded: "I will usually know this person well enough to know how they would best receive such information so I prefer to hear and convey that to the patient and also convey that to them." (GP1: 28).

The giving of a diagnosis will be explored in more depth later on in this chapter in section 4.6. If the results of all the investigations pointed to a diagnosis of early dementia it was at this time that treatment would be discussed and instigated.

### *4.4.3 The task of treating*

For doctors in this study, treatment meant pharmacological intervention. Over the previous five years there had been an increase in the number of drug treatments available for people with Alzheimer's disease. These drugs, because of their relatively recent arrival and because of their cost, were under the jurisdiction of Secondary Care which allowed a more stringent control over their prescription. The Consultants had to follow strict criteria for instigating their use and for their discontinuation, governed by both local and national guidance protocols. For some GPs this was frustrating because although the drugs were licensed they were not allowed to prescribe them. One GP felt that having to get into the Secondary Care system for the prescription of drugs added to the patients' burden and was an unnecessary process when they could have been prescribed in Primary Care. "They have to move back into secondary care just to get that [*medication*] kicked off and that is disappointing and I am not always convinced it is clinically necessary." (GP1: 53).

The effectiveness of treatment was also debated and doctors voiced opposing viewpoints. Some felt that the drugs had not been life transforming, and at best they slowed the decline slightly, and they questioned the benefit of drug therapy for patients. "I'm not so sure if it is of any great benefit to be honest. Certainly the patients we have, have not done well but that's just anecdotal." (GP2: 126).

The focus on pharmacological interventions served to consign other forms of assistance to lesser import. "You can get so involved in just the drugs and the side effects; monitoring a drug you can lose sight of the other stuff you should be doing ... they are not the be all and end all." (Consultant 6: 81-65).

The drugs had become so important that they seemed to have overtaken everything else and in practice it was hard not to raise the hopes of patients who could have probably been eligible for them. Besides, they did seem to offer some form of hope: "in terms of that hope thing, they need to know that we can give them something," (Consultant 2: 115), although the need for balance was also expressed to ensure that responsible information was reported to people about the likelihood of how effective they were known to be, tempered with a bit of caution so that they did not give false hope

> "we are having I would say moderate success but I think patients maybe you know they read things in the press and think gosh this is wonderful, this is a cure and it's kind of emphasising that this isn't a cure but it's maybe just temporarily giving a slight improvement to the quality of life I suppose" (GP10: 126)

The drugs for Alzheimer's disease have become a very important focus of the doctors' task and although there was no consensus as to how valuable they really were, and differences of opinion as to whether the scientific evidence for their use was valid, nevertheless they did seem to serve a purpose for which they were never intended. Many of the doctors thought that since the medication had become available this had a positive effect on public awareness and increased early referral, and because the public thought that there may be a treatment for this, there was less fear and more hope. However, if there was hope for people with early dementia who were diagnosed as having Alzheimer's disease, this was not the case for people who were diagnosed with other forms of dementia, and especially vascular type dementia. Whilst the Consultant would follow up the people on the anti-cholinesterase medication, the management and treatment of people with vascular disease was handed straight back to the GP, "if vascular risk factors sound appropriate I'll suggest that we go back to the GP for management of these as a priority." (Consultant 3:62). For many patients seen by the doctors in this study, the treatment is a major factor. If people are prescribed anti-cholinesterase medication they are usually followed up within the first six months by the Consultant or their deputy in clinics throughout the area, but for people who did not fit the criteria there seemed to be less opportunity to be seen regularly by the

Consultant. They tended to be discharged back to the care of their GP, or sometimes referred on to another part of the service. Referrals were made to various professionals and voluntary agencies. The criteria for referral to other services seemed to be down to the individual's practice and a little ad hocery with no clear pathway to be followed in the task of referral.

### *4.4.4 The task of referral*

Following an early diagnosis of dementia, referral to other services was dependent on what existed in the regions rather than being defined by patient need. Some Consultants referred everyone with early dementia to the Community Psychiatric Nursing Service while others felt that this was totally unnecessary and saw it as 'a luxury item' due to the scarce resources. People were referred to others for very specific tasks, for example referral to the Occupational Therapist was deemed necessary if people needed advice about some basic skills of daily living. "The OT doing assessments on these people and we sort of look at their skills, look at their road crossing skills, looking at all sorts of activities that we all take for granted." (Consultant 3: 69). The CPN was viewed as mainly to deal with family carer anxieties and "for them to spend a few sessions at home to talk about diagnosis, to talk about legal matters i.e. the new legislation, what the implications have for them and if we start medication to monitor that as well." (Consultant 7: 54). It was also seen to be dealing with more established dementia rather than someone with a new diagnosis. Referral to voluntary agencies was done by giving information and recommendation for such services as group support if this was deemed appropriate. Referrals to others seemed to be prescriptive of the tasks that the doctor ordered rather than referring to the service to allow autonomous needs' assessment to define what that service had to offer the patient. Again, it was not the case with all referrers as GP1 demonstrated, "specialist CPN teams who are really skilled at getting alongside the patients and their relatives can really take that forward, that is a much better way of using our healthcare professionals so that I continue to do the more medical side of things." (GP1: 24).

For the ultimate task oriented profession to help find a way forward for people with a new diagnosis was not always seen as an achievable task. What seemed to be a common occurrence around the sequence of events is reflected in the words of one GP as, "the diagnosis is made, treatment is or is not started depending if the patients fits the criteria and then I feel there is a limbo where the family are left just to get on with it and I think that's very difficult." (GP3: 134).

There was a dearth of suggestions for follow up for the newly diagnosed patient within the six month period and it did not appear to be a priority area for doctors. Follow up from diagnosis was akin to other tasks and, without protocols to follow, was left very much up to the individual practitioner. We now concentrate on what the data said about follow up in the six month post diagnostic period.

## 4.5 Post diagnostic follow up

Post diagnostic follow up for people with a new diagnosis of Alzheimer's disease would seem to be the province of the Consultant, but only for patients who had been commenced on anti-cholinesterase inhibitor drugs. There were exceptions to this when some Consultants did not take on the task of follow up but left it to colleagues working in the clinics. For those who were not diagnosed with Alzheimer's disease or were unable to take the drugs because of contra-indications or side effects, it was less clear if follow up took place or if people were left to their own devices, "they really get dumped don't they. Just into nothing, into the ether." (GP4: 206).

GPs were acutely aware of follow up not being stringent. "I would certainly say that those families probably need even more support because they are not getting the support that the Alzheimer's are getting." (GP8: 71).

People who were diagnosed with vascular dementia were referred back to their GP for management of the vascular risk factors although occasionally they would be referred earlier to the CPN service because the Consultant knew that they would not be doing the follow up. That was rare, however, and the majority of people received their follow up care from their GP. "Whatever happens with the psychiatrist we are the mainstay of the long term support and even if we are not seeing them all the time we are always the person that they come back to." (GP8: 99).

The follow up for people with early dementia seemed to be imbalanced with Consultants' main efforts being invested in Alzheimer's disease while GPs were left to deal with vascular disease. GPs felt that people with a new diagnosis of vascular disease were not being given the appropriate support and this led to "a lot of anger actually, because people know there is that treatment out there, but they don't fit the criterion, that requires a lot of support too." (GP3: 119).

Doctors were divided over the need for post-diagnostic support and only the two types of dementia were discussed, that of Alzheimer's disease and vascular dementia.

### *4.5.1 Identifying the need for post-diagnostic supportive follow up*

The impact of a diagnosis of early dementia was not something that was well known within the profession and the need for support was mainly identified through doctors' reflections of how the person reacted to being given the diagnosis of early dementia, and to their subsequent observations. It varied from person to person but it seemed that it was the GPs who were most aware of the how the person had reacted emotionally in the period following diagnosis, describing the traumatic and catastrophic reactions they had witnessed as being distressed, depressed, suicidal, worried, grieving, scared, very frightened; experiencing feelings of going mad, negative feelings leading to clinical depression; being unhappy, frightened of the future, and shocked.

These strong emotional responses to the diagnosis were much more rarely witnessed by the Consultants who described the patients' reaction to diagnosis as sometimes being surprised but not shocked, relieved, rarely distressed, acceptance, and one of trying to ignore it or deny it. There was a definite difference in their experience of patients' reactions.

Consultants would have been seeing an immediate reaction to giving the person the diagnosis whereas the GPs were witnessing the reaction once patients had had some time to process their feelings. It was understandable, therefore, that GPs identified a gap in the support services available to meet the needs of people who were experiencing difficulties with post-diagnostic emotional processing. The emotional processing was affected by the fear of what would happen next and patients brought their own fantasies and horror stories to bear on their understandings of the diagnosis and that sometimes fuelled their fears and anxieties

> "where there is a huge gap and I think that's where patients are very anxious because certainly here probably they see day-care and have knowledge of what the people there do and think gosh is that going to be me in three months time and that must provoke a lot of anxiety" (GP10: 55)

Thinking of the worst case scenario was, according to GP7, part of the condition of being human, to think that "it's always going to be terrible, it's going to be just like the lady over the road or something like that. We will always look at the worst ones and not the best ones." (GP7: 83). And thoughts that people with dementia require 24 hour care and remembering their friends who were in nursing home care were also cited as worst case scenarios.

Follow up was also inconsistent with only one Consultant referring all the newly diagnosed people routinely to CPN service, while others were more ad hoc and in some GP practices, in the absence of other professionals willing to take this on, the emotional work was left to the Health Visitor who felt ill equipped for the task. GPs felt that there was a need for someone to get alongside the person in order to "help you to live with this illness," (GP6: 153), and to provide appropriate support in order that people can live a more fulfilling life. However, the main thrust of what GPs felt was an important task of follow up was summed up by GP10

> "it's such an important time in them kind of formulating how they feel about their diagnosis, how they are going to move forward and how they react at that stage is so critical in a way to how they cope with the disease at a later stage and how the family copes with it" (GP10: 84)

The need for immediate post diagnostic supportive follow up was highlighted mainly by GPs although Consultants did recognise that some people did need some kind of psychological support but felt that it was not necessary for everyone. "For some people things are very stable and they don't want any input and we have to respect that as well." (Consultant 7: 217). Resources again were blamed by one Consultant, who did not describe any of the strong emotional responses to diagnosis that the GPs found, which led to considering that follow up may not be as necessary as the GPs did

> "They are thinking about well I've got something to think about here and I've got some tablets which might help, or you know I've been told that there is no tablets for me, but actually the level of my lifestyle is still acceptable, I don't think I need anyone involved at the moment, I'm not sure that that is a healthy position actually but that is limited by resources" (Consultant 3: 78)

This type of experience however did not stop the majority of doctors thinking that post-diagnostic support should be available for people to be able to access in an endeavour to alleviate what one GP succinctly describes is required, "I think the whole family needs somebody to talk to, listen to their anxieties and tell them what the future does hold." (GP3: 74).

The question around which professional should or could provide such a service was explored with various suggestions as to who could fill this identified gap in the service.

### *4.5.2 Filling the identified gap*

The vast gap in services for people with an early diagnosis of dementia identified by the doctors is so great that it is "just a huge gap from early dementia to later stage and nobody dares to fill that gap." (GP10: 70). It was almost as if no-one had addressed it because it was just too big to contemplate what needed to be done or how best to do it.

There was no consensus of who could best fill this gap in the service post-diagnostic support. This need was identified as post-diagnostic counselling and some felt that this work should be best undertaken by CPNs. "I could make out a good argument for a CPN doing that post diagnosis counselling work but we are only talking really about one or two sessions. I don't think we are talking about an extended role in the most part." (Consulant 3: 83). Others thought that CPN training would not equip them for such work and saw it as inadequate for the purpose of counselling, "I suppose they have counselling exposure everyday of their lives, but formal training seems unlikely doesn't it?" (Consultant 2:55).

However, it was felt that if counsellors were to be available to do this type of work they would have to be knowledgeable about dementia. There was also a need seen for pre-diagnostic counselling in the waiting time between first referral and diagnosis, when people were waiting for investigations to be carried out and sometimes they had to be placed on a waiting list for appointments. It was felt that a counsellor would be able to explore with them their fears of what was going to happen, "for services who have to wait a long time and people are kind of thinking about it, it would be nice to have someone to give that information about how they feel if this to happen or whatever." (Consultant 7: 95).

Counsellors working with people with a new diagnosis would not only benefit the patient but would also be a great support to fellow professionals and would be able to save a lot of time and money. "It would be a big cost saving in the long term because the time of the other professionals would be used in a more highly efficient way ... I saw this lady weekly because of the upheaval and the emotional distresses it had caused because she was upset." (GP9: 163-41). So, seeing a counsellor would be cost effective compared to a GP having to see someone at length at regular intervals.

The majority of doctors felt that a counselling service for people with a new diagnosis would go some way to filling the gap and, coupled with flexibility, was seen by some as an ideal. "If we talked about what my wish list would be, I would like to be able to refer somebody with early dementia to the counsellor." (GP4: 177). And a clear picture of the ideal service for people at the very beginning of the dementia pathway would include their family

> "It would be an ideal dementia service if, prior the diagnosis being given, perhaps after the initial referral themselves and while the investigations are ongoing that a counsellor was there to support the patient and family in the 'what if situation' if Alzheimer's is diagnosis what do we do and then when they actual diagnosis is given to continue counselling" (GP3: 93)

A resource akin to family therapy was muted by a number of doctors in the study as being appropriate for people trying to come to terms with a new diagnosis. A counselling service was felt to be a very appropriate way of supporting people together with the hope of developing something new as one Consultant suggested

> "it would be a new type of therapy, but it would definitely come under the umbrella of encounter work and the idea of that encounter would be very much addressing the psychological and emotional side of what they are going through at that moment" (Consultant 2: 136)

> Although it was recognised that counselling type therapy was not for everyone "counselling is fine for the right people not everybody needs it, not everybody responds to it. I have always been a great believer that counselling is right for some people same as some drug therapies are right for some people." (GP7: 107).

But it was felt that it should be on offer. In order that immediate access for such a service could be available for patients receiving a diagnosis, the person allocated to do this follow up work would have to be present at the 'telling' of the diagnosis to hear what was said by Consultants and to witness the reaction of the person receiving that diagnosis. This was only one of the many issues around the complex task of telling that generated much discussion and debate and, therefore, is worthy of its own section in this thesis.

## 4.6 The 'Telling'

Telling someone they had an early dementia was described as one of the most difficult tasks that the doctors had to undertake. Within the diagnostic process the giving of the diagnosis was frequently seen as the premise of the Consultant who made the diagnosis, although this was a task that fully involved the GPs because the patient returned to discuss their diagnosis with them following their hospital consultation. Some GPs were involved in discussing probable diagnoses prior to the patient being seen by the Consultant, although a definitive diagnosis had not often been reached prior to the clinic visit and the conclusion of investigations. The telling raised many complex issues and deliberations which were explored within this study. Within the theme of the telling there were many different sub-themes based around whether to tell, who to tell, who should tell, what to tell, how to tell, when to tell, where to tell, and the doctors' constructions of patients' responses to the telling.

### *4.6.1 Whether to tell*

The question of whether to tell or not would to a certain extent be overtaken by the instigation of treatment because people being commenced on pharmacological treatment had to do so by informed consent; therefore, if the diagnosis was Alzheimer's disease, this was not an issue.

There was the question of people with other types of dementia and it was much more likely that they would not be as fully informed as people with Alzheimer's disease. Doctors tended to try to read the body language of what people wanted to be told although some did ask patients directly whether they wanted to know what their diagnosis was, and consequently be guided by what the patient wanted. "Unless I pick up a sense that this is a bad thing to do, if I'm clear in my own mind I would share the diagnosis at the end of that first contact." (Consultant 4:44).

The only time that GPs felt that it would not be appropriate to tell was when the patient was suffering already with some life threatening illness. "If someone has that sort of terminal illness you are not going to tell them that they've got dementia as well." (GP7: 75).

Doctors collaborated with patients to ascertain whether they wanted to know, although there was sometimes a complicating factor when the family supporter asked that the patient should not be informed.

### *4.6.2 Who to tell*

The dilemma about who to tell only became an issue if the family supporter did not want the doctor to tell the patient the diagnosis. This did happen quite regularly when families wanted to protect their loved one from the trauma and pain of having to listen to the diagnosis. However, many of the doctors did not collude with this and would not countenance keeping information from their patients unless they had indicated that they did not want to know. “I’ve got into terrible trouble with the family for telling the man his diagnosis although he asked me…the family were livid.” (Consultant 6: 271).

The accepted pattern for most patients was that most accompanying family supporters were in the consulting room at the time of the diagnosis. It was not always clear who had issued the invitation to be present, whether it was the doctor or the patient or indeed if it was a ‘taken for granted’ assumption by all parties that this would happen

> “normally at the diagnosis giving interview I would see the patient just quickly to check over some of the intellectual function and then bring in the carer so that they both hear exactly the same thing and that has avoided any sense of one person knows one thing and one person knows another” (Consultant 3: 48)

Only one Consultant mentioned that the patient’s permission would be sought to clarify if this was an acceptable situation for them. The normal procedure then was for people to be accompanied at the time of the giving of the diagnosis so that the person receiving the diagnosis and their supporter heard what was being told, and this was rarely challenged by either the doctor or the patient.

### *4.6.3 What to tell*

The content of the discussion around ‘the telling’ and the language used was a contentious issue and again was characterised by a lack of consensus from the doctors in this study. The main thrust of the argument surrounded whether patients should be told the truth or not, or if it were acceptable to use euphemisms. There was much less concern about using the term Alzheimer’s disease because it was now associated with pharmacological treatment that could be offered, although even this did not stop a Consultant trying to couch it in terms that were somewhat euphemistic, “I use slightly ridiculous expressions like you have got a touch of Alzheimer’s,” (Consultant 2:95), “to try to break the bad news more gently.”

The word dementia was difficult for the teller to use within the consultation and would frequently not be initiated until either the patient or family supporter had introduced it, and some doctors actively avoided the term. “I must confess I am not sure if this is a good thing but I tend to avoid the word dementia.” (Consultant 7: 46). Such avoidance of the term dementia was common among GPs and Consultants alike, with comments like, “eventually you would have to get to the word,” (GP11: 111); and “of course the other thing is that I do not use the word dementia" (Consultant 2: 95); and the use of metaphor was in evidence with one Consultant explaining the diagnosis in terms of brain problems, "I don't want to sound patronising, but for some people I tend to talk about things like your brain is getting older than the rest of your body. I tend to use a wee bit of metaphor rather than a specific name." (Consultant 7: 54).

The tendency towards a model of 'telling the truth' had become more of 'the norm' for many of the doctors and some could not envisage not telling someone even if it meant that the patient would be upset by what was being said to them. A degree of openness and honesty for the most part prevailed, although there were occasions when doctors felt that they were being less than honest, "you then get the feeling that you are not being entirely truthful as to what you know what might lie ahead" (Consultant 3: 95).

However, most doctors were aware of the litigious nature of their work, and because of the uncertainty of the diagnosis being definite, they tended to use the terms 'possible' or 'probable' Alzheimer's disease, or a type of dementia, or one of the dementias, rather than appear to be giving a definitive diagnosis as illustrated by Consultant One

> "I will usually try to clarify that diagnosis is a fluid thing so perhaps if something crops up in the future it may change your diagnosis. It may be that something is not apparent now, which in the future if something occurs that we don't know about, we might have to review it and go back and say well actually that was our best diagnosis at that point in time but now it seems much more like an alternative diagnosis" (Consultant 1: 58)

For some doctors the information that was given appeared to be a difficult concept for the patient to grasp within the limited time that the doctors had to give it and spend on explanation, although there was no consensus of an ideal of 'what' should be told. Nor was there any uniformity of tailoring the diagnosis to meet the need of the patient. Some practitioners used a similar format for all patients and others tended to weigh up what they thought the patient needed to hear.

This led to the discussion around 'how' the diagnosis should be told.

### *4.6.4 How to tell*

The concept of how to tell was again cloaked in the difficulty of the task of 'telling', and while there were a number of 'give it to me straight' people, there was a tendency to try to give the diagnosis as gently as possible, "it's never going to be easy for them but you want to do it in the least painful way." (GP10: 43). The ideal appeared to be over a few sessions rather than during a one-off visit to the clinic or surgery, together with the offer of further follow up if necessary in order that more information can be given, that practitioners can be questioned, and that anxieties and uncertainties can be shared with the practitioner and patient

> "I don't think that's one you can give at one session. It's going to be ongoing for a lot of questions that people may want to ask and unfortunately a lot of questions that you can't answer so it's not a pleasant diagnosis to give and also it's one that is riddled with the uncertainty. I have always led to sharing that uncertainty with the patient and with who ever the family or carer is as well you know there is a lot of don't knows" (GP7: 91)

Some doctors felt that it was important to couch the diagnosis in layman's terms so patients would understand what was being said and not to hide behind medical jargon, while others felt that it was important to be as positive about the diagnosis as possible. Some felt that it was necessary to have other people there to support the person who was being told, but the bottom line was to keep the patients' needs at the forefront of what was happening, "trying to tune into what the patient wants to hear because if you tell them things that they aren't ready to hear they don't hear it anyway." (GP6: 145). This brought debate about the timing of the giving of the diagnosis and the question of 'when' to tell.

### *4.6.5 When to tell*

The timing of the giving of a diagnosis again varied and doctors had different ideas as to when was the right or best time to tell the diagnosis, with ideas such as after all the tests are completed, "I will tell them when I think I've got all the information. I need to be certain that they do have what I think is a dementing illness," (Consultant 7: 41); at the end of the first visit to the clinic; or over a period of time rather than telling someone within a single consultation. Again, there was no consensus, with some Consultants comfortable about telling people in one consultation with no follow up appointment, "if I'm clear in my own mind I would share the diagnosis at the end of that first contact." (Consultant 4: 44). Others felt that it was unthinkable to tell the diagnosis without offering follow up, "I would never give a diagnosis and then not see anybody again even although somebody else in the team is seeing them. I would always see them. I don't think I would ever not do." (Consultant 6: 86).

GPs also varied, but were much more likely to opt for a disclosure over a period of time, pacing the information given, and matching it to what the patient was able to absorb at any one time, or by being guided by the patient as to how much information was required at any one time

> "It is pacing the information to what the patient wants and I don't mean by that telling them what they want to hear but pacing it with their need for information so one wouldn't be pushing information at people who are not ready to accept it or to receive it but one would be open to the patient for information and asking the patient how much do you want to know about things, are there any other questions you would want to have answered in a similar way to patients that have got other kinds of sinister diagnoses that are going to be progressive bad news for them" (GP6: 145)

Most thought that it was best to tell early in the disease trajectory, explaining that with the belief that there should only be disclosure when the patient was ready. There was no scientific way of measuring when the patient was ready to hear the disclosure and doctors relied on their own intuition, skills and knowledge to decide when this should be with GPs often relying on their previous relationship with, and knowledge of the patient.

The question of whether it should be the GP or the Consultant who told the diagnosis was also discussed.

### *4.6.6 Who should tell?*

There seemed to be 'a taken for granted' assumption amongst the Consultants that they would give the diagnosis as they had made or confirmed it. It did not occur to them that they would not be the ones to give the diagnosis and some even felt that they were getting the hard end of the deal because fellow professionals were then doing the nice bits, "I think it's a really medical type thing when the doctor does the hard bit and then the nurse sort of is there to be nice and spend the time and brings out the tissues." (Consultant 6: 194).

There was some expectation from GPs that this should be the way and one GP did not feel confident enough to give a diagnosis of dementia. However, some GPs felt that they should be giving the diagnosis because they knew their patients better and had an established relationship with them. They felt that because of this relationship and prior knowledge they would know how to present such a diagnosis to patients in a way that they would find perhaps easier to accept, and whilst GPs did not like giving the diagnosis, they did not see that as a reason for not doing it. "Personally I don't have a problem with it, I don't like doing it, but I don't have a problem with it. I will be looking after them for the vast majority of the time." (GP5: 18).

Some GPs felt that it is never discussed with them whether or not they would want to give the patients the diagnosis, believing that they had ultimate responsibility for the diagnosis even although the Consultant had made it initially. They believed it should be them, especially "if it was a family I knew well, then I would feel comfortable giving them the diagnosis." (GP10: 31).

There seemed to be a debate waiting to be had and there is no evidence of dialogue to date, but it is clear from the data that debate and dialogue to clarify or determine practice procedure would be helpful to determine who the most appropriate professional was to deliver the diagnosis. The 'taken for granted' practice that it should be a doctor who gave the diagnosis was not challenged and there was no suggestion that any other professionals within the health service would be considered for the task.

However, a less contentious issue was where the giving of the diagnosis should actually happen.

### *4.6.7 Where to tell*

There was little significance ascribed to where the telling took place. The majority of the time the telling happened in the clinics and surgeries of the doctors delivering the diagnosis although two of the Consultants felt that it was better for the patients to be in their own homes when they received it. It was assumed that it would mainly happen within clinical areas of health service premises but not necessarily always, and a GP felt that it would be best "where they [*the patients*] would be least stressed by it and where we could sort of explore all their concerns and their anxieties and have a bit of space and a bit of time," (GP10: 35), and although there was no actual place mentioned, the most important consideration highlighted was that the environment should be conducive to allaying stress.

Some of the stress of receiving a diagnosis was attributed to the stigma surrounding the diagnosis.

### *4.6.8 The stigma of the telling – creating a monster from one word*

Doctors perceived the stigma associated with the diagnosis of dementia to be a big issue that sometimes had quite alarming consequences for the patient. Their experience of the stigma was an amalgamation of how they viewed society's response to the diagnosis and their own feelings of their interpretation of how the patient perceived the negative connotations related to the diagnosis. The diagnosis of dementia was still not seen as being one that was understood by the general community "as clear and worthy a diagnosis as other conditions that we can suffer from, so that is a hindrance, there are prejudices around and that for many patients can be the problem and that can mean that their fears are huge." (GP1: 109). This view was shared by a Consultant who felt that the stigma associated with a diagnosis of Alzheimer's disease had not really been addressed by the wider community and was always left to dementia related organisations to attempt to de-stigmatise the illness rather than having it on the agenda of generic organisations. "I think that is unacceptable and I think that organisations such as Age Concern or Help the Aged, or other organisations in elderly care need to grasp the idea that they are in a position to do something about this." (Consultant 3: 147).

The word dementia itself seemed to conjure up fear of different things, such as losing one's personhood, which was seen as being worse than a diagnosis of cancer, fear of people not being able to do anything for themselves, fear of poor memory, but the predominant fear was "the fear associated with the stigma" (GP 5: 213), and the need to be "fighting against a very negative image of dementia that people already have in their heads." (Consultant 6: 307).

These negative images were strongly linked with the word dementia and the stigmatising power of the doctor could "create a monster using one word." (Consultant 2: 107). By giving a diagnosis of dementia it seemed that the doctor was consigning the patient to a life of stigmatisation.

How the doctors perceived the patient as responding to the diagnosis did not always seem to correspond with their views of the stigma of dementia.

### *4.6.9 The impact of 'the telling'*

The telling of the diagnosis had a wide ranging impact on the patient. There were two factors that appeared to influence the reaction and these were the patient's age and personality. There seemed to be a much more dramatic impact on people who were of a younger age, usually under sixty, when they received the diagnosis. The personality of the pragmatist seemed to cope with hearing the diagnosis by taking everything in their stride and just getting on with life. This was not the case for others who reacted in a different way. The impact that the telling of the diagnosis had on patients as witnessed by doctors was divided into three different groupings. These were immediate reactions, feelings and actions.

#### *4.6.9.1 The immediate reactions*

The immediate reactions were witnessed mostly by the Consultants giving the diagnosis and although these were not without emotional attachment, they were reported as being much more matter of fact. There seemed to be very little shock, "very few people have reacted with any sense of shock" (Consultant 3: 48), or surprise, "quite often it is not a surprise to the patient, by that time they have started to think that it might be something along these lines." (Consultant 5: 145).

When receiving their diagnosis many people claimed that they had thought that this was what the outcome would be. Furthermore, there seemed to be relief that there was a disease process. "In my experience people are relieved that you say that there is actually a brain disease that is causing this" (Consultant 7: 149), that explained the reason for the changes that they were experiencing, or that they did not have to hide their diagnosis any longer. "People are relieved that it is out in the open ... they've got a diagnosis and they can talk about it." (Consultant 6: 130).

There seemed to be an acceptance of the inevitable that did not appear to cause distress. "People haven't gone away from a diagnosis session thinking that their world is going to fall apart the next day." (Consultant 3: 23). No-one seemed to think of it as a diagnosis of terminal illness, "they know that it is not the kiss of death, they know there is life beyond the diagnosis." (Consultant 1: 72).

Other reactions seemed to centre on denial, and preparation for loss that doctors felt could possibly lead to distress later.

#### *4.6.9.2 Feelings*

The feelings expressed following the diagnosis were mainly witnessed by the GPs but not exclusively so. The path taken by most patients was to return to the GP a few weeks after having received their diagnosis, by which time the GP would have received a report from the Consultant, to discuss the outcome of their visit to the clinic and also to be prescribed any medication or undergo further investigation requested by the Consultant. It was at this time that GPs reported the emotional reaction that they observed following diagnosis. Strong negative feelings were expressed to the GP and these included anger, anxiety, fearfulness, depression, devastation, shock, unhappiness, suicidal thoughts and feelings sometimes leading to a manifestation of clinical depression. Although their Consultant colleagues had experienced the reaction of relief amongst patients, this was not a frequent expression heard by the GPs, although one tentatively stated that a patient had been observed who had been "almost quite relieved" (GP3: 83), because sometimes patients had the feeling that they were going mad. One GP recalled a patient who had "overdosed and terminated themselves because they've just not wanted to be demented...the diagnosis was just too much for him and he decided he didn't want the indignity." (GP5 : 180). Another stated, "every patient has negative feelings and some of them develop clinical depression." (GP6: 165). Part of that depression may have had its roots in the disappointment the patient felt at not being offered a cure by the doctor as they had expected. Others put the distress patients felt down to having had experience of someone they knew with dementia and thinking about what it had been like to watch them sink slowly into oblivion, "it's so distressing to have seen other people like that they just hate the idea of being like that themselves." (GP8: 120). One GP had to see a patient weekly following a diagnosis of dementia, "because of the emotional upheaval and the emotional distress it had caused." (GP9: 41).

Fear, or being fearful and anxious, was about what would happen in the future and the fear of the perceived losses that the patient was going to suffer throughout the disease process, and the fear of not knowing what the future held. The losses included the "end of life in a way, end of a normal life anyway ... end of their life as they knew it" (GP3: 269), and that included the loss of independence. These strong feelings or emotions were not exclusive to the GPs, but it was less likely for the Consultant to observe such raw emotion at the time of giving the diagnosis. Sometimes these feelings led on to actions which manifest themselves in various ways. Some of these will now be highlighted.

#### *4.6.9.3 Actions prompted by the feelings from the 'telling'*

The actions which accompanied some of the feelings reported above are the doctors' perceptions of how people acted on these emotions. Some people had become more pro-active in setting their affairs in order, whether personal or financial, in preparation, which was seen as akin to a grief reaction. People had been observed as having become withdrawn. The act of withdrawal from their current lifestyle was described as "having to shut off from many things, friends, family, it's a withdrawal, it's a slow, slow withdrawal from the world ... and your part of the world is becoming completely different and it has become passive and unpleasant and dependent and that is not a nice prospect to we who are independent beings." (GP5: 188).

It had also been discussed that after receiving their diagnosis people sometimes deteriorate more quickly, and act out the behaviours they think someone with dementia should be experiencing and portray these behaviours in keeping with their construction of what dementia was like. Another action noted was the slide into clinical depression which could sometimes have been avoided by more prompt treatment or, sometimes if left untreated, could lead to suicide, although this was considered to be rare.

These were the main actions which doctors observed as having led from the thoughts and feelings of patients following a disclosure of the diagnosis of dementia.

## 4.7 The doctors' experience: conclusions

This chapter has presented detailed findings from interviews with 19 doctors around their work with people diagnosed with dementia during the immediate post-diagnosis period. The analysis of the doctors' accounts yielded six main themes: *understandings of early dementia; working within a fragmented system; the difficulty of the work; views of patients' needs; post-diagnostic follow up; the 'telling'*. A detailed summary of the main findings arising from the chapter, and how they relate to the research questions which the thesis seeks to address, is provided below in Chapter 7 at Sections 7.1.1 and 7.1.2. The aim of this concluding section is to highlight the most significant aspects of the doctors' experience.

The doctors who were interviewed for this study expressed a variety of individual understandings around the subject of early dementia. Although common threads emerged, no two doctors viewed the topic in exactly the same way. An important aspect of this diversity appeared to be the influence of personal as well as professional factors. On the whole, the doctors perceived the system in which they operated as professionals to be fragmented and often depending on professional relationships rather than guiding protocols. There was no clear definition of the role of GP and old age psychiatrist, with some functions being interchangeable between the two groups. A few of the doctors regarded the system as sometimes hindering rather than enhancing patient care.

All 19 doctors felt that working with people with dementia was a difficult and complex area, largely due to a lack of both physical and emotional resources and support. The services that were provided were not felt to be adequate to meet patient needs, especially their psychological needs. There was a lack of availability of clinical supervision to help doctors work through difficult decision making processes or to provide support for doctors working through some of the issues that provoked an emotional response, especially for the doctors working full time within the specialty.

Patients' needs were primarily understood in terms of tasks to be completed, such as assessment, diagnosis, treatment and referral to others. There was more focus on the task than on the doctor-patient relationship, although some GPs did mention relationships when they talked about patients whom they had known for many years. On the whole, doctor-patient interactions seemed to be more about an exchange of information rather than a relationship oriented encounter.

Post-diagnostic follow up seemed to be the responsibility of both groups, with people with Alzheimer's disease being followed up by Consultants while GPs tended to follow up other diagnosis such as vascular dementia. There was an acknowledgement that post-diagnostic follow up did not always require to be carried out by a doctor. It was while the doctors were identifying this need for other post-diagnostic services that the main difference in the two groups was highlighted. Consultants rarely witnessed an emotional or catastrophic reaction to the diagnosis whilst GPs reported that they witnessed a vast array of negative thoughts, feelings and emotions. GPs therefore identified a strong need for a post-diagnostic service that reflected this critical psychological need. Consultants also identified this need but were much less strongly oriented towards it than were their GP colleagues. It appeared that they were each seeing the same patient from different perspectives.

The disclosure of the diagnosis was not a contentious issue for the doctors who took part in this study. There was no sign of any reluctance to inform people of their diagnosis. The challenge was more around who should tell. While the Consultants took it for granted that it was one of their tasks, some GPs felt that if they had a long established relationship with the patient that it should be their responsibility to do the telling. Many of the doctors were aware of the stigma that the diagnosis provoked and were wary of the language used as they struggled to try to reduce the stigma by using euphemisms or metaphors.

In conclusion, it is clear that doctors regard themselves as having a crucial role to play at this critical time in the patient journey. They acknowledged that how the diagnosis is presented and how post-diagnostic support is offered and organised is important for patient well-being. This view was encapsulated by a GP who stated that

> "it is such an important time in them kind of formulating how they feel about their diagnosis, how they are going to move forward and how they react at that stage is so critical in a way to how they cope with the disease at a later stage (GP10: 84).

The patient's journey through the diagnostic pathway is presented in Chapter Five.

# Chapter 5

# Pathway to Diagnosis

## 5.0 Introduction

In the previous chapter the professional and personal voices of the doctors have been heard in relation to their understandings of early dementia, and how they view early diagnosis and the subsequent six months. However, the voice of the person with dementia is all too infrequently heard in research. In this and the following chapter, that voice is given primacy. A key aim of these chapters is to present the perspectives of the people with dementia within a relationship context. Previous studies have repeatedly sought the perspective of the person with dementia or their carer in isolation, but have seldom addressed that person within the milieu of their social relationships.

This chapter tells the story of five participants as they journey towards an early diagnosis of dementia. It introduces their key relationships, describes the participatory role of the first person recruited into the study as co-researcher, and presents the key themes that emerged as they talked about their pathway to diagnosis. These themes are: ***an unfamiliar road, no turning back*** and ***the ultimate destination***. The three themes covered all the places visited along the road that the participants followed towards their final stop on the diagnostic pathway. The chapter opens with an introduction to the people travelling that pathway to diagnosis along with significant family and friends who accompanied them on that long and winding road.

## 5.1 The travellers on the road

Five people, who had been given a diagnosis of early Alzheimer's disease, were introduced to this study by three of the Consultants who had taken part in Study 1. As I entered into the lives of the participants I found that it was important to talk about their network of key relationships. Due to the constraints of space allowed within this thesis it is not possible to give detailed biographies of the five case study individuals. I have therefore chosen to illustrate them as network maps, not to advance network theory but to support thinking around how people were accessing support through key members of their social network. In order to build as full a picture of their current lifestyle as possible I have included interests and hobbies, plus the various health professionals with whom they had contact during the study period.

The first person who agreed to be part of this research was a man called James, and his involvement in the study became more than that of a participant. He became a collaborator in the design of this project and for this reason his story has been related in much more detail than the others, because it sets the pattern of how data were gathered and, to some extent, analysed. That pattern of data collection and analysis was then repeated with the other four participants throughout the study.

Although the detail of the process of involving James as collaborator could have been portrayed in the methodology section of this thesis, it was important to place it here because this was as much about the process that James was going through as he worked out how he was going to live with a diagnosis of Alzheimer's disease – and so this method of data collection evolved.

The following section was the result of how we co-constructed and made meaning of the time we spent together.

### *5.1.1 The account of James as participant and collaborator*

My main aim in this research endeavour was for the voice of the person with the diagnosis to be heard and permeate this phase of the research. To do so would require more than good listening and interviewing skills. When I started working with James our agreement was for me to spend time with him. This time was to be spent talking with him, asking him questions, encouraging him to tell me what it was like to be living with a new diagnosis of dementia. However, this felt researcher led and driven. If it was to be a collaborative venture, James would have to become an active participant in the research design rather than a passive participant who responded to researcher questions. I believed that this was important, not only to have user involvement, but also to enable James to have more power and autonomy, and to encourage the continuance of his valued social identity.

James had been involved in research projects in his training as a pharmacist and had also conducted postgraduate research. Two of his adult children had attained PhDs and so he was well informed on the process of research, albeit this was his first venture in qualitative work. Following our first session together we discussed different ways of gathering information. We initially worked out a schedule to meet monthly for three-four hours and to review the process after each meeting to discuss progress and think of different ways of 'finding out'. After our initial meeting, James wondered if I would like to speak to his wife, Mary. She readily agreed, and I interviewed her on her own at first and after discussion with James he suggested that it would be more open and honest if we all met together rather than separately. His wife quite happily agreed to be part of the project and that set a pattern for the three of us to spend talking and listening to each other for the whole six months of the project. James also invited me to accompany him and his wife to the clinic and I did this on two separate occasions with the consent of the Consultant Old Age Psychiatrist who also agreed to these appointments being audio recorded.

Initially, James had decided not to tell people about his diagnosis, however, as the weeks progressed, he changed his mind. He began by telling his friends and his minister. This happened between our second and third meeting and it was this that prompted him to suggest that I interview his friends and minister to see what impact he had had on them by telling he had Alzheimer's disease. He also believed that they would give a good account of what they had observed of his behaviour in the 'telling'. He contacted them to ask for their agreement to participate in an audio recorded interview and once this was secured he informed me of their details so I could send out information about the study and make appointments to interview. This proved to be a rich source of new information. The time I spent with James varied between two and six hours at any one time and was mostly at monthly intervals. However, it was kept flexible and James had my telephone number to inform me of anything in which he thought I could be involved. My visits usually involved talking and listening with James and his wife (who had become part of the project on James's invitation), sharing a simple meal together at his home, or we would go out either in his own community or to the neighbouring city. This too proved a rich source of data as it enabled me to observe and participate in a more social part of his life.

On the fourth visit I took my laptop with me to share the information I had gathered and recorded about them. Normally we all sat on the same chairs when we were doing the recording but on this occasion the positions changed and they sat together and were closer to me, in order to view the laptop. This seemed to create a very significant 'shift' in the relationship and whilst we were closer in space, we were also closer within the relationship, and it did now feel very much like we were all in this enterprise together. The purpose of sharing the information with them was threefold. First, it was an attempt at openness and honesty and to enable them to see where I had their data stored; second, it was to share the life map around key relationships and activities in their life at this time and to check that I had not missed out any crucial relationships or activities of what they had told me; and third, it was to test out my early formation of categories with them. To do so, I realised, would also increase the validity of my study.

The fifth visit was spent discussing the changes that we had already observed and some time was spent planning how we were going to conduct our last session together. I wondered what it had been like for James to be part of a research project and as always he just said, "well ask me!" So we thought about the questions that would be helpful for me to understand how it had been for James and I wrote them out in order for him to be able to think about them before our next session. This was the only time that he had a set of prepared questions and the rest of the time we had informative conversations. When the time came for the final session James had written some of his responses to the questions, but both he and his wife then recorded them on audiotape. We also discussed the format of the data gathering process and wondered if it should be refined for other participants. James's advice was to ask people about how often they wanted to be interviewed, how long they were prepared to spend with me, who else they would be happy for me to interview, and to let each person and their family dictate the pace of the data collection. The method that was 'piloted' with James and his wife gave power and autonomy to the participant as well as ownership over how the data collection was directed. The relationship of researcher and researched still felt very equal and collaborative. The partnership required a fitting ending and following the research design and participation, discussion ensued as to what that would be. It was a unique and special relationship that both researched and researcher had experienced, and so it was again a collaborative decision to go somewhere for a special meal that would be both an agreeable solution and fitting celebration of the work that we had shared together for six months.

Social network diagrams have been created to represent key relationships and interests of each of the participants. Participants and their families checked the accuracy of these diagrams in the fourth month of their involvement in the study.

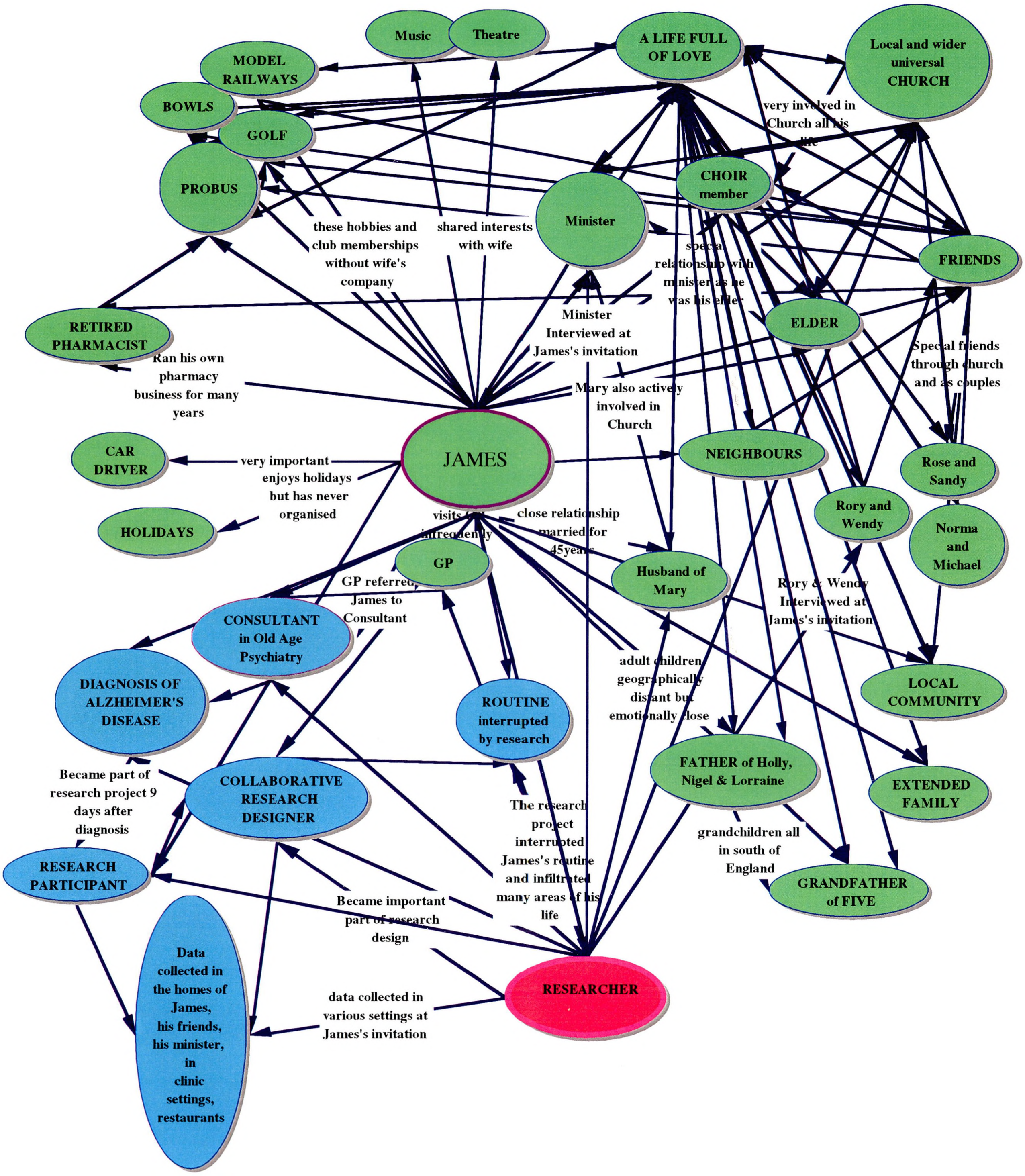
Each participant and their network of relationships are represented by a unique colour. Their GPs are included in the same colour as they all knew their GP prior to their referral and subsequent diagnosis. The diagnosis/treatment path is identified by the same colour throughout. The researcher is represented by the same colour in each of the diagrams.

🟩 James
🟪 Beth
🟦 Ian
🟨 Maggie
🟨 Jenny
🟦 Contacts with secondary Care services & research project.
🟥 Researcher

The first figure below illustrates the key relationships and interests in James's life at the time of the study and following his diagnosis of Alzheimer's disease. The lines and arrows denote connections and relationships within his social network. Arrows emanating from the researcher are the different areas of the participants' life that had been part of the research process: for example, in the network below, the researcher's arrows point to James, his wife, his friends, his minister, his church, and all the secondary care services, with arrows from James to each person and area. Some other areas in his life were also interconnected: for example, some members of his Probus club were also member of his church.

## Figure 1 JAMES

James was the youngest person in the study at 68 years of age. He lived with his wife and had many different interests and relationships. Many of these relationships were interconnected despite representing different areas of his life. He was a very active member of his community.



## Figure 2 BETH

Beth was the second person introduced to the study at the age of 71 years. She lived with her husband George and although her map shows fewer relationships and interconnections than James she nevertheless seemed to enjoy many long term relationships and shared interests and hobbies with her husband and friends.

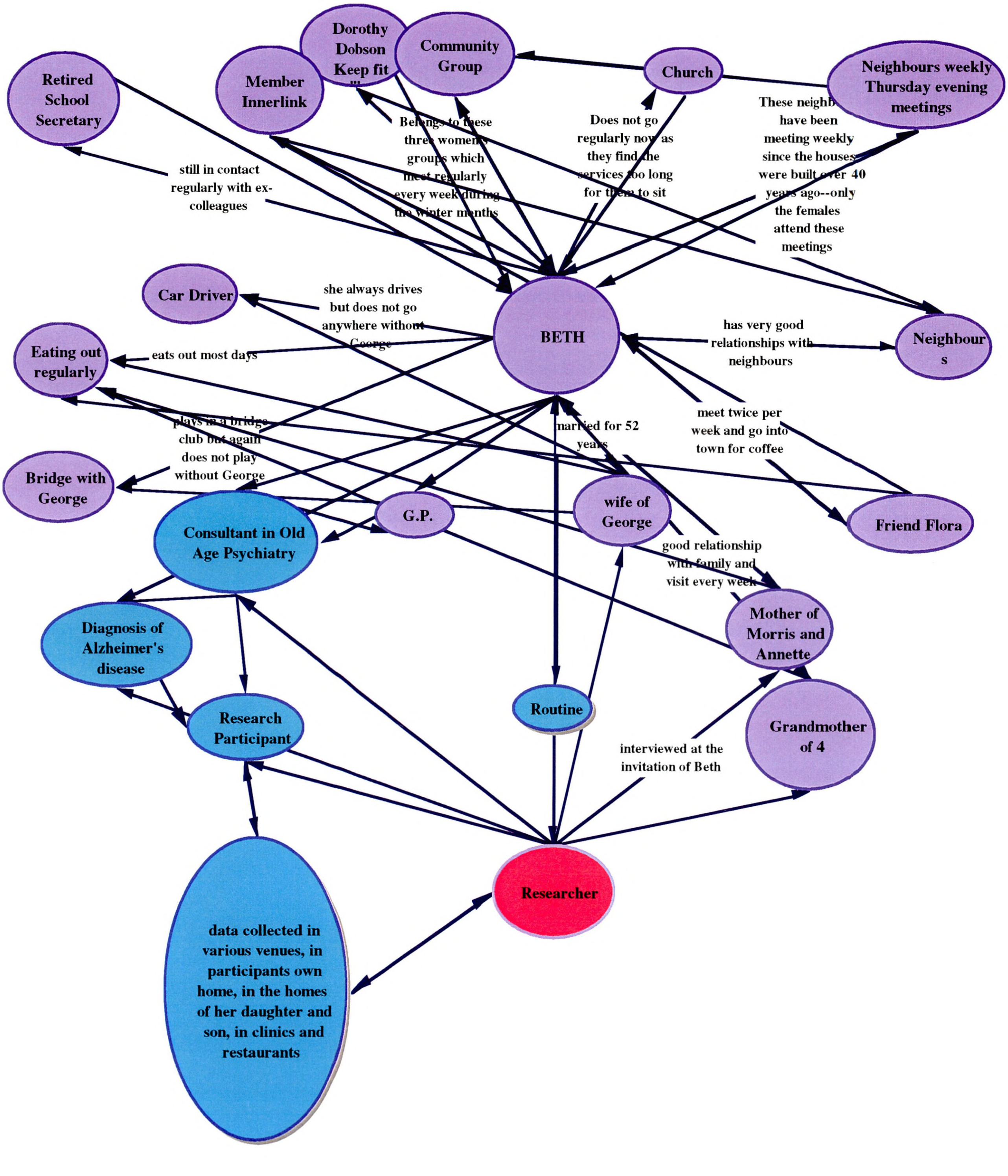


**Figure 3 IAN**

Ian was the eldest in the study at 79 years of age and he celebrated his 80th birthday during the study period. Ian lived with his wife in a small village. His social network had become smaller which was due to his poor physical health which constrained him more than his diagnosis of Alzheimer's disease.

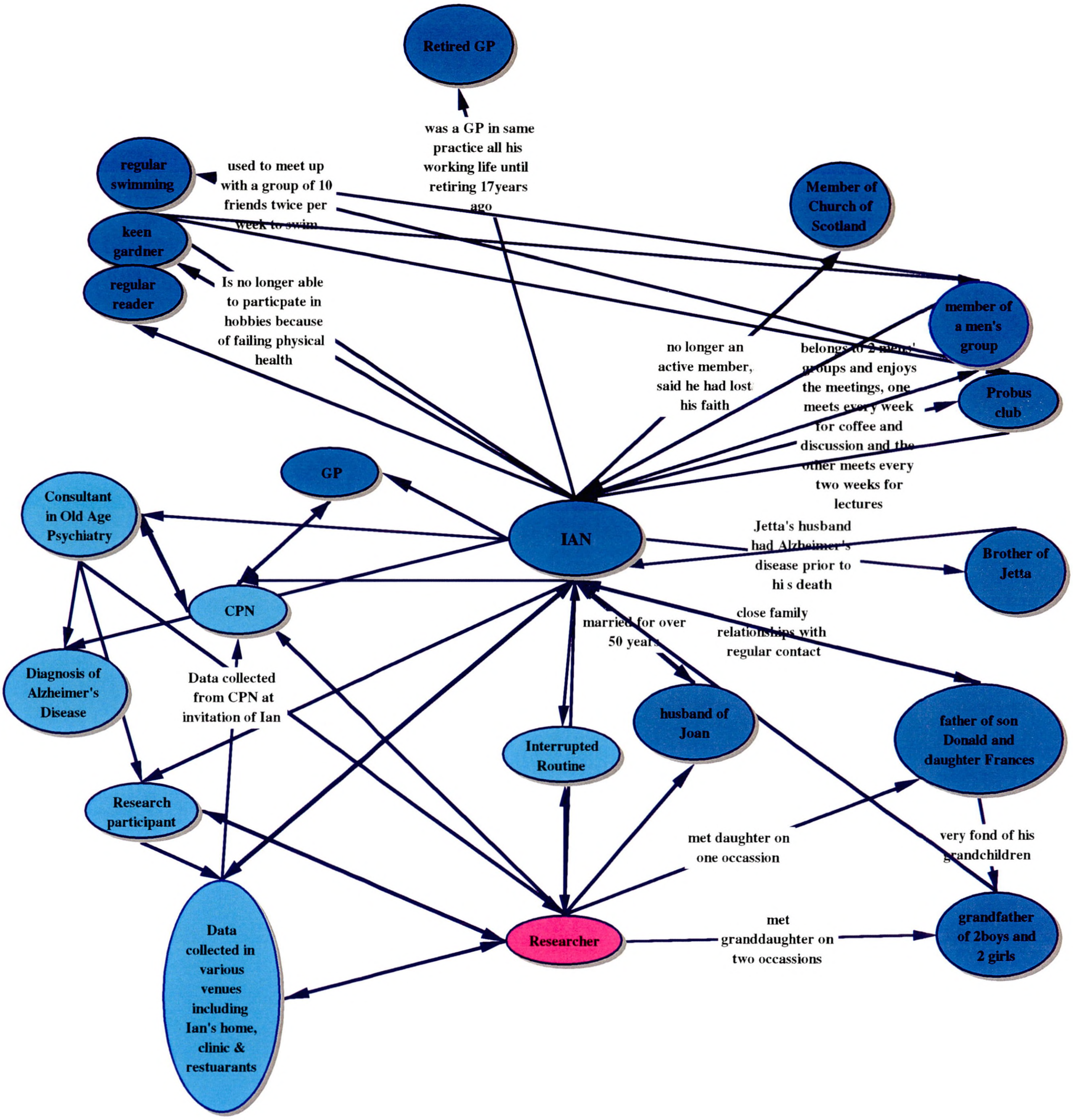


**Figure 4 MAGGIE**

Maggie was 69 years of age and the only one of the study participants who was widowed. Her husband died four years before the study began. She was also the only participant who did not own her own house. She lived in a council house with her unmarried daughter and her fifteen year-old granddaughter in a busy county town sixteen miles from the nearest city. Her map reflects fewer connections and interests than the preceding three participants.

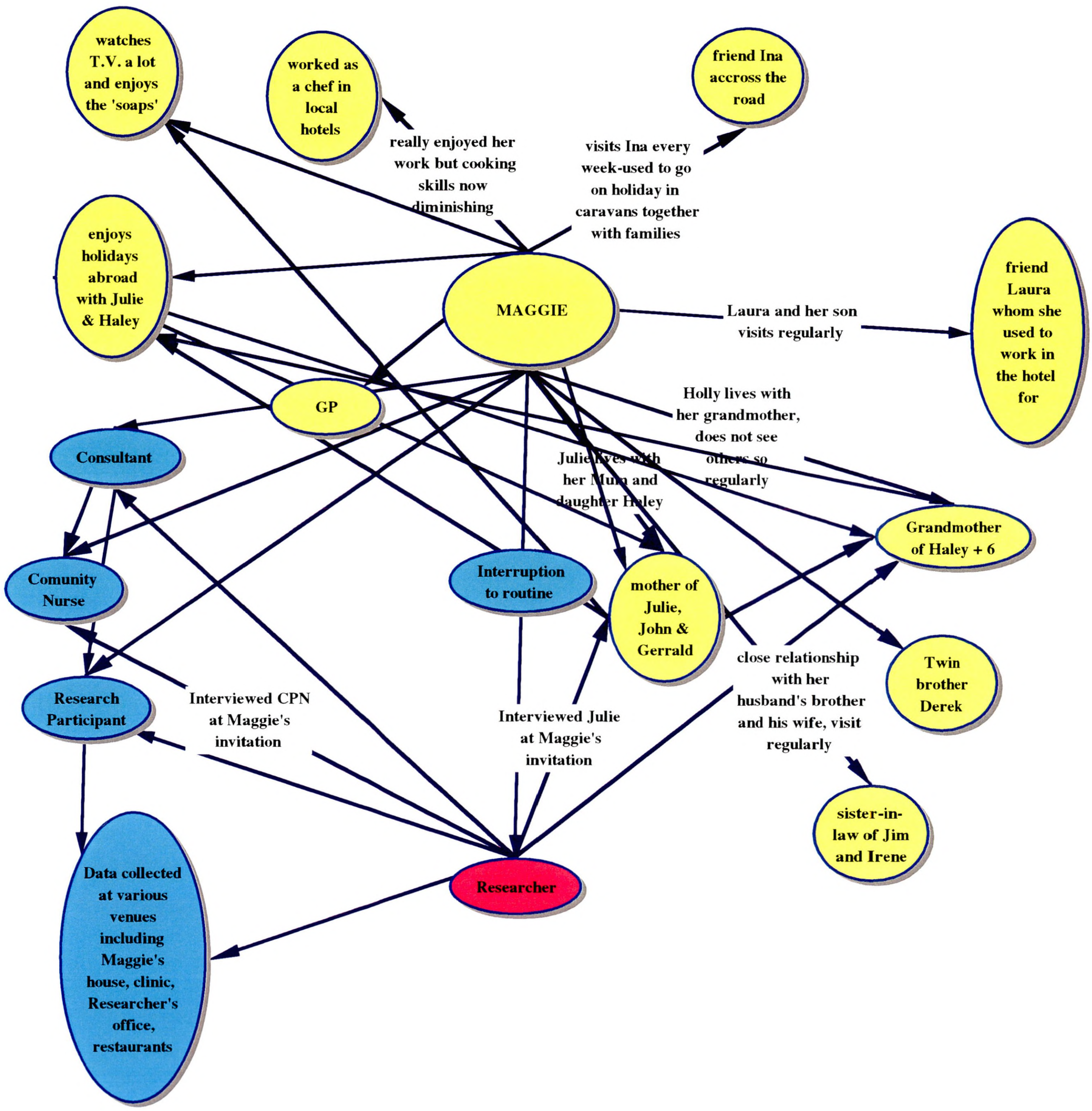
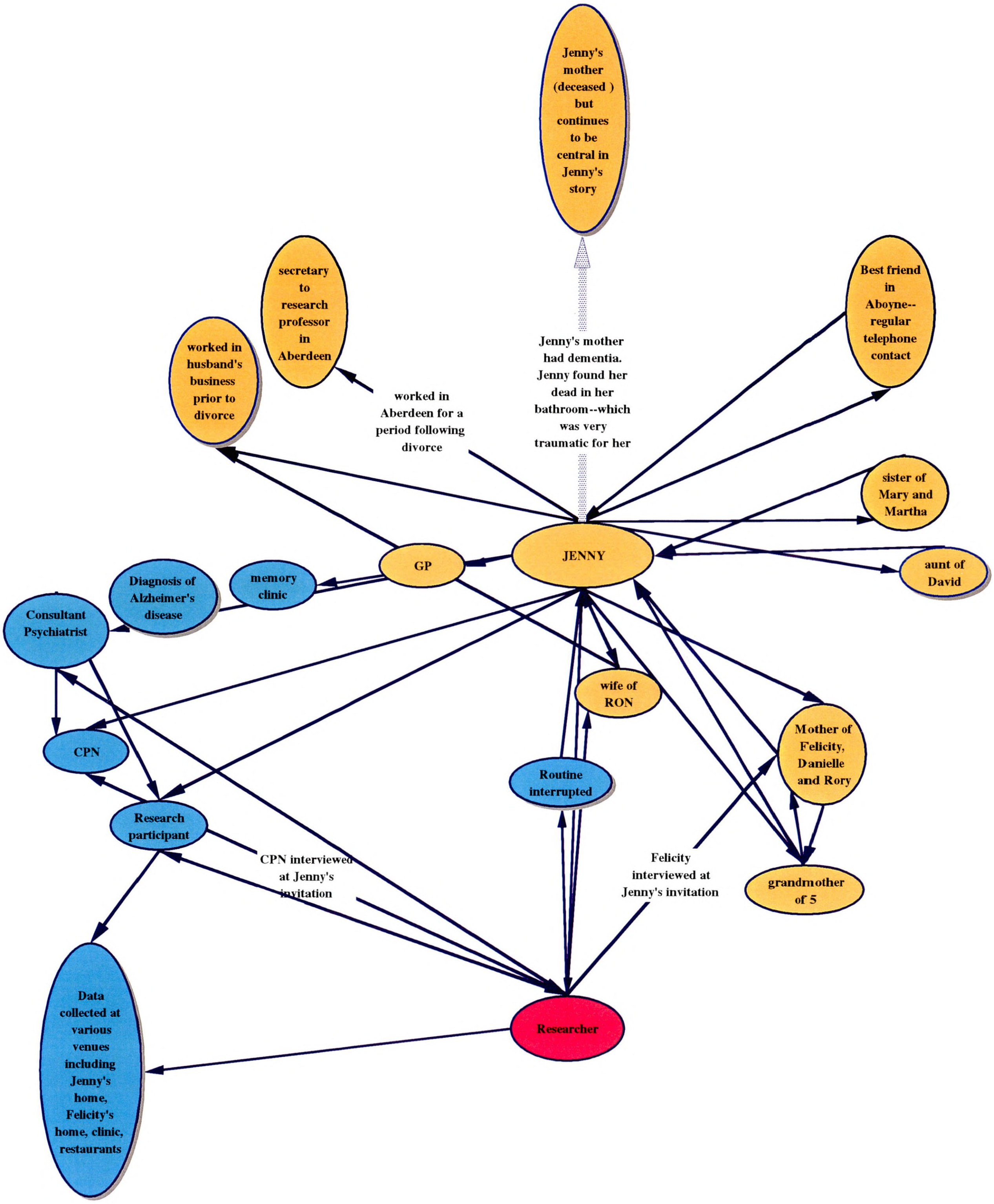


**Figure 5 JENNY**

Jenny was the second eldest in the study at 77 years of age. She lived with her husband Ron, whom she had divorced, but had recently remarried. They lived in a bungalow in quiet little hamlet about 3 miles out of the major city in the region. Her map was shows there were few social contacts outside the family.



The illustrations above showed in detail the social relationships and activities that encompassed the daily lives of the five participants and reflected the travelling companions who were alongside them on this unfamiliar road.

## 5.2 An unfamiliar road

This theme relates the unfamiliar road on which these five travellers found themselves and highlights some of the changes that were happening to them prior to their diagnosis. The changes were reported to me rather than being observed. The themes were: acknowledging the changes; the response to these changes; and the events which precipitated the need for seeking a diagnosis. Some of these experiences were shared by all of the participants and some were unique only to them, but all of the participants were on an unfamiliar road and they did not know where it was leading at this point of their journey.

### *5.2.1 Acknowledging changes*

The changes that people noted mostly were of differences in memory, with less reporting of changes in behaviour. Some of these changes were noted subjectively, "I was aware I had a good memory and this just gradually got a wee bit worse and the symptoms, I couldn't pronounce a word." (Ian 1-908). Sometimes the changes were pointed out by relatives, "George could pick this up as well, you know. I would ask him something and a little while later probably say the same thing again just to check and I never used to do that." (Beth 2-95). Some readily acknowledged that there were changes while others took more convincing

> "I thought I was perfectly normal, you know. I didn't feel that there was anything wrong at all. I couldn't say that I found any pointers along the way that would indicate to me that I wasn't you know, fully appreciating things, but obviously somebody else can tell or notice" (Jenny 1-287)

For others it was a continuance and gradual worsening of traits that were already present and therefore there was a difficulty in assigning a timescale to when the changes began. "I mean that has not been something that has suddenly appeared out of the blue, I have always been a bit like that," (James 5-456), and his wife agreed with this, stating that he had always had a selective memory. Apart from James, everyone else claimed to have had a good memory prior to noting the changes.

### *5.2.2 Responding to the changes*

Different and similar responses to the changes were noted among participants and their families. Jenny was not sure how to respond because, as she noted, she did not know how to respond "because I have not really had a problem of this nature before you know." Therefore, it was very much an experience of being in unmapped territory. She had no previous experience of her own to draw on and when the changes were minimal, then "it doesn't have much effect day to day." (Beth 1-107).

There were some very pragmatic responses to the changes and these included using a diary, relying on a spouse's memory and organisational abilities, going out to eat when the memory deficit affected the cooking skills, giving up driving when it was difficult to remember the directions of a journey, reducing the interaction with the social network, and re-organising outings and meetings when they had been overlooked. Others made comments about the cause of their memory deficit, "after all we are getting old, it will come to us all," (Maggie 3-41), and, "I just think it is because I am getting older" (Jenny 2-65).

The use of humour was also used as a response and Beth, referring to her husband's hearing deficit, pointed to him then pointed to herself saying "no hearing, no memory," (Beth 2-105), and laughed heartily as if to say well, we all have our failings. James commented "well it doesn't make any difference to my golf, you know, I am still pretty poor." (James 4-65).

### *5.2.3 Precipitating events*

These precipitating events relate to events described and were influential in persuading the participants to seek a diagnosis.

They are presented here in stanza format to portray the spoken rhythm of the discourse, which enables the reader to enter more fully into the drama of the story as it was told initially (Gee 1989, 1991).

They are similar in many respects in four of the cases but one case stands out as particularly different. In all four cases the greatest similarity was that it was at the relatives' behest that consultation with the GP was requested. With the other case, it was the person experiencing the symptoms who instituted the appointment. Three of the cases were out of their usual routine at the time, which made the changes more obvious. Beth was coping with her husband becoming seriously ill and being suddenly admitted to hospital, and she described having to try to find the hospital in a strange city, in the midst of winter, followed by the stress of finding that her husband had been moved to another ward, which she said happened frequently. Beth's account of the situation was

"My husband had a quadruple heart op.
It was hellish weather, snow and ice
I hated it
It was dark
There was nobody round about
Then I had to get a car park
I had to find my way to the building
They are huge places
I would go along these long corridors
Find he was in another ward
Had to go back and start again
I think that took quite a bit out of me actually
I found that quite a strain"
(Beth 1-35)

Jenny was on holiday abroad and was misidentifying her husband and at times not recognising him at all. Her husband's account of the situation was

"We were out on holiday
We were down in Spain
We were in an apartment there, which was very comfy
Quite easy, a pool there
But one night she sort of woke up about midnight
Started to ask me who I was and why I was there
It went on almost the whole night
It was about four or five in the morning
I realised we had a serious problem
It really was very serious at that stage
I didn't know what to do with it at that point"
(Ron 1-37-43)

James had forgotten where he parked his car and could not find it – he had parked it in a different place from his routine park. His wife's account of the situation was

"He went to town
It was a Saturday
I can't remember what he went for
But he went off on his own
And he was away a lot longer than I was expecting
Then he phoned…
I can't remember where I've parked the car
So I said
Well I'll come in on the bus and we'll look together for it
We were round

Walked and walked and walked
I said to James I just don't know what to do now
We've looked almost everywhere
We went to get the bus
And just before that I said
Well you know there's one place we haven't looked
That was round in St John's Square
But we never, ever go there,
But I said I think we'll have a look
And that's where it was"
(Mary 1-712-714).

These events were all frightening for both the people and their relatives. It was the results of these experiences that allowed the relatives to make GP appointments for the participants. Maggie did not have a precipitating event, and it was her daughter's knowledge of dementia that enabled her to recognise the changes in Maggie and the need to consult the doctor. And Ian, who was a retired GP, had diagnosed himself before he consulted his doctor and he did not discuss going to the GP with his wife which was completely different from the others who were all accompanied to their GP consultation by their relatives.

Four out of the five people did not actively seek a diagnosis on their own accord, and only Ian was proactive in seeking a diagnosis. Therefore, it would be wrong to assume that they all wanted a diagnosis, but their relatives wanted to know what the reasons were for the changes. Four out of the five had a history of changes over an average of an 18 month period and only James had a longer history of memory changes, although it was difficult to put a time to this due to his long history of absent mindedness, and because he was reluctant to be investigated by the medical profession until the incident when he could not find his car.

All five of these people had received their diagnosis by the time they entered into this research project and it was not always a smooth path to get to this point. Once these people were entered into the medical system there was no turning back and all of them went on to have full investigations. However, negotiating the system was not simple or altogether straightforward.

## 5.3 No turning back

No turning back relates how the people within this study negotiated the health care system from the time of their visit to the GP until the time of diagnosis. It tells of the difficulties that were faced trying to find the local Psychiatric Hospital, their thoughts and feelings about the issues, their experiences of the system, and recounts their feelings of powerlessness having to wait until the system was ready to provide a diagnosis.

### *5.3.1 Entering the system*

The entry into the health care system that specialises in dementia is almost always through the GP. No-one is usually referred for diagnosis by any other route and it would be very rare for this to happen within the services that this study covered. The visit to the GP for four of the participants was very straightforward. Elementary testing was carried out and preliminary discussions took place as to what the diagnosis might be, prior to a referral being made to the Consultant in Old Age Psychiatry. These were the four people who were prompted to seek appointments with their GPs by their relatives and they were accompanied by their relatives on their visit to the GP

> "I had to really push him to go and have a diagnosis. I didn't know whether that was because he didn't feel different or because he was afraid of getting the diagnosis, I didn't really know" (Mary-James: 2:81)

For one person, Ian, the entry into the specialist service took longer and required repeated requests and more perseverance to achieve a referral to the specialist. He visited the GP on his own and said that he reckoned he had got the early symptoms of Alzheimer's disease

> "He [*the doctor*] almost poo-pooed me and well I said maybe I am making a fuss about nothing ... but I am maybe having the symptoms of Alzheimer's disease, och he says rubbish, so I went away ... he says a lot of people your age their memory isn't good and well this is quite right, so well I said okay then, but as the weeks passed it got worse" (Ian 2-19 & 3-129 & 2-23).

Ian had to return twice to get a specialist referral

> "I went back to him in two or three weeks and said I wanted to see a specialist, I am sure it is Alzheimer's, oh well, he said, if that's the way you feel I will make an appointment" (Ian 3-129).

It took some time to get the appointment and for the Consultant to be involved as the GP initially referred Ian to the Community Psychiatric Nursing Service that then had to go back to the GP and request that he send a referral to the Consultant. Not a straightforward journey for Ian. It took him quite a long time to get into the system.

However, it took Jenny even longer because her GP referred her to their local memory clinic in February and an appointment came through for mid-November. Jenny's husband, because the situation described above was becoming more acute, had to write in desperation requesting that she be seen earlier and an appointment was given for September. Four of the people, accompanied by their relatives, had to make their way to the local psychiatric hospital to get the diagnosis, and Jenny was seen in the General Hospital Memory Clinic. Finding the clinic in the local Psychiatric Hospital was likened to trying to find the proverbial needle in a haystack.

### *5.3.2 Finding the road into the psychiatric system*

The first visit to the Psychiatric Hospital was quite an experience for the people in the study. For those who had not been there before it was quite a puzzle to find. You could be forgiven for not being able to find the *'local asylum'* because, as with most nineteenth century asylums, it was built as far out on the periphery of the town as possible, tucked away up at the top of the hill, although since it was built the borders of the town had extended and an up-market housing estate had been developed nearby. The grounds of the hospital sprawl over a large acreage with in-patient wards and departments planted throughout the grassy gardens. The clinics of the Consultants in Old Age Psychiatry are held in their offices which are incorporated within the main building which dates back to 1826. This building used to be full of patients, but it is now utilised for office space and administration departments. All of the Consultants used the same waiting room, which was situated quite near the main door and to get to it you have to come through reception where, hopefully, there will be someone to guide people to the waiting room which sits to the right of the grand entrance hall. This waiting room has enough seating for about twenty people. It has a brown, patterned 'sixties style' carpet, with drab wallpaper and information leaflet stands hung on the walls. There are some tables round the edges beside the seats and in a corner was a monstrous cheese plant which took up more than half the wall space on one side of the room and sprawled proprietarily over its territory. It could feel like this gigantic cheese plant was taking over the asylum. Within this grand listed building, in the drab brown room inhabited by the giant cheese plant, the majority of the people in the study waited to hear their fate.

Beth and her husband, George, recalled their initial encounter with the hospital

> G: It is an extraordinary building, like a luxury hotel in a way
>
> B: That's right, all curved and lights, no more like the place it is, it's unbelievable
>
> G: Well, the first time we came it was a bit of a nightmare, nobody came and we sat there
>
> B: We sat for ages and ages
>
> G: And then we saw a woman going along and we asked her and she went away to find out what was happening
>
> B: It hasn't happened again though. The first time we waited to go in and it was a long sit, we began to wonder if we were in the right place didn't we?
>
> G: The right place? We didn't know where to go in the first place, we went in the first gate you come to and of course we were in different places before eventually getting diverted to this
>
> B: Main building
>
> G: Centre as it were, but we know the routine now, we know how to get there, yet he [the consultant] is in a poky wee room
>
> B: It's a dreadful wee room, all these rooms and he is in this room, I mean they could put him in the waiting room, we've often said it's [consulting room] like a cupboard You would think that they would be bound to have a room, he is so nice with it isn't he. Often when we went we would both say, fancy squashing him into there. (Beth and George 1-325-338)

For Beth and George it was an anxiety provoking experience, described by them as 'a bit of a nightmare.' First of all, the building belied its function, appearing more like a hotel than a hospital, and second, they were not able to find their way in, having to choose between three entrance gates, and having chosen the wrong one they had to negotiate their way within the grounds to the main building, like finding a way through a maze. Once they found the right place they were made to wait for what seemed like a long time, and this led them to believe they were in the wrong place. Eventually they did find someone to assure them and finally, after their long wait, they had their consultation in what felt for them like an exceedingly small room which seemed to both Beth and George to be inadequate and inappropriate for the purpose of the assessment.

Finding their way geographically round the system was something that was not straightforward. However, none of them embraced the thought of having to go to the Psychiatric Hospital for their investigations well, for fear of the stigma that surrounds mental illness and mental health institutions – Maggie least of all

> "I didn't want to go up there, I just didn't want to go, but Julie [daughter] said it's only a hospital, there will not be anyone about, it's not as if you are going into hospital, it's only to an office. It was all right. He was quite nice anyway" (Maggie 3: 234)

The first visit was always tough for the people waiting to see the specialists. However, the time in between the consultations, examinations, scans and waiting to hear their diagnosis was another source of anxiety.

### *5.3.3 The long wait for results*

The initial appointment with the Consultant was normally an exploratory one with history of the progression of the changes being taken from the people and the relatives who accompanied them to the clinic. Consultants occasionally had a medical student or nurse attending the consultations, but most of the time they were on their own. Blood tests would have normally been completed by the GP and the routine in this area was to order an angled CT scan.

The different possible diagnoses were discussed although this knowledge was not always retained by the recipient, "I can't remember if he gave it a name or not. No, I can't remember that." (Beth 2:15). Some of the participants and their families had their own ideas about what the diagnosis was going to be, especially Ian, who had diagnosed himself. James's wife thought that it would be vascular dementia because that is what her father had and she saw the similarities, while Maggie's daughter thought that it might be Parkinson's disease, and both Jenny and her husband Ron had their suspicions that it could be Alzheimer's disease, although his suspicion was stronger than hers. Beth did not give it a name.

The wait for the results of the various tests and investigations, on which the Consultants relied for confirming their diagnosis, took anything from five months to just over two years. "There was a long gap of time when not a lot was happening and then I rang up and I did think I lost my cool a bit. I was concerned about the long delay." (Ron Jenny 1: 111). The reasons for the long gaps were that there was a long waiting time for scans, "I've to wait six or eight weeks. He says it will take a long time. I am not really too keen to go and get an x-ray you know … I would rather he just left me alone" (Maggie 1: 13 & 3:7). Because x-rays have to be interpreted by a radiologist, and because of staff sickness, both in the radiology department and with Consultant staff, waiting time at the Memory Clinic was nine months. A two year wait for the diagnosis of Alzheimer's disease was experienced by Beth, who was originally diagnosed with Mild Cognitive Impairment, which over the two year follow up period had gradually deteriorated and following further scanning, the diagnosis had changed.

Each person had different periods of time to wait for the diagnosis once they had entered the Secondary Care system. Each reacted differently to the waiting time. Some were angry, some were reluctant to have the tests carried out, some were anxious and some were scared. But for each one in the study, once they got into the system, there was no turning back and they were on the road to their ultimate destination.

## 5.4 The ultimate destination

The ultimate destination tells of the experience of receiving a diagnosis of Alzheimer's type dementia and of the response to receiving that diagnosis in the following two weeks. The journey towards this final point had been a different experience for each person. Some had their diagnosis given at the first meeting, which was called a 'working diagnosis' by the Consultants, with the confirmation of that diagnosis coming once all tests had been concluded. Some saw the same doctor each time they had an appointment while others had their first encounter with the Consultant at the time of receiving their diagnosis. Some Consultants seemed to work on their own while others were part of a diagnostic team with Geriatrician, Neuropsychologist and Old Age Psychiatrist working together to come to a diagnosis. Sometimes coming to a diagnosis took much longer than had been anticipated by the person waiting for it. The diagnosis was given differently by each of the Doctors involved. Some were very tentative, while others were very definite.

All patients had relatives present in the consulting room when they were given their diagnosis, yet none had been asked if they wanted them present. Once all the information was to hand, the people in this study were all given their diagnosis of Alzheimer's disease.

### *5.4.1 Receiving the diagnosis*

Getting the diagnosis was a major event in the lives of the people receiving it. James recalls that he was told even although he was quite emotional at the time, and he was clearly still very affected by it. "Honestly, I find it difficult to say...they said that this was the start of something which was not very pleasant and was probably Alzheimer's disease." (James: 1 43 & 87). His wife continued by saying that she had gone into the appointment with James and recalled the Consultant saying "I've been having a look at the results of your brain scan; you had these tests with Dr— and he said there's not a lot showing on your brain scan, but he said I can tell you it's not vascular, therefore it's Alzheimer's." (James-Mary: 1757). They felt to them that there had been no lead into this diagnosis and all that they received were 'matter of fact' statements. They also felt that the appointment was too short to serve the purpose well. In a later interview this couple felt very sorry for the Consultant and James asked

> J: How do you tell people they've got this kind of problem...it is a very difficult thing I think for him to do
> M: I suppose to an extent he can't get emotionally involved with the patients
> J: Oh no, that would be disastrous
> M: But I think he ought to be aware of how devastating the diagnosis is.
> (James: 6: 622)

While they were acknowledging the difficult task the doctor had in conveying the bad news, they were also looking for something in return – acknowledgment of their devastation at having to receive such a diagnosis. Whilst James remembered clearly what he had been told at diagnosis that was not always the case with the others.
Beth remembered getting the diagnosis when she got her scan results

> "The scan confirmed that I had got what we thought I had ... that my memory had gone a bit... I can't remember if he gave it a name or not. No I can't remember that ... I hadn't forgotten it but I just couldn't remember what the name of it was. I knew it was, I suspected it, you know that's what it probably was before we started" (Beth: 2 7-27)

Although she remembered what it was she had been diagnosed with, she could not, or would not name it. She acknowledged the name when I reminded her of what the Consultant said because I had accompanied her to that appointment, but throughout the study she failed to verbalise the term 'Alzheimer's disease'.

Jenny and her husband also found the diagnosis giving appointment very short

> "Dr— only saw her and said well in my opinion you really have an early Alzheimer's ... at that point they then said well, it was quick appointment, all they said was the community team nurse situation was set up and off we went" (Jenny-Ron 103).

Jenny had had extensive tests in the memory clinic prior to the appointment to impart her diagnosis and again, for them, it all seemed very brusque and to the point.
For Ian, the situation was somewhat different; he was waiting to have his own diagnosis confirmed. He had been sure of this for some time prior to his appointment to hear the results of his scan. The Consultant showed him the picture of the scan

> "He showed me the wee variation with this, so I said I was right after all ... there was not very much to ask because it was quite clear ... the doctor said they will try out this tablet and he said it might have no effect at all, it might have some effect, but he said I can't tell, it differs"
> (Ian: 2-55 & 215)

Having had his diagnosis confirmed was satisfying for Ian at some level. To know he had been right all along was important to him. It was also important that he saw the evidence on the scan and was prescribed medication, all procedures that he knew and understood within his own sphere of medical knowledge.

When Maggie got her diagnosis she was also invited to look at the scan and the Consultant explained all the parts of the brain to her. She told me she could not remember much about the consultation because she had been quite nervous and had not wanted to go. She could not recall what the Consultant had told her was wrong with her. When Alzheimer's disease was mentioned to her she remembered that was what she had had been given the pills for, although it was her choice whether to take them or not. "I can't remember what he said...I don't have to take them if I don't want to take them. I just have to say there and then I don't want them but that's all I can mind." (Maggie 3: 251).

Each experience of receiving a diagnosis was different, as was the recollection of what was said within the consultation. For two it was difficult to say the word, while for two of the others it was difficult to remember the word, but for Ian it was an affirmation of his own knowledge as a Doctor when the Consultant agreed with the diagnosis he had already made. Within the consulting room there was always a polite exchange of conversation following diagnosis and an opportunity to ask questions, but this was seldom taken up. For all participants, hearing that diagnosis was quite an emotive time, and all they wanted to do was to leave the consultation as soon as possible after the diagnosis had been given. They displayed little emotion in front of the Consultant. However this social façade was dropped when they got out of the clinic and their reaction to their diagnosis in the immediacy of time that followed diagnosis was recounted and recorded. It is now presented.

### *5.4.2 Reaction to the diagnosis*

Four out of the five people in this study had not actively pursued a diagnosis but it had been pursued on their behalf by their relatives, and in some ways that made them passive partners in this endeavour. Only one person, Ian, the retired GP, was proactive in seeking a diagnosis and his reaction to receiving it was very different from the other four. As stated earlier, his diagnosis served as an affirmation of what he had diagnosed himself accurately, and he felt good, not about his diagnosis, but about his continuing medical ability to recognise the changes in himself and assign the cause of them to a disease process which was confirmed by a brain scan and a Consultant Psychiatrist.

The remaining four had similar reactions to each other. Some of them had suspected Alzheimer's disease or other types of dementia prior to their consultation. All of them experienced shock to a greater or lesser degree and fear for the future when the diagnosis was eventually given.

Jenny described it as

> "a pretty devastating diagnosis, you know, and it would always be that to me ... I didn't believe it in the beginning, although from what I've read I was wishing to goodness that I didn't have it you know That has been the worst episode yet for me." (Jenny: 5-169 & 1-17).

For Jenny, receiving that diagnosis was distressing. The knowledge she had gathered from reading about Alzheimer's disease had been frightening and she remembered sections of a book ['Iris', by John Bayley] very vividly and was fearful of her future. Although she cared for her mother who had dementia, it was the story of Iris that she remembered and referred to.

Maggie was similar in many respects. She also felt shocked by the diagnosis and perplexed at not being able to work out why she had this diagnosis. "I got a shock, I really did...I don't know how I have got this. I am a twin you see and he is fine so far anyway." (Maggie: 3-11 & 19-25). Maggie thought that if she had it her twin brother would have it as they have other ailments such as osteoarthritis in common, and was perplexed as to why he did not have it and she did. She was also scared by her knowledge of dementia, which came from programmes she watched on television, "I was upset because I have seen a lot of people on the television and you see the state they get into...when I watch the folk on the television that's what I watch and there is a programme it sometimes comes on and I watch it and I say oh don't tell me I'm going to come to that." (Maggie 3: 29). She continued to say that she had seen nurses on television not treating people with dementia very well and she was anxious that she would be treated badly in the future if she were to go into residential or nursing home care.

James's initial reaction was to think "it has been a blow, yes, yes...I must admit it [*the diagnosis*] kind of bowled me over to start with. I think I fell a bit silent." (James: 1-574 & 3-573). His thoughts were that he "was on the slippery slope and that things were going to go down and down and down and I would end up, well I don't know, an incoherent vegetable." (James final interview: 55). This again displayed James's fear of what he would become, and what would become of him, in the future. He thought that his world had come to an end. He knew he had a bad memory and he knew that Alzheimer's disease was associated with a poor memory but he had not put the two together and he associated it with people much older than him. He was 68 years of age when he got the diagnosis and consequently the youngest person in the study.

Beth described herself as feeling "not happy" (Beth: 2-31) when she heard the diagnosis, despite the fact that she seemed prepared for it. She had been attending the Consultant's clinic for two years prior to the diagnosis being given.

> "I knew really when I went in first you know that it wasn't just plain forgetfulness ...we knew something wasn't right, we both of us I think guessed what was coming, you know, couldn't have been anything else really that I could think" (Beth: 2- 75 & 117).

Nevertheless, she was still stunned and could not believe it because she felt that she was managing well in doing all the things she used to do. Her fear for herself came from worrying what would happen to her if anything happened to her husband, as she had become more reliant on him. She never did say the words Alzheimer's disease.

## 5.5 Summary

In this chapter the pathway to a diagnosis of Alzheimer's disease has been followed through each twist and turn. For four participants, this was not a pathway of their choosing as they had been set on it by their relatives. For all, it was not a pathway that they desired to be on or even near.

The diagnostic process took varying amounts of time ranging from five months to two years, and delays were due to staff sickness and long waiting times for scans and results. However, once these results came in, the diagnosis was given to each person and their family member by a senior member of the medical profession, four by Consultants in Old Age Psychiatry and one by a Specialist Registrar in Psychiatry. The ultimate destination on this journey was to have a diagnosis and they had all reached their destination. Or had they? What happened in the consulting room could be observed by the doctors but when they left that room what happened to the people who now had received that information from which there was no turning back? They could not live life as they had prior to the new knowledge they now had about themselves, because what they had been told in that consulting room would affect who they were, how they thought about themselves, how they acted, and how they constructed a different identity that would incorporate (or not) the diagnosis of Alzheimer's disease. It is rare for a researcher to gain access to people with such a new diagnosis and I was privileged to be able to gain that access. The five people with whom you have become more familiar in this chapter all agreed to be part of this research project for the duration of the six month period following their diagnosis. The following chapter will concentrate on these six months and continue to tell the story of what happened next to these five people who all now had Alzheimer's disease.

# Chapter 6

# Dealing with the Aftermath

## 6.0 An Overview

This chapter tells the story of what happened in the lives of the five people in the study who had been diagnosed as having early Alzheimer's disease. All of these people entered the study less than fifteen days after receiving their formal diagnosis and it is from this time, and during a subsequent period of six months, on which this chapter concentrates. The co-construction of a different identity, as a person with Alzheimer's disease, was the underlying/overarching theme of the whole process through which they were going. This different identity was constructed both implicitly and explicitly, through exploring various issues current for them at the time. It involved all of them in a difficult process of trying to come to terms with their diagnosis. Their different identities emerged in the face of a pessimistic framework of spoiled identity thrust upon them by society and its perceptions of illness and disease. Not only did they have to grapple with their diagnosis but also with their perception of how society now viewed them. There were four key themes that guided this process: *struggling with the emotional impact*; *daring to talk about Alzheimer's disease; re-authoring their story;* and *the challenge facing relationships.*

These key themes represent the 'aftermath' that had to be dealt with following the diagnosis. Each of these themes were inextricably linked with each other and were interwoven as they laboured to find meaning in their new situation. Although they are presented here in linear fashion, there were no time lines for each theme, neither was there an order – they unfolded in parallel throughout the six months, as a process in progress. Just as illustrated in the relationship maps in chapter 5, the *complexities* of this process and the relationships involved were of paramount importance for understanding what happened to these people.

## 6.1 Struggling with the emotional impact

*Struggling with the emotional impact* tells of the emotional turmoil that people experienced following the devastation of receiving the results of the diagnostic process and of the myriad of emotions that were encountered during this time. The emotions experienced by the five case study individuals varied in their duration and intensity, but it is fair to say that all were left with feelings of dejection, distress and devastation, leading, in some cases, to depression. The most frequently felt emotion was that of fear. Other emotions described were feelings of uncertainty, bitterness, loss and relief.

The emotions elucidated in this section were mainly seen as negative feelings. There were positive emotions experienced and they will be reported in further sections of this chapter. The emotional processing continued over the six month period and how each individual processed these emotions was also different. Some were more inclined to internalise their feelings and try to work through them on their own, while others were more open to sharing these feelings and thoughts. There was no predictable pattern and although they are reported here in what appears to be separate sections, that does not reflect the order in which they were experienced. This is done merely for pragmatic reasons, for clarity of reporting and understanding, and is not a natural division.

Positive and negative feelings were felt at different times and were interspersed throughout our conversations together. That each person struggled with their emotions became more evident over the months of the study as they became more comfortable in articulating their feelings during our conversations. One of the most notable influencing factors in how they co-constructed meaning from these emotions was their previous knowledge of Alzheimer's disease, which again was different for each participant. Prior to the emotional impact being discussed, the three domains of participant knowledge are presented.

### *6.1.1 Influence of previous knowledge of Alzheimer's disease*

The participants all had different experiences and knowledge of Alzheimer's disease and this could be broken down into three different components: professional knowledge; personal knowledge; and knowledge gleaned from the media. But their knowledge did not make them immune from having to process their different emotions, but it did inform how they constructed a view of how others would see them. They all knew that they had been diagnosed with a degenerative disease that would not be a stable entity, but would progress. It was also this knowledge that underpinned much of their anxieties and fears.

### *6.1.2 Professional knowledge*

Two participants had professional knowledge. Ian, who had been a GP, and James, who had been a pharmacist. Both would have agreed that their professional knowledge was not as up to date as it was when they were in practice, although James did know about the latest pharmaceutical research

> "the report I saw in my pharmaceutical journal about vitamin C and E taken together can arrest the progression of Alzheimer's disease and I hope to take this further and see if I can find out more information about that which would be a great benefit" (James: 1 230)

Both had enough professional experience to know what it was that they were dealing with. Ian recalled some patients he had cared for who had poor memory function and said they would come in to his surgery worried about what to do, "but that was before it had this fancy name." (Ian:1 157). And he described how in his day it was known as senility. Both of these men referred to having dementia as akin to "like having someone who has tuberculosis," (James: 1-218); and "I mean it's an illness isn't it, it's nothing to be ashamed of, it's an illness" (John:1 434); and both were working from the biomedical model of understanding.

### *6.1.3 Personal knowledge*

Personal knowledge mostly came from having a member of the family or close friend who had been similarly diagnosed of having some type of dementia. Four of the five participants had close family relationships with someone who had dementia with only one, Maggie, not having had any previous familial history. The experiences varied from being a very involved 'hands on' carer to being aware that there was something just not quite right about the relative. James thought that because his father-in-law was in his late eighties, that it was different from what he had been diagnosed with, thinking that his father-in-law's dementia was really just old age.

Beth could remember her father-in-law also having difficulties in his old age and towards the end of his life, but did not relate that directly to her current experience, while for Ian and Jenny the memories of their relatives were much more vivid and frightening. Ian's brother-in-law, who was looked after by his wife (Ian's sister), had frequent aggressive spells, "he was attacking her and then he stopped that and the keys they have to be hidden from him and there was something else … he disappeared." (Ian: 4 21). Both Ian and his wife were fearful that the time might come when he might experience the same type of behaviour.

Jenny, on the other hand, had been looking after her mother up until the time she died, visiting her three times a day, until one evening when she visited she could not get an answer at the door. Using her own key, she entered her mother's flat to find her lying dead on the bathroom floor

> "I can't understand yet you know my mother got out of the bath. Well I only got home about 5.30 at night I had been at work and there she was lying on the bathroom floor and her legs were all burned like she had stepped into hot bath now she had a bath everyday and it was always about 11 o'clock" (Jenny: 2 541)

Prior to this episode she had to contend with her mother wandering about the city and also inviting what she described as 'tramps and tinkers' into her home, unaware that she could be in danger. She was very involved in her mother's care and remembered vividly the different problems that dementia had introduced into her life through her mother – none more vivid than the night she found her mother dead.

The personal experience of the four participants was very different but it all had an effect on how their own construction of how they perceived themselves with Alzheimer's disease. Only Maggie had no personal experience and cannot even recollect anyone she knew with dementia. She had heard her daughter, who was assistant manager in an 'Elderly Care Home', discussing some of the residents she cared for as having dementia and describing some of the problems that they experienced, but Maggie had not had any face to face contact with anyone else who had a similar diagnosis to her.

### *6.1.4 Knowledge from the media*

Knowledge from the media was something that all of the participants experienced to a greater or lesser extent. These experiences ranged from television documentaries and characters in soap operas to vivid memories of books and articles in papers and magazines, to breakthrough research being reported on the national news. This knowledge, for some reason, seemed to appear more powerful to them than their own personal experiences.

The book that was remembered most vividly was written about the author Iris Murdoch, by her husband John Bailey, in which he details the journey they had through Iris's dementia – and this had left its mark, especially on Jenny. Although it was several years since she had read it, the impression it had left on her was very clear

> "It's ages since I read them but I just thought oh gosh it must be a terrible thing and then the whole thing struck me as very depressing...and I thought it must be terrible and it never sort of left me...it's years ago since I read it, but it still sticks in my mind. Maybe it was harbouring the idea that has brought it on because although my mother was forgetful I don't think she was at that stage you know. Well maybe they didn't diagnose it then" (Jenny: 1 127 & 135 & 139)

So although Jenny's mother had dementia, and she was very involved in her care, she does not associate her own experience so much with her mother as she associates it with what Iris Murdoch was experiencing. Somehow it was more akin to her experience. She was also aware of "some pretty well known people who had the same thing." (Jenny:1 339).

Maggie was influenced by what she has seen on television

> "When I watch the folk on the television that's what I watch and there is a programme [about someone with dementia] it sometimes comes on and I watch it and I say, oh don't tell me I'm going to come to that and Julie [daughter] says no Mum as long as you take your tablets and do what your told" (Maggie 2: 413)

The programmes that Maggie watched were soap operas rather than documentaries and she saw people deteriorating very quickly over a few weeks when they had a storyline to perform. Having this type of media portrayal was far more scary than helpful and she was very fearful of a rapid decline in her memory and functioning.

The two men in the study were less influenced by this sphere of knowledge and more by the professional sphere. Beth was only influenced by the personal experience she had of her father-in-law but was not closely involved with his care. These were the three spheres of knowledge that seemed to inform the perceptions and experience of having a diagnosis of Alzheimer's and influenced the emotional processing in which each of the participants were involved.

Much of this emotional turmoil and the need for emotional processing centred on the feelings of fearfulness.

## 6.2 Fearfulness and other emotions

Fearfulness was the most frequently expressed emotion in the post diagnostic experience of the people involved in the study and it was common to all. Fear of the future was high on the agenda along with the fear of how the disease would progress. There was also fearfulness experienced when they discussed what they thought might happen to them along the way, what it would be like, and what they would be like at the end. Anxiety about how others would perceive them and subsequently treat them was also experienced. There were many emotions expressed that included feelings of confusion, uncertainty, bitterness, relief and loss. These were much less prominent than the feelings of fear, but were nevertheless emotions that required to be processed.

### *6.2.1 Fearing the future*

This fearfulness that was experienced had a lot to do with how people saw their future and the decline that they thought would happen. Much of this was informed by their previous knowledge, with deep philosophical questions being raised by James

> "I am a bit apprehensive about the long term prospect of this ... the thing that worries me, is this going to go on deteriorating you know or then I get to a stage of I don't know who I am etc, etc...What I really dread, if this gets worse and worse and worse, progressively worse, and I forget who you [wife] are, forget who I am, and I don't know whether that is possible or not. The end stages" (James: 2 170 & 371 & 415)

The question of who he was going to be by the time he reached his death troubled James, and he harboured thoughts that he would become "an incoherent vegetable," (James 6: 55), and a huge burden on his wife.

Maggie questioned her identity following her diagnosis. "After that I still don't know who I am?" which reflected that she had not at that time completed the process of working through her thoughts and feelings.

This fear of what the future would hold was common throughout despite, or perhaps because of, their previous knowledge. The fear of the disease progressing was for Jenny very tangible and at times she felt that death would have been preferable to the fate that would await her, "I don't think the way ahead looks very promising at all you know, and in fact I would think that death would be a great relief" (Jenny: 5 137). She was not depressed or suicidal when she expressed these feelings but was being very philosophical about the whole process thinking that it would be a relief if she died before she had to go through the indignity of experiencing the decline that she knew was almost inevitable.

The other three, whilst being fearful of the deterioration, focused mainly on the act of deterioration rather than the extent of it, "the only thing that would worry me was if it did really go a lot worse," (Betty: 5 291), and Ian's biggest fear was that he did become like his brother-in-law, who had been aggressive towards his wife: "if I get a lot worse that really worries me, you never know." (Ian: 4 33). But he consoled himself with the knowledge that "all people with this are not like Harry [his brother-in-law]" (Ian: 4 21). Maggie was less expressive about her fears for the future and the progress of deterioration. She was the only participant in the study who had not experienced dementia within her close family; however, she did worry about how it would all end for her.

### *6.2.2 Fearing the judgement of others*

The perception that people would change towards them if they knew that they had Alzheimer's disease was a real threat to their sense of self. Anxious that they would be treated differently if others knew about their diagnosis made people secretive about telling others (see section 6.3 for discussion on telling). They thought that people would then be watching out for any changes in behaviour, "just when your next big mistake would be, you know that would make it obvious to anybody you were talking to, nobody would say anything, but they would think it" (Jenny: 1 347). Maggie was fearful of her own performance too, "I'm going to say the wrong things or stupid words or something" (Maggie 1 247). James became agitated when he had made arrangements to meet people and could not remember the details, and his wife recalled a conversation, "I didn't know what was wrong and you said I think I've made an awful faux pas because you had made some arrangement and you couldn't really remember what it was." (James: 2 343). His agitation was due to his anxiety of letting people down and led to him being uncertain as to how people would view him if he had let them down by missing an arranged appointment.

Jenny in particular was more articulate about how others would judge her, "they look at you in a different light…they would put you in a category…anyone who knows you would think less of you…I am the one with the stigma and I feel that anybody who knows is bound to treat you differently." (Jenny 2-205 & 5-65,81 & 105).

James also felt people would shy away from him if they knew that he had dementia and Beth felt that her friend would “be on the defensive a bit,” (Beth: final interview 102), and not want to share things with her as she had once done. The perceived judgement of others led to a feeling of being different and being viewed as different by others. They also felt that it would threaten their relationships (this will be discussed more fully in section 6.5.2).

### *6.2.3 Other emotional issues and struggles*

At times throughout the six month period of the study people struggled with their emotional responses to their diagnosis. Three participants felt a tinge of bitterness, continually questioning why this had happened to them. Ian questioned the age factor, despite being the oldest person in the study, “just why have I got this blooming thing and people older than me have nothing wrong with them,” (Ian: 4 33), while Maggie was quite perplexed with how she came to have the disease at all, especially when her twin brother had no signs of it and at times she questioned the accuracy of her diagnosis, “how did I get that? [Alzheimer’s disease]. Are you sure that it’s that?” (Maggie: 3 15).

Jenny also was perplexed and sometimes left confused by the episodic nature of her experience, “I still feel I am normal enough, it was only just that one episode that I had that I felt, why I am thinking like that?” (Jenny: 1 189). And she had difficulty understanding why she was not confused all the time. This was not consistent with the knowledge that she had gleaned, mostly from books and papers, which portrayed the person with Alzheimer’s disease as consistently confused and disoriented, and Jenny then compared and contrasted her experience with theirs.

James was more preoccupied by his perceived loss of autonomy and independence, “the thing I would be sad about was if I had to give up driving...but I don’t think that would be for a while yet...I suppose a car is freedom you know, and if you haven’t got your car your freedom is limited. That’s what I feel” (James: 1 230 & 524). This limited freedom was associated with feelings of being constrained by the label of Alzheimer’s disease and Jenny expressed similar consequences of this constraint when she discussed feeling that her world was narrowing, and the meaning that she put on this was, “that I will have less, less to talk about, less of everything ... I guess it will catch up with me” (Jenny: 5 205).

This limited freedom and narrowing world reflects the sense of loss, especially of autonomy and a diminishing sense of self. Ian felt a real frustration and loss of spontaneity and independence when he took the decision to stop driving. "It bugs me that I can't say to my wife, come on we will go somewhere" (Ian: 5 257), and although it was his decision, it still did not quell the feelings of resentment.

There were times when both men described their mood as depressed. James described feeling that he wanted to hide away a lot of the time, "I had been rather depressed...I felt that I might have retreated into my shell and refused to come out...I had closed the shutters down and been miserable." (James: 3-84 & 6-286-366). Ian had no motivation to do anything and lacked interest in the things which used to give him much pleasure, like gardening or reading his latest detective novel. He felt wearied and commented, "sometimes I just can't be bothered" (Ian: 5 247).

Jenny was the only female who experienced what she believed was depressive episodes. She described being overwhelmed at times, and found the whole concept of having Alzheimer's disease difficult to comprehend, and when she thought a lot about it she felt devastated, "the whole thing struck me as very depressing you know." Jenny (1: 127). Neither Beth nor Maggie reported or discussed feeling depressed throughout the study.

During the course of the study there seemed to be a time when participants came to a point of deep resignation as to what providence had assigned them for their future. Jenny described her fate as "it's just one of these things; I guess I must have a brain that's dipped in favour of it. I don't know. It's a lot of bad luck anyway. However, there is nothing you can do about it." (Jenny: 5-229). The feeling that she thought that there was nothing she could have done to prevent it, or be proactive in dealing with it, was at times a relief, "well in one way it is comforting and in another not comforting at all, but I guess that is just how it goes." (Jenny: 5 271). But there was also a feeling of ambivalence mixed with the relief. And there was an inevitability about some of the comments: "I know there is no cure but it will get worse and there is nothing I can do about it," (Ian: 1 496); Beth acknowledged "there is nothing you can do about it ... so I just ignore it ... I just get on with what I am doing." (Beth: final interview 59): and Maggie commented "I've got it and you can't do anything about it." (Maggie: final interview 139).

### *6.2.4 Talking about feelings*

Whilst there was no reluctance about expressing their emotions to me during the data collecting period of the study, there was an anxiety about sharing those feelings with others. One of the participants in the study, Beth, tried to repress her feelings about the impact of her diagnosis, "I try not to get any feelings ... I try to forget it. I just don't think about it if I can help it." (Beth: 4 43). This seemed to be a conscious choice that she made and she utilised it as a preferred coping strategy. There were times when it was not possible to bury these feelings and they still had to be addressed when they surfaced, although it was difficult to express them, "well you tend to think of things, but they are never brought out in a conversation, you know, things occur to you that you don't bring out in a conversation." (Beth: 4 3). It seemed that there was a struggle to process the emotions internally, yet she was reluctant to externalise her feelings and discuss them with others.

This reluctance to share their feelings with others was quite common, especially directly following the diagnosis. Talking about the diagnosis seemed to be an important factor in the emotional processing, yet some of the people in the study were reluctant to share their diagnosis or how they felt about it with others. There seemed to be some kind of taboo surrounding the discussion of dementia with others. This clearly needed to be explored in order to reach a new understanding of what it meant to the people who had been given their diagnosis, and why there was this need to avoid such dialogue.

## 6.3 Daring to talk about Alzheimer's disease

This theme explored the reluctance to discuss Alzheimer's disease outside the parameters of the study. This was a subject that had been a frequent media topic, with prominent international figures like the late American President Ronald Reagan being prepared to go public, and yet there was something that prohibited personal discussion. There was a feeling of holding a dark secret, and yet the participants in this study were all quite relaxed about sharing that secret with me. The women were more guarded than the men were about sharing their secret, while some had their secret revealed by their families without prior agreement; that confidence in keeping their secret was then violated by the family's public proclamation of it, although this was always done with the best of intentions.

I felt very privileged to be allowed access to these inner secrets and it is with great care that I now continue to open more widely the secret hiding places of their hearts and minds so that we can come to a deeper understanding of what it meant to them to be holding onto something that was in Jenny's words, "a terrible imposition." (Jenny: 1 151).

### *6.3.1 Daring to tell*

The following section concentrates mainly on what I have come to know as 'the telling'. This was one of the most complex concepts that the people in the study had to grapple with and it is one which is rarely discussed in professional circles. The act of telling friends and family that they had been given a diagnosis of Alzheimer's disease was a very challenging and demanding task, which each person and their families tackled differently. One of the controversial issues was whether they should tell their diagnosis to others or not, and this matched other situations detailed in the study with the decisions being very much based on individual or family choice – although it was not always quite as clear cut as telling or not telling.

There were degrees of telling, perhaps deciding to tell one or two close friends, or indeed keeping it exclusively in the family. There was also a timescale to the telling when some people did not want to tell until it became more noticeable to others. The attitudes towards telling changed over the six month period: some people had moved from being secretive to being open; some had moved from secretive to less secretive; and others continued the same attitude from start to finish. However, what they did have in common was similar sets of reasons for both telling and not telling.

### *6.3.2 To tell or not to tell*

The reasons given for *not telling* were varied. They were private people and did not like to divulge their business to others, "I don't like telling folk things like that," (Maggie: 3 83), and James felt that he would not like it in the public domain, "I don't think we should broadcast it you know." (James: 2 479). This was the same with four of the case study families, but again Ian was different, "I think it is a good idea [*to tell people*]... och yes, I mean you don't hide things these days do you?...no we are not whispering about it." (Ian 2 376-423).

He felt that today's society was much more open and accepting with no need to hide away such a diagnosis, whereas the others felt that it was something to keep to themselves, or at the very most, within the family. Another reason given not to tell was trying to protect people from bad news until absolutely necessary, "I thought there is no point in saying anything until...later on is in plenty of time, there is no point in worrying them all starting now you know." (Beth: 2 43). James felt that he "didn't want to upset them [family]" (James: 2 185).

Sometimes it was not told to help preserve an intact self, "I would prefer to think I am still a bit normal...but whether one of these days it will probably be all out you know, but it depends...no doubt it will worsen so I feel that I just should be quiet and wait until it becomes obvious." (Jenny: 1 185 & 5 77). By telling people, she felt that she would be admitting to both them and herself that she was no longer normal. James was also keen to delay having to tell until people noticed themselves, "the time may well come when I have to say to people...I am an Alzheimer's victim as it were, but I don't think that time has been reached yet." (James: 2 142).

There was also a feeling of shame and to confess to others was unthinkable, "I feel that...for me to say that I have Alzheimer's would be, well, I wouldn't own up to it for a start...I wouldn't like to mention it to anybody actually and wouldn't you be the same?" (Jenny: 1 151 & 2 185). This thinking was related closely to the fear of being judged by others (mentioned in the previous section), and also to the anxiety of the relationship changing, "well if I told a lot more people I would think that relationships would change, but I haven't told that many people...it's a stigma I think that I wouldn't like broadcast to all and sundry. For instance, I would never dream of telling the lady next door" (Jenny: 5 73 & 61).

Feeling stigmatised by the diagnosis was a barrier to telling people in common with perceived negative reactions, "I wouldn't want people to think I was doo wally or whatever you know. I think that could be disastrous" (James: 6 286).

Something that troubled most of the participants was the lack of control they had if they told. They knew that it was inevitable that some people, when they found out, would then tell others. There was a need for trust and confidentiality to be conditions of a disclosure, and the diagnosis would be shared "only to people I know will be circumspect in passing it on you know" (Jenny: 5 247).

These were the main reasons why people were reluctant about disclosing their diagnosis to others, especially when it stretched beyond the boundaries of the family, although Maggie did not even want all of her family to know, and only shared her diagnosis with her daughter with whom she lives, but not her sons. She was the only participant who did not want all of her adult children to know.

The reasons for *telling* the diagnosis were also diverse, with some unique to one family while other reasons were shared. There was a much stronger feeling, especially among the female participants for *not telling*, or limiting the telling to family rather than telling their wider social network. The main motivation for telling the diagnosis was to offer an explanation to people who might have observed changes in the person's behaviour or way of being. This was certainly the case for both men. "I just said this memory etc., isn't working. I have seen the Consultant and the brain scan says early stages of Alzheimer's, so if I start to stutter it is not the whisky!" (Ian: 3 135). James was keen for people to know that he was not responsible for any changes in functioning and was worried that people might think him discourteous, "I feel it is quite important in the sense if they notice that I am doing something that I ought not to be doing, or if I have forgotten something they know it is not deliberate, but something which I have no control over." (James: 5 15).

The worry that it may be genetically inherited was a motivating factor for telling the family whom they all felt should consequently be alerted of the potential danger; indeed, one daughter did go to her GP to check out if this was so once she realised her relative had such a diagnosis. Another reason for telling was the stress felt in trying to hold it in, "it's more stressful than it should be and…I think where the stress of it has come is trying to keep everything on the surface going while things are just not really quite the same" (James: 2 339 & 355). The realisation that it is also stressful for the partner to be maintaining the façade as well, and the dawning awareness that his wife was trying to shield him, "you have been protecting me," (James: 2 333), from people finding out, encouraged James to tell people about his diagnosis. This happened gradually over the six months, whereas Ian had told people from the start, feeling it was best to be open about things.

One female participant had changed too over time, with Jenny being happier to tell people towards the end of the six month period. Both Beth and Maggie, however, were as loath to tell at the close of the project as they were at the beginning.

As can be seen from the above section there were more reasons given to keep quiet than to disclose the secret. But whose secret was it?

### *6.3.3 Who should tell and who to tell*

Debate about who has ownership of the diagnosis has been highlighted earlier in the thesis and within the 'rights' movement it was claimed that the diagnosis belonged to the 'patient'. However, it was less clear who has the 'right to tell' the diagnosis.

At the time of diagnosis, without exception, the next of kin of the participants was present at the time of the diagnosis giving, so although the diagnosis was made 'on the patient,' it was given to both patient and family by the diagnosing Consultant or Specialist Registrar. It is fair to say that families processed this whole area of who should tell differently, and there was more weight put on tacit contracting rather than on overt discussion between the diagnosed person and the family member about who should tell the diagnosis.

There was no discussion between Ian and his wife. He told the family, "the family all know...I just said well I've got this and it might last for years...we've told them, sons and daughters, grandsons and granddaughters...so that's it." (Ian: 2 231). His wife had taken the opportunity to tell a gathering of friends, ten in number

> "I just felt we were out for lunch last Sunday and with our particular ones [friends]...I just said I think perhaps you had better know that Ian has been diagnosed as Alzheimer's. We have to accept it, our family and our grandchildren [have to accept it] and that's it. So it's better to do that I thought than hedge because I think they suspected that things were not just quite as they should be" (Ian-Joan: 1 364).

Although there was no prior discussion, there was no discord about who told what to whom, and they were both pleased that their family and friends knew. This was not so with all of the participants though, and Ian and Joan were the only ones who told everyone as soon as they could following diagnosis. Once again Ian was proving to be very different from the other cases. James, on the other hand, started off wanting to keep the diagnosis within the family. Again, nothing was discussed, but he took it for granted that his wife would tell the family, "I don't think I ever discussed it with them ...Mary has mentioned it to the family" (James: 1 199). James was reluctant to disclose his diagnosis even to the family and admitted, "I have a tendency if something is unpleasant to try and avoid or how can I put it...avoid or run away from it...I am a head in the sand sticker!" (James: 2 202-210).

His previous pattern of avoiding unpleasant tasks was continuing and he said that he would have no objection to his wife telling people, and the decision was made to tell people on a 'slow release' basis rather than 'broadcast to everybody'. Following that decision to keep their secret less private, James decided to experiment with telling people himself, first of all telling the car insurance firm to check that he was not breaking the law, then telling someone he met from the Church choir. Both of these encounters were successful, and while James did not find it easy to tell, he was amazed at the empathic response he got. As his experiment had been successful (he was still a scientist), he was prepared to repeat it. He wanted to inform his Pastor, for two reasons. Now that he had made it more public, out of respect he did not want the Pastor to hear this news from others and he also wanted to make sure that the Pastor knew why he might not be so willing to take on extra Church duties as he would have normally done. He continued to tell and informed many key people in his social network. He tried to weave it naturally into his conversation, "we were just drinking coffee together and I said you would maybe realise it but I am an Alzheimer's victim, sort of thing, but it doesn't make any difference so there we are." (James: 4 39). He chose who he told in the various clubs of which he was a member, confident that the news would spread and he would not have to tell everyone personally. Initially, he just could not envisage how he could possibly tell his friends that he had a diagnosis of Alzheimer's disease and spent many hours questioning, and trying to find an answer to that puzzle. He had gone from being secretive and trying to run away from it to embracing the challenge and being very positive about it all. Over the six months, it was James's attitude to telling that had changed most.

The changes in the attitude of the women in the study were less dramatic. Jenny had moved from not wanting to own up to having Alzheimer's disease to thinking that she was "not unhappy about letting it be known because I feel, well it's better to talk about it and let everybody else know what is going on," (Jenny: 1 399), thereby oscillating between the two positions until she became more comfortable with selective telling later on. Beth restricted the telling to her immediate family, "just the family, my daughter, son and them [grandchildren], that's all, nobody else," (Beth: 5 111) and she left the telling to her husband, and for the full six months of our contact Beth did no telling. I never heard her utter the words Alzheimer's disease but she referred all the time to 'it'. When questioning Beth if she ever discussed the subject with her husband she said, "well we are sort of into a routine and he knows that I've got it and I know he knows I've got it and we are just ordinary, we don't bother, just forget it if we can."

The situation was very similar with Maggie, although she would not tell her sons, "I've never told my son, Jason, or my other son, he is the youngest one," (Maggie: 3 79), and the only reason her daughter knew was that it was she who persuaded Maggie to go to the doctor initially, and she accompanied her to all the appointments. She also lived with Maggie, and persuaded her that she should tell her brother-in-law and sister-in-law with whom she had close relationships. Maggie would not tell but allowed her daughter Julie to tell on her behalf.

Telling someone that you had been given a diagnosis of Alzheimer's disease was clearly a very difficult task and one that provoked much discussion with the people in the study and their families. At times families were united in the way that they tackled *the telling*, and at times it was a cause of great stress and concern between them. Difficulties arose when some people wanted to keep it hidden while their relatives wanted to tell others, and this caused friction between them and fuelled already stressful situations. The situation was much more straightforward if the two parties had agreed either *to tell* or *not to tell* – or was it? There were implications to consider for both of these positions.

### *6.3.4 The implications of telling*

There were both positive and negative implications of telling. The positive implications were that needs could be highlighted to friends, as Ian very succinctly demands, "we don't want sympathy, and we want their friendship ... and we don't get sympathy from our family either, we get support, they treat their father the way they have always treated him and that's the way it's got to be," (Ian: 1 450), Ian very much expecting to get what he wanted. James experienced many offers of help, with driving, with friends calling to remind him that he had meetings to attend with them, and there was a concern for him within his circle of friends. He also experienced considerable relief when he told his Pastor, "there was a load on my back and he took some of it off," (James: 3 898), and in sharing his concern he was able to unburden.

There were also negative implications and some were experienced by Ian, who had been open about his diagnosis from the beginning, when two of his friends started to treat him in a patronising manner. While the increased concern and assistance offered to James was perceived as helpful by both him and his wife, it could just as easily have been perceived as a loss of autonomy. The females in the study did not share many of the implications of telling, simply because they rarely told, and then only to their close relatives. Nevertheless, there were relationship losses as well as relationship gains and this will be explored more fully in section 6.5.

### *6.3.5 The implications of not telling*

There are implications for not telling, most of which appear to be negative. One of the implications experienced by Beth was that of isolation and although her husband knew and worked hard to help her keep her secret, she said, "no, we are on my [sic] own, just George and I" (Beth: 6 23). Even with George there, and referring to them both as we, it seemed very much that she saw herself as being on her own with this diagnosis even although she was with George and the family knew, "well they know, but we didn't really discuss it." (Beth: 3 86).

It is difficult to access appropriate informal support networks when there is a *not telling* rule. Another implication of not telling is that people would notice anyway and draw their own conclusions, "if I didn't tell people they would think I was drunk," (Ian: 2 87), or, they would begin to think of people being unreliable and stop arranging meetings with them, "people think that they can't make arrangements with you, because you don't keep it," (James: 2 331) and that would bring unnecessary disruption to social relationships.

Trying to keep everything the same without telling was also felt to be a strain by James and Mary, and keeping the secret made the situation even more stressful than it needed to be. Maggie never did tell. The implications of not telling would seem to have a mainly negative effect on the person with the diagnosis and the fear of the reaction of others had been what had frequently stopped them.

For those who decided *to tell*, the reactions of people had mainly been favourable although at times it was less favourable than what they had expected.

### *6.3.6 Reactions to the telling*

There were mixed reactions to people being told that their relative/friend had Alzheimer's disease. Two people felt that their situation was being minimized by family members and although they recognised that it had been done from the best intentions it has not always been useful. When asked how people told had reacted, Beth commented, "how have they taken it? Well my son's wife is a nurse and what he said was it's not as bad as you might think, you know, Sheila has had folk on her books for years, so well I don't know…what can you do you just have to wait and see," (Beth: 2 291), and without it being discussed with his mother he did not know how bad she thought it was.

Jenny experienced a very similar situation with a phone call from her son, "I remember once talking to him on the phone, he lives in Edinburgh, and I said to him, I am forgetting a lot of things these days, and he said don't worry Mum, I forget too, and I thought oh my goodness...but I suppose it was just a natural reaction." (Jenny: 1 411). Jenny's fear at that time was that it was genetically inherited and she thought that this was her son starting to experience the first signs of Alzheimer's disease as well.

Even although Ian's family was under instruction from both parents to accept it, his son found it very difficult initially. "Our son wasn't very willing to accept it, but he does now, he realises now…I think he saw that there was a change." (Ian: 2 286). The rest of his family conformed more quickly, with one granddaughter finding lots of new information on the internet which she printed for her grandparents to read, and this made them feel very proud.

James's family were not local and they were told on the phone by their mother and they were upset, feeling helpless because of the distance between them, but up until the end of the study they had still not discussed it with their father, and neither had he sought to discuss it with them. His friends, however, expressed sadness, but reassured him that it would not make any difference, "there were no flames or anything…they just went on as usual, nobody seems to worry about whether I have got all my full marbles or not you know" (James: 4 27 & 43).

James got the most positive response from his Pastor

> "He was exceedingly good, he knelt down and prayed with me and I felt that was a very good thing. I think that it released a feeling of tension, that I had actually told somebody and they were sympathetic to me, and everything was more or less as before except that he knew…I felt a great sense of relief at that point that I had told somebody and getting it off my chest…it wasn't a shut out process like you cannot come to Church anymore…I think he understands" (James: 3 35)

He was able to have a good discussion with his Pastor about how it felt to have this diagnosis and this was an opportunity not afforded to him by anyone else.

Reactions to *the telling* were mixed, with some surprises, some disappointments, and in some cases it seemed to be no big deal. For James and his Pastor, it was an intimate moment in their relationship. For Maggie there was no reaction because there was no telling. But in all of the activity that was *the telling*, the only person who was prepared to discuss the implications of the diagnosis with the person was the Pastor.

### *6.3.7 It's good to talk*

Telling is different from talking or discussing issues around the diagnosis. Telling demanded little of the listener other than an acceptable, appropriate response, while talking or discussing raised difficult issues. For their own different reasons most of the families found it difficult to discuss the diagnosis with each other, "you tend to keep all the talk about it in the family, they know you have got it but ignore it, so it is a help [to talk about it]." (Beth: final interview 140). Yet, they all commented on how beneficial it was to talk about their thoughts and feelings following their diagnosis within the research context. It is a subject that people shied away from, even the nurses visiting tended to concentrate on problems and effects of medication rather than have a discussion about their thoughts and feelings about the diagnosis. Nobody, it seemed, ever brought it out in conversation. Maggie felt that "a lot of folk don't talk about it because they think that you don't like to." (Maggie: final interview 185).

For Jenny it was more about her not daring to bring it up, "I never mention it, I never bring it up, you are the only one who brings it up," (Jenny: 2 335), and yet there was a realisation of the need to talk, "it is very good to talk to somebody, you feel I must discuss this with somebody you know." (Beth: 4 240). Within the research project, it was possible to have a conversation that they might otherwise be denied, as in the following interview dialogue

> Researcher: Right so you are able to speak about things that you are not able to speak about anywhere else
> Beth: That's it exactly. You see George is with me all the time and you come in and it is a different conversation ... prior to that you are in a sort of vacuum" (Beth: 4 5 & final interview 148)

Ian raised the point that it was not just that people did not want to discuss things but that they were uninformed and would shy away from something that they did not know. He felt that talking about it "is good for you, you know we were talking and ordinary people, they don't know." (Ian: final interview 7). Talking to professionals rather than lay people who did not know about the subject seemed preferable to some participants and they cited the need for being understood as important. Being able to talk about it helped to minimise the associated problems, "it's better to discuss it with you than with anybody who doesn't have any experience at all...it made it seem less of a problem." (Jenny: final interview 93). Being able to discuss thoughts and feelings was also something that the participants found to be important. "To be able to talk about it, we were able to express our own feelings and then talk about it together." (James-Mary: final interview 69).

The value of talking through their thoughts and feelings has been highlighted in this section, but only the Pastor had been able to offer the kind of experience that facilitated the expression of thoughts and feelings. Being part of the research project had led to the participants being enabled to discuss these thoughts and feelings in a different way and they felt that this "enabled a communication channel to be opened up that wasn't possible before," (Jenny-Ron: final interview 219), with each other, and they were able to discuss issues pertaining to their diagnosis that they had not previously been able to do. Being able to talk with families, friends, or professionals was a crucial factor in the emotional processing and also in the shaping of a different identity, and indeed in coming to terms with and working towards acceptance and integration. Not being able to talk inhibited this process and resulted from participants having to process their emotions internally with little opportunity to have these emotions validated or indeed invalidated. This concept of integrating will be explored further in the following section.

## 6.4 Re-authoring the story

As people talked about their diagnosis and reaction to it, it became clear that it was in the talking that many of the issues had become resolved over time. Their stories needed to be told and re-told to reach a point at which they could come to terms with their diagnosis and all that it meant to them. They had to re-author their own stories; no-one else could do that for them. In the re-authoring, they came to integrate their diagnosis into their being. In re-authoring, they came to incorporate that diagnosis into their doing. This theme will tell of how people moved from receiving the diagnosis to integrating it as part of their lives, and how they adapted their lives to learn to live with it. It also tells of a future that had to be faced, a future that for some was just too horrendous to contemplate. This story had three temporal influences: past, present and future, which shaped the way that people thought about, and adapted to their diagnosis. At times, for some, there was great clarity of movement from one domain to another, and for others it was extremely blurred and shrouded in a haziness that made it very difficult to delineate one from another, and that, to some extent, slowed the process of actively moving on. These three domains were named *the shadows of the past*, ***learning to live within a limited freedom*** and *facing an unpredictable future.*

The people in the study referred to this moving through the dimensions of time as 'coming to terms' with what life had dealt them. This process was unique to each individual, some moving swiftly through while others got stuck on the way. Although they are presented here in order of past, present and future, there was no predictable pattern or order as to how this re-authoring took place, and some participants were unable to complete the re-authoring or integration process – for their own reasons.

Coming to terms with a diagnosis of Alzheimer's disease was a daunting task to embrace. An account of how the five participants accomplished this will now be considered.

### *6.4.1 Shadows of the past*

Shadows of the past incorporated trying to co-construct a meaning of the present from experiences or events in the past. It also gave an insight to the different realities that people experienced and wanted to cling on to rather than leave behind. The way that people coped with different traumatic incidents in the past had an effect to some degree on how they processed their diagnosis, although this was not the case for everyone and again all of their processes were unique. This was achieved by re-visiting fantasies and horror stories relating to their past and also exploring the impact this had on how they were able, or not, to move forward into the present and contemplate the future.

Long standing and well rehearsed coping strategies were implemented to help participants 'come to terms' with the diagnosis. Beth coped by ignoring it and not complaining about it. Her husband George said "she is very good that way. She has had a lot of illnesses and she just takes it and she doesn't complain...she has had burst appendix, hysterectomy, varicose veins, quite a few things." (Beth-George: 2 205). She herself talked of just ignoring it, "I just put it to one side...I don't want to know about it to tell you the truth...I talk, I talk quite a lot but I never mention what's wrong, never." (Beth: 5-233 4-57 5-203).

She did acknowledge her diagnosis although she would not say the term Alzheimer's disease. She seemed to have made a conscious decision to ignore it rather than it being an inability to grasp what was wrong. She also blamed events in the past for causing her to have Alzheimer's disease, citing the stress of having to cope with her husband's sudden admission to hospital to undergo cardiac surgery. She was fearful of looking at the future and kept telling herself she would be all right as long as she did not get worse and hoped the tablets were "keeping it at bay as far as possible." (Beth: 4 39). This seemed to indicate that she knew what the likely course of events would be but she would not be drawn into discussion. The only time she referred to the future was when expressing her anxiety about being kept in the 'health system' so that "somebody was keeping an eye on what we were doing." (Beth: 4 39).

Skills she had utilised in the past had not successfully transferred into the present. She had stopped cooking but blamed that on there only being two of them in the household now (her two children had both left home over twenty years ago), and said that they ate out rather than cook, as it was just as cost effective. Her family confirmed that it had only been in these last two years that she had stopped cooking and she had always been happy to cook for them all when they visited with their families. Now their parents took them out to a hotel for lunch when they visited, so even if there were more than the two of them, they still went out to eat.

Beth blamed past events for the cause of her Alzheimer's disease. She did not talk about it in self-limiting terms, but considered it to be external factors that mitigated against her, and she chose to ignore and not discuss the impact it had on her with anyone, apart from when she discussed it within the research project. It was difficult for her to 'come to terms' with her diagnosis.

Exploring horror stories has already been mentioned earlier in this thesis when family or media experience can sometimes impact negatively on the person. These horror stories and fantasies did influence how people integrated their diagnosis, as did operating in different realities. For Jenny, her reality was different from that of her husband. She firmly believed that her mother (who had been dead for 12 years, according to her husband) was still alive and visiting her. Jenny had found her mother (who had suffered from Alzheimer's disease) dead on the bathroom floor of her flat one evening when she was carrying out a routine visit. She could acknowledge that her mother had died and that she had arranged her funeral, but she could not acknowledge that it was not her mother who came to visit. When pressed about why her mother came to visit her, she said "my father knows [the diagnosis], and no doubt he told my mother and I think that is why she is, that is two weekends now that they have been down here and I think probably that is why she has been down." (Jenny: 5 515). She could believe her mother was visiting her out of concern since she had been given the diagnosis.

Experiencing these different realities caused friction in the marital relationship. It also made for a slow journey into the present for Jenny, who resisted accepting her diagnosis completely for several months.

Horror stories from the past also affected Ian, as he was anxious about turning into an aggressive monster with whom his wife would not be able to live. Indeed, horror stories from the past projected themselves through the present and into the future because it was the future about which he was fearful.

Making meaning of the present from the experience of the past was frequently what happened to the participants in the study. This included exploring horror stories and different realities and blaming past events for the diagnosis to acknowledging how good life had been to them: "I have had a good life there is no question about that" (James: 3 527).

There is no doubt that the events and experience of the past had a very important bearing on how participants 'came to terms' with their diagnosis. Bringing *the shadows of the past* into their present day reality was necessary for the co-construction of their different identity as someone who was *learning to live within a limited freedom* with a diagnosis of Alzheimer's disease.

### *6.4.2 Learning to live within a limited freedom*

Learning to live within a limited freedom was a pursuit of the present time and was an active life choice rather than a passive acceptance. This entailed *acknowledging and accepting the changes, pragmatic planning*, and *taking a positive philosophical stance*, all leading to an integration of the diagnosis into the identity of the participants. This was an individual journey that took people down their own path towards integration, and was unique to them, although there were similarities between some cases.

The time factor was also different. Of those who had integrated their diagnosis by the end of the study, Ian had come to acceptance prior to being diagnosed, James took the best part of two months although the process accelerated after two weeks, and Jenny took almost all of the six months in which she was in the project. Beth had begun to journey towards a tentative acceptance but had not begun to integrate her diagnosis and this was similar to Maggie, who had just begun to accept the concept of her memory problems being related to Alzheimer's disease.

Five different individuals with five different ways of being and doing, but nevertheless only three had integrated their diagnosis into their identity by the time they had completed their commitment to this research project. The process through which integration appeared to be achieved was through the three different components mentioned above which will now be explained more fully.

*Acknowledging and accepting a change* was difficult to achieve without talking and discussing with a friend, relative, or professional. Acknowledgement of change did not automatically lead to an acceptance, and while they acknowledged the medical opinion and the giving of the diagnosis as valid (this is what the tests show and the doctor said, and I heard that), there was not always a willingness to accept this on a personal level and believe that this was about them

> "I didn't believe it in the beginning...I could hardly believe that I had it...I still feel normal...I am virtually not aware that there is anything unusual...I don't think of myself as being any different...I was surprised anyway. I know when it was first mentioned and I thought I haven't got Alzheimer's, I couldn't think that I had anything wrong ... but that's the way it affects me" (Jenny: 1 17, 13, 147 & 2-33, 53, 131)

This illustrated Jenny's struggle to acknowledge and then accept that this was something with which she, personally had been diagnosed. and also acknowledged that in her disbelief that this disbelief too was a facet of the cruel tricks of Alzheimer's disease. Three participants felt little or no change initially, it was family members who had encouraged them to seek a diagnosis, with the exception of Ian, who had already reached an acceptance earlier than the others because of how he utilised his previous knowledge.

James found it extremely hard to accept his diagnosis and because he had always had a bad memory he could not see that there was any change to acknowledge until there was evidence presented to him by his wife that he could no longer ignore. Following his diagnosis, James plunged into a deep depression that he described as

> "the picture I had was that things were going to go downhill...I am in the middle of a maze and I don't know where I am going...I retreated into my shell and I think I would have closed the shutters down and been miserable." (James: 5 380 & 6 366).

His acknowledgement led to his reaction of wanting to withdraw from the world which was the most profound reaction that any of the participants disclosed. However, James's acceptance of his diagnosis was equally dramatic when he described how he had been thinking about life and how his diagnosis was affecting him, and from the profound depression he described what seemed like an epiphany

> "It was not too long after my diagnosis [two weeks] that I decided I would go for a walk. I have a tendency to go for a long walk if I am thinking about something and I don't know, the sun started to shine brighter, the grass was greener, and the birds sang sweeter, everything was just marvellous you know. And I had a feeling of euphoria is the only way I can put it ... I felt that I was 14 feet tall and the world was my oyster, so I had been rather depressed and suddenly I felt elated and I can't really explain it" (James: 3 58 & 84)

James had been chatting to his friends on the golf course and discovered that none of them had treated him differently. He realised he was still the same James as he was before he had been given the diagnosis and it did not need to change how he lived his life in the immediate future. This feeling of elation was related to James acknowledging that his world had not come to an end as he had thought but that he still had opportunities to take and choices to make, and accepting that he would have to adjust his life accordingly.

Acknowledgement and acceptance of the changes they experienced included cognitive deficits, the need for support and backup, unreliable memory, being only 'slightly dented' rather than a complete wreck, slowing wit and a narrowing world. Along with these changes was also an acknowledgement that in order to continue to live life to the full there would have to be adaptations and adjustments made in order to accommodate these changes brought by Alzheimer's disease. Learning how to live with Alzheimer's disease was a concept that was very much at the forefront of James's thinking when he talked about how he felt about adjusting to his diagnosis. He said "your freedom is limited ... but I can learn to work within a limited freedom if you see what I mean" (James: 1 524 & 539). Learning to live within the limited freedom captured what the meaning of adjustment meant to James. The meaning co-constructed from his worldview and through interaction with others epitomised how he had come to accept how he would live his life in the wake of such a diagnosis. This living within a limited freedom had a clear component of practical application.

*Pragmatic planning* was something that all participants became involved in even if they were loath to acknowledge changes and included different activities such as exploring alternatives like moving house, changing from driving a car to buying a bicycle or walking, and regular use of a diary for appointments. Making the best use of time and not putting things off for years when it might be too late to accomplish was encouraged, like trips abroad to far off places. Maximising skills and enlisting support were other suggestions, for example, working out the content of a telephone conversation beforehand and writing it down so that all points could be certain of being addressed, and asking a relative to stay nearby to make sure that this was done. This was preferable to relatives taking over the tasks completely. As well as these practical solutions, there needed to be a change in attitude if living life to the full and an adoption of *a positive philosophical stance*.

The need for an 'I can' attitude, rather than seeing the pitfalls and dangers that may befall an Alzheimer's victim and of continuing life as before were recognised: "life goes on, I mean I think we can live with it quite easily, it's not so serious yet." (Jenny: 4 339 & 371); an acknowledgement that life was seen as still worth living and, making the best of it: "you make the best of the hand that you get...I can function quite well... there is no great problem and life is still sweet" (James: 3-179 & 4-138).

These three elements were incorporated into how people changed in the present in order to live within their own limited freedom and assisted in the process of integration. This seemed to work well for most of the participants, although when it came to facing up to what the future might hold, it was quite a different matter. Coming to terms with the future was as important for the integration process as either the past or the present and it was not until these fears had been faced and worked through that it was possible to weave the diagnosis of Alzheimer's disease into a changing identity. *Facing an unpredictable future* played a key role in shaping that co-constructed identity.

### *6.4.3. Facing an unpredictable future*

Facing a future with Alzheimer's disease was never an easy option and it was not one that all of the participants chose to explore or examine. The recognition that it was a degenerative disease was acknowledged by all five people in the study, but only three ventured to pay close consideration to a future that was unpredictable in the extreme, and uncertain both in rate and time of decline and deterioration. The thoughts and worries of these three individuals are offered here in order to increase our knowledge and understanding of the integration process. These can be classified into three distinct areas of thoughts and feelings: *anxious uncertainty, inescapable knowing,* and *tentative hopefulness.*

The feelings of anxious uncertainty encompassed the 'scariness' of how their Alzheimer's disease would progress and again shadows from the past influenced this uncertainty. People remembered others who had gone along this road before and were questioning whether their experience would be similar to people in their family or perhaps to figures in the media. The 'not knowing' feature weighed heavily on people as they pondered over the rate of progression and how it would all end. There was ambivalence about their support system because on one hand they wanted reassurance that support would be given by their loved one(s) and on the other hand they were anxious not to be too great a burden.

The indignity of other people knowing and observing her deterioration was not something that Jenny relished, especially when she may not be aware of the extent of the decline, "we will just have to see how it progresses, it's something that you don't know when it is full blown or wearing that way" (Jenny: 5 225). Fears of a diminishing self, with questions about not being able to identify themselves were also felt very keenly: "when I get to the stage of I don't know who I am." (James: 2 371.) The question of whether allowances would be made for them as they deteriorated was also mooted.

The anxious uncertainty of having to face an unpredictable future alongside a backdrop of their past experiences impinging on their thoughts was at times devastating. However, despite giving that credence, they did not allow it to dominate their lives, and at times the uncertainty was replaced by an *inescapable knowing* that again pointed to that deep resignation to accept the things in life that cannot be changed. "You have to take what you get … I am a bit apprehensive about the long term prospect of this but in the long term we're all dead anyway." (James: 1-385 & 2-170).

There were many references made to death, from thinking that death would be preferable to a long slow decline and thankfulness that whatever the outcome death would not be too far away, to the more philosophical attitude that death had to be caused by something, so it might as well be Alzheimer's disease. They knew well that this was a progressive disease and that staying the same was not an option, "I know there is no cure but it will get worse and there is nothing I can do about it so why worry?" (Ian: 1 498). All had the knowledge that it would not get better, "I have no doubt that it will worsen," (Jenny: 5 77), and trying to make meaning of it all was an enormous task that has both an emotional and practical element to it, "I think I accept the fact that it can be an emotional thing and I do feel it, you can't level with that all the time, so you just accept it and get on with it more or less." (Jenny: 5 9).

There was also a practical element to some forward planning when James informed me that he had been to his lawyer to have him draw up a continuing power of attorney and welfare attorney. He had also drawn up a living will and planned his funeral, and he informed me of the hymns he had chosen. He had decided that he needed to do this so that he could go into the future knowing he had made his wishes known.

It was not all doom and gloom and there was a *tentative hopefulness* that the participants had invested in the scientific community. They were hopeful that in the not too distant future there would be some sort of cure, but until then they all were hopeful that the medication would keep it at bay for as long as possible. James had continued to take an interest in the pharmaceutical developments and had read that "vitamin C and E taken together can arrest the progression of Alzheimer's disease and I hope to take this further ... I think that it may be more difficult in the future, but I hope that there are treatments coming that might alleviate things." (James: 1 230 & 426). All the participants were very keen to be included in future research projects whether they involved drug trials or similar projects such as this.

All of this emotional processing, talking about Alzheimer's disease, and integrating their diagnosis into their identity did not happen in a vacuum. The five participants all lived within a family context. The relationships that they experienced were with close family members with whom they lived, the wider family, friends and acquaintances. It would, therefore, be unwise to neglect to mention the impact that the diagnosis of Alzheimer's disease had on their significant relationships and this final section of chapter six will concentrate on the different aspects of the relationships that were affected.

## 6.5 The challenge facing relationships

The challenge of learning to live with Alzheimer's disease has already been discussed in the previous section of this chapter. The challenge it brought to the relationships of the people within the study was explored and observed. During the six months of data collection of this research project, I had the advantage of being invited by the participants to meet and talk with their close family members, wider families, friends and professionals involved in their lives. The chance to spend time being part of that network of relationships was something that I had not envisaged at the outset of the study but thanks to their generosity of spirit and keenness to help advance knowledge from research, this opportunity was made available to me.

Being able to witness first hand the challenges that Alzheimer's disease brought to these relationships was indeed remarkable. These challenges were characterised by the changes that were incurred by the physiological changes in the brain and also by how Alzheimer's disease was perceived and co-constructed within the relationship context. These changes had started to take place prior to the diagnosis. Within the context of the relationships it was possible to witness these changes as they were happening. These changes in turn brought with them some threats to the stability of the relationship. These threats were mainly to the reciprocity of the relationship and to the autonomy and independence of the person with the diagnosis, which in turn changed the positioning of each person within the relationship. The change in the position of the person with Alzheimer's disease was seen as being something that they changed themselves, as well as being positioned differently by others. Renegotiation of tasks was not something that happened within the relationship.

These threats to the relationship were compounded by poor communications between spouses, families and wider social networks. These *changes* and *threats* will now be explored in more detail.

### *6.5.1 The changes*

There were noticeable changes in every relationship that I encountered. These were mainly discreet and unchallenged with a tacit understanding of the change being necessary. The changes were in relation to who performed the different *household tasks*, changes in *attitude and behaviour* and changes in *feelings* that subsequently led to different positions being taken up within the relationships. In most of the relationships within the study, the allocation of tasks was well established, but with the onset of Alzheimer's disease, and especially following the diagnosis, the distribution of these tasks changed. The person with the diagnosis was never expected to do more! In many ways the tasks that they performed over the years which were well rehearsed were now no longer seen as their domain.

Ron had taken over many of the kitchen tasks previously carried out by Jenny, however she did not seem to object, stating, "my independence in the kitchen is not worth all that much I don't think, but he can cook a meal quite well and I enjoy that. I think he can turn his hand to anything." (Jenny: 4 199). And although there had never been any renegotiation of this task it seemed to suit them both that it was now part of Ron's task to, at least, oversee the kitchen activities, and at times take over completely. This seemed to be a gradual acceptance rather than instant change, and although Jenny seemed to have no objection that was not always the case. "You didn't [like me taking over] to start with maybe, but that is understandable but I think that you quite enjoy it now because I do different meals but you still have your recipes you like for baking," (Jenny: 4 Ron—209), and Ron thereby offered Jenny another reason why he was doing the meals apart from because she was less able to manage. He was also quick to say what her strengths were in the kitchen too, and each seemed aware of the other's need to know that it was all okay.

Some of the tasks that Ian no longer managed to accomplish were driving and managing the finances. "From the time we were married he was very meticulous and kept a book, everything that was paid in and everything that was paid out went in this book. I don't do that...but I haven't gone out and signed big cheques for lots of money." (Ian: 4 Joan 107). Joan did not seem resentful at having to take over this money management task and used humour to make light of the fact that she was not as meticulous as Ian, but neither was she overspending! She was not so sure of how Ian felt about her 'taking over' his tasks, but Ian talked about becoming more dependent on his wife and eventually thinking that total dependence would mean a wheelchair: "if I get a lot worse ... my wife is 81 and I don't see her pushing a chair, but it might not come to that, I might get knocked down by a car on the road." (Ian: 2 238). Ian had recognised the limitations of his wife's ability to take over the tasks completely and hoped that he would not have to face that time.

Maggie had given up many of her kitchen tasks, and it was especially poignant for her because this had been her job. Her daughter told her "your soup is not the same as it used to be...a lot of things that she does that I can't do." (Maggie: 3 138 & 150). She had been a chef but her daughter did all the cooking with Maggie's tasks reduced to preparing vegetables since the occasion she had forgotten to turn off the gas. She had also been relieved of completing other tasks like "forms to fill in, she [daughter] does that for me, I'm no good at filling in forms so she just says just sign your name and I'll tick all the things for you." (Maggie: 3 182). Maggie blamed her 'crumbling bones' (osteoarthritis) on the need for her daughter taking over more of the household chores despite the fact that she had been forgetting to put off the gas.

There was very little change in the division of tasks with Beth, although she had given up cooking. She and her husband either shopped for ready meals or went out to eat, so there was not the same erosion of tasks but rather a change in how it was done, and who should do it, with appreciation: "George keeps me right, he does it all the time ... so I don't need to bother, he is very good." (Beth: 1 115 & 85).

With James and Mary things were somewhat different. They had very clear lines of demarcation. "We have our own spheres of operation, Mary runs the house and gets the messages in etc, etc, and I cut the grass, etc. I do that sort of thing, maybe prune the roses, but it's a very pleasant life." (James: 1 404). However, these tasks, while still being performed by James, had to be directed by Mary who said the only assistance she was required to give was "I only help you with your memory." (James 2: 578). The direction James needed was minimal, amounting to gentle reminders by Mary.

These were some of the changes in task allocation that happened in the daily lives of the participants during the study in their close relationships. Within the social network of friends there were some changes, but were limited to offering to do driving that would normally have been shared to various outings, and reminding participants of meetings and appointments, but otherwise the changes within the friends' network was minimal.

The changes in *attitude and behaviour* were sometimes attached to tasks while others were changes experienced within the relationship itself and were usually much more subtle than the changes in task allocation. Changes in *attitude* and *behaviour* were experienced mostly by Ian, who felt patronised by two of his friends, and others left him out of the conversation, "one of these friends, he is an awful man, conversations being held with two or three and he barges in with something completely different...last week my wife said to him...you talk too much." (Ian: 2 115). Sometimes Ian had difficulty in expressing himself, but managed fine if he was given time, however this friend was either embarrassed or impatient by Ian's changing ability and took over the conversation, thereby leaving him out. His wife reported, "very often Ian is going to say something and he doesn't get it out and this friend starts talking about something different altogether and so then Ian just clams up" (Ian: 2 Joan—302). Such an attitude left Ian feeling marginalised by friends and left his wife feeling very angry and needing to protect and defend him.

James felt that it was too early in the disease trajectory for him to detect changes in attitudes and behaviour of friends and thought that this would become more obvious as the disease progressed. He did experience one man he had told reacting differently, "I am sure he made a special effort...he greeted me very warmly" (James: 3 856). The changes of attitudes and behaviours within the close family relationships were evident too. Jenny's daughter became more concerned about her and visited more regularly. She also made a point of taking her mother out every Sunday for coffee and enjoyed spending the extra time with her which is something that she would not have made the effort to do before the diagnosis. Jenny's husband had become much more protective and fearful

> "She stands very near the gas flame when she switches it on...I try to say to her don't do that, let me do all that bit ... I am anticipating much more than I would have done before...I am not sure that is a good thing, maybe I am anticipating too much at times...if she was hanging out clothes and she fell, I would never forgive myself for not being there...I am following her like a mother hen now" (Jenny: 4 & 5 Ron—231, 255 & 267)

He had not only taken over the things Jenny could no longer do, but tried to take over everything she could still do

> "I keep saying to Jenny all the time she has done all this kitchen bit and the washing bit and everything and now is the time to relax and let it all go...it's less traumatic than it used to be, but for a while I could not understand why she wasn't happy about it...I thought that there would be loads of people that would be only too pleased for me to step in and get on with things and not have anything to do...I do let you go out to the library...I don't sort of smother you" (Jenny: 5 Ron—283 & 301)

This change in attitude and behaviour towards Jenny as someone who should just sit down and let it all happen had a detrimental effect on their relationship, and the erosion of her position as being a competent, capable housewife was in jeopardy and very disempowering for Jenny.

Beth did not experience much change in attitude or behaviour towards her because she had not told anyone apart from the family and change, she noted, was minimal, "not a lot because I don't want them to become involved and I am quite happy here doing it with George, they are very good, we go and see them so we really just continue as it was before I had this more or less." (Beth: 5 171). For George it was a little different; he had become more protective of Beth and their privacy and continued to help her maintain the façade in front of her friends. This led to him colluding with Beth to continue as normal, but he would talk about it to the family because he felt so stressed about the situation. This was a change in his behaviour because he would not normally have discussed anything like this with the family. He also discussed the changes and what was happening with his GP who commenced him on tranquillising medication.

The main change for Maggie was that her daughter sometimes drew comparisons between her and the residents of the care home where she worked. When she tried to persuade her mother to take medication for Alzheimer's disease, Maggie related

> "I wasn't going to take the tablets, I was sitting looking at them, she says they will not do you any harm, Mum. She says two or three of them up at the home, they have them for that and it's the same tablets as you and she says it's not going to kill you ... as long as you take the tablets and do what you are told ... I didn't believe in taking a lot of tablets ... I get constipated ... she says the tablets do that because some of the old ones up at the home, they are constipated with all the tablets too" (Maggie: 3 29, 154, 204).

Julie was positioning her mother in a different way by comparing her to the residents in the care home. While this was to try to reassure her mother, it seemed that she had categorised her as someone who could not look after herself.

The changes in attitude and behaviour were mainly associated with relatives and friends. The participants were not immune from these changes in attitude and behaviour and there were observable differences, although often not stated differences. Ian adopted a 'can't be bothered' attitude, while at times Jenny became argumentative and belligerent. This happened when she and her husband became caught up in their different realities, when Jenny was adamant that her parents had visited and her husband tried to argue that they had not. Jenny's parents had been dead for many years. Maggie was actually acquiescent much of the time and this became more pronounced as the months passed and she looked to her daughter for a lead in all things. Beth became more secretive and dependent on her husband to keep her right, and James's attitude to others about his diagnosis changed from being very closed to extremely open. He also struggled to continue to pull his weight in the spousal partnership.

The *feelings* that these changes elucidated were a sense feeling closer, "I know that she has got a problem, I am protective and that makes me feel closer, you know ...

we have always been close but we are closer now, absolutely." (Jenny: 5 Ron— 251 & 239). Feelings of increased appreciation and intimacy were also evident, "he is still a honey-pot...we get on fine...we don't often have any problems." (Beth: 5 409). James thought that he has "the best wife in the world...the lady looks after me with a lot of care. I am a happy chappy...thanks to my wife who is the pillar around which everything revolves...the only thing she can't do is help me with my golf" (James: 3, 4 & 5 100, 374 &396).

Along with these feelings of intimacy and appreciation were also feelings of being taken over, of frustration and impatience, and resentment: "he resents me having to do all these things" (Ian: 2—Joan 378). The changes experienced within the relationships of spouses, family and friends were sometimes expressed pragmatically when 'taken for granted' task allocation had to be altered, sometimes as changes in attitude and behaviour, and at other times as changes in feelings – but none of the changes were verbalised outside of the research project.

Without the facility to discuss these *changes* there was a real *threat* to the relationship.

### *6.5.2 Threats*

The relationships observed were constantly under different threats as the people in the study struggled to understand and make meaning of the changes in themselves and others within their social relationships. The two major threats were to the *reciprocity* of the relationship and to *autonomy and independence.* Renegotiation of roles within the relationships was found, to a certain extent, to be a myth and rather than open discussion there was a tacit shift in the power base as positions within each relationship altered in response to Alzheimer's disease. The threat to the reciprocal arrangements that were well established in the relationships came about mostly by the people with Alzheimer's disease feeling that they were becoming an increasing burden both in the present, and in the future, as expressed in a conversation between James and Mary

> J: I am sorry because I would have liked to think of Mary and me to be helping each other, instead of me being the one who needs all the help
>
> M: Oh but you help me still
>
> J: It's not a one way thing I admit that
>
> M: I only help you with the memory

> J: I'll do my best to help obviously, but it gets me slightly anxious that I sometimes can't remember (James: 2 572)

The promise to do his best was voiced as a hope that the reciprocity enjoyed in the past would continue and although anxious about his continued ability, James wanted a relationship in which he could continue to be as independent as possible, as helpful as possible, and in which he could make decisions. He also said, with a touch of humour, that he was glad that this relationship had a good and lasting contract in which he had invested his faith: "Okay it may be for better, for worse, for richer or poorer or in sickness and in health but so much the better." (James: 5 400). Although he reiterated the marriage vows he had taken over forty years ago he was still vexed at the thought of the sickness clause coming into force, "this is not what I want at all ... being a big burden on Mary's back." (James: 5 380). He had always done his share within the relationship and the thought of it being weighted to Mary's disadvantage was causing him sadness and anxiety.

The reciprocity enjoyed by Beth and George appeared to continue on the surface, although it seemed from how they acted together that George had taken on more responsibility than previously and Beth relied on him for many things. Beth, however, still described their activities as being shared, like playing bridge together and going to different meetings together, and she had alternatives arranged for her when he went out. "George goes to golf and I meet a friend and go downtown." (Beth: 1 175). A few months later she was still adamant that they managed everything together, "we just plutter and do our best with each other and you know, you fit in as and when." (Beth: 3 162). Doing things together was very important for Beth, but when I spoke with her family they were very keen to try to interest her in something of her own so that her husband could have some time to unwind. He found it all very stressful and had consulted his GP about it. Although the threat to their reciprocity was not coming directly from George, the family was heading someway towards endangering it.

There were many other instances of threat to reciprocity and sometimes it had already been breached, although Maggie's daughter would have embodied the notion of delayed reciprocity and stated that she was paying her mother back for all the years of care that she had given her. Maggie herself did not feel this and experienced an erosion of her position in the household. For Ian and Jenny the hope of true reciprocity was fading into a distant memory, with Ian's wife confessing that she had become impatient and she wished "he would still keep doing things." (Ian: 2 318). Jenny was resigned to losing the equality she had shared as her husband took on more and more of the responsibilities in the relationship, "well, in one way it's comforting and in another not comforting at all, but eh, it's just how it goes, I guess." (Jenny: 5 271). She also acknowledged that she was not the only person in the relationship to experience the difficulties of Alzheimer's disease

> "It can't be easy to live with somebody who's well not all there as you would say, you know I think that you must always make allowances and I don't know what else. It can't be easy you know. It is certainly no easier for a carer than for me, in fact it must be worse ... if someone is compos mentis enough in the past you anticipate that to continue, you know, instead that it is not going to, not by any manner of means" (Jenny:5 125)

In positioning her husband as carer she had acknowledged that this relationship had changed already and would continue to do so, with less hope of reciprocity than before.

Other instances of a threat to the reciprocal nature of relationships outside the family have been highlighted elsewhere in this section, for example, when friends of Ian began to treat him in a patronising manner and James's friends took over all the travel arrangements for their golf outings and other meetings. This could also be classified as part of the other major threat that these five people experienced in their relationships – the threat to their *autonomy* and *independence.* As with the other themes and sub-themes, there was an overlap.

Relationships and all their component parts do not fit neatly into pre-prepared categories and so it was with *autonomy* and *independence*, which were interlinked. Following the labelling of the diagnosis, the participants expressed a greater dread of becoming more and more dependent, and admitted that they were in fact becoming more dependent, but continued to find ways of maintaining some independence – a very ambivalent place: "you keep an eye on me. I don't need keeping an eye on really, I do forget things but I am quite good with my diary, it's easy to refer to." (Beth: 1 119). Beth stated that she did not need as much 'care' as her husband was giving her, thus admitting to the problem, but really saying that it was quite simple for her to be independent, all she needed was her diary, not a (re)minder. She was dependent on both George and her diary to get through her day.

Jenny's husband was very puzzled when he had tried to exclude her from kitchen chores and found her unhappy about this. He was happy to do the chores and said he was very able to take everything over, "it's less traumatic now than it used to be

...but of course it's losing independence, that's right" (Jenny: 5 Ron—301). He eventually realised what he was doing and was able to pull back from a complete takeover when Jenny said "I feel that I can't expect you to do everything, oh no, I feel that I should be doing something" (Jenny: 5 303).

John feared the physical and mental dependence and Maggie tried to find things to do when her daughter was out at work, "I've got to do it because you can't just sit on your bum all the time" (Maggie: 3 123). The restrictions that Maggie's daughter was unwittingly placing upon her mother were similar in a way to how Jenny was being positioned by her husband, even although they had spent a lifetime 'doing' tasks in the house and were still perfectly capable of carrying out the majority of those tasks. They were being disempowered by the anxieties of their loved ones. James's wife would hardly entertain the thought of him going anywhere independently, "I always go with him anywhere" (James: 4 Mary—262).

Further on in the study, Mary was able to become more confident that James could still go to familiar places himself, without being accompanied, and his 'limited freedom' was, therefore, reinstated. This reflected autonomy as well as independence. Being able to make his own decisions independently was just as important as being able to carry out tasks independently. Making the decision to tell his Pastor about his condition was James's own decision, which he made in the realisation that

> "I might not be able to perform certain functions in the church ... like standing at the door welcoming people and forget who they were; this sort of thing might be embarrassing both for me and for them, so I felt it was as well he knew about it so that is what I did ... I am not as active as I was but I would be very reluctant to give up going to church" (James: 3 39)

In making this autonomous decision about revealing his condition, he adopted a positive position, in order to preserve dignity in his relationships within the church. He valued those relationships and was not prepared to give up all church activities, just those he felt unable to fulfil and that might risk his relationship with others.

The importance of relationships to people in the study cannot be overstated. In the co-construction of meaning of the experience that had been the diagnosis of Alzheimer's disease, and subsequent six months of learning to live with the diagnosis, they were essential. Without relationships it was not possible to co-create a valued social identity.

Alzheimer's disease initially brought very subtle changes to these relationships, with a gradual erosion of positions and responsibilities. Changes in attitudes, behaviour and feelings were noted, as was the threat to relationships. These threats centred on reciprocity with an added danger of losing autonomy and independence.

For all the participants the renegotiation of these areas in the relationship was a myth. Power balance shifted mostly in a tacit way with no real discussion, but rather as a 'taken for granted' assumption by those in the relationship that this was now how it had to be. Renegotiation is a reciprocal activity and the diminishing hope of reciprocity, coupled with the unwillingness to discuss the diagnosis and its implications along with the protective stance taken by some of the people in closer relationships, made renegotiation a myth that disempowered people and diminished the contributions they could make. This was done by people with the best of intentions who hoped that their actions would benefit the people with the diagnosis. This was not always how it worked out.

## 6.6 Dealing with the aftermath: conclusions

This chapter has presented detailed findings from ethnographic observation and interviews with five people diagnosed with early Alzheimer's disease, during the six month period following the diagnosis. The chapter provides a rich descriptive account of the challenges faced by these people and their families, and the strategies they adopted to deal with a changed life. Although there were important differences between each of the research participants, it was found that the experience of all of them was dominated by these four themes: *struggling with the emotional impact of the diagnosis*, *daring to talk about Alzheimer's disease*, *re-authoring their story*, and *the challenge facing relationships*. A detailed summary of the main findings arising from the chapter, and how they relate to the research questions which the thesis seeks to address, is provided below, in Chapter 7 at Sections 7.1.4, 7.1.4.1 and 7.1.4.2. The aim of this concluding section is to highlight the most significant aspects of this chapter in the lives of a group of people who have been diagnosed with dementia, as perceived by them.

Listening to the accounts that participants gave of receiving the diagnosis, and coming to terms with it in the ensuing weeks, one of the most consistent elements of their experience was the strength of their emotional response to the diagnosis. A wide range of emotions was felt, but the predominant emotion was fear. However, at the same time it was almost impossible for participants to express this emotion to the other people in their lives. They reported few opportunities to explore and express emotions, although all of the participants acknowledged that they believed that it was important for them to speak about their feelings. The source of much of this fear had its origins in negative images and stigma, which formed the backdrop for participants of their experience during this six-month period.

The other constant thread through the stories of the research participants was the extent to which the meaning of Alzheimer's disease for them was bound up in the network of relationships within which their lives were lived. It was in interactions with family, friends and community representatives that a new narrative, of being a person with dementia, was co-constructed. It was notable that health professionals did not figure to any great extent within this web of relationships. Their meetings with their old age consultant had a powerful impact, but this took the form of being a recipient of information and treatment from a powerful other, rather than being a relationship within which dialogue and re-authoring might take place.

The act of *telling* emerged as a central preoccupation for this group of people. There was the painful and sometimes confusing task of assimilating the information they had been told by their doctor. There was then a complex set of decisions to be made about who to tell among the people in their lives, and how. Finally, there was the importance of how the telling was received. On the whole, these people with dementia found that others responded more positively, in terms of stigmatising attitudes, than they had expected them to

> "I would like people to know that this is not the end of life you know, life goes on, you can still play golf, you can still be part of social intercourse, you don't need to climb down into a hole and shut the door behind you. People are much more approachable and much more sympathetic than I ever thought. I think people are actually nicer than I ever thought they would be about it, so I would say, don't be shy, be straightforward and tell people and you will get an amazingly sympathetic response" (James 6: 756).

Alongside this, only one of the participants reported one occasion in which the telling resulted in an open and honest exploration of the fears and other personal issues that had been triggered by the diagnosis.

Receiving a diagnosis of dementia was experienced by the research participants as the beginning of a new chapter in their lives. It was an event of immense personal significance. They described the aftermath of the diagnosis not in terms of any dramatic changes to lifestyle and relationships, but instead as a subtle yet profound alteration of their sense of self in relation to others. The diagnosis represented a massive challenge to their spirit and their sense of what might be possible in life. The diagnosis was experienced almost as an invitation to accept a sense of being a lesser person, a diminished self.

The people who took part in this study differed in the ways in which they responded to this existential challenge. In the final chapter of the thesis (Section 7.2.6), a tentative theoretical framework is offered, as a means of making sense of the interplay between self and others in the period following an early diagnosis of dementia.

# Chapter 7

# Discussion and Conclusions

## 7.0 Introduction

The aim of this thesis has been to contribute to our understanding of how a diagnosis of early dementia affects the lives of different people. By adopting a social constructionist perspective, I have been able to explore what early dementia means to two specific groups of people, the *diagnosticians* and the *diagnosed.* The work has taken into account the historical and cultural context, and has challenged some taken for granted assumptions. I acknowledge that what is presented here is my 'truth' as I have come to know it. It is a form of 'local' knowledge, hopefully of value for this time and this place. It is knowledge that has been co-constructed with the people with whom I have interacted along the way.

This final chapter will be presented in four sections. In the first section the original research questions that were specified at the end of Chapter 2 will be revisited, and key findings from the empirical research will be related to these questions, in a form that shows how the research questions have been addressed in detail within the thesis. In the second section of the chapter, these findings are discussed in relation to previous theory and research. The intention here is to demonstrate the ways in which the current study both confirms and extends previous knowledge in the area of early dementia. In the third section of the chapter, the methodological strengths and weaknesses of the study are discussed. Section four considers some of the implications of this study for future research, policy and practice. The final section of the chapter offers some personal reflections on the meaning of the study.

There is a certain amount of repetition across Sections 7.1 and 7.2 of this chapter. Section 7.1 itemises the findings of the study in the context of the research questions. Section 7.2 discusses the same findings in relation to previous theory and research. This strategy was adopted in order to deal with the tension between being designed to fulfil the requirements for the PhD (Section 7.1), while at the same time addressing broader issues (Section 7.2).

## 7.1 Return to the research question

The main goal of this study was to gain an understanding of the impact of a diagnosis of early dementia on the people who were given such a diagnosis and on the medical profession. In Chapter 2, a critical review was undertaken of theory and research that was considered relevant to this topic. This critical review generated a set of research questions, which in turn functioned as the basis for two empirical studies. The aim of this section of the concluding chapter is to show how these questions have been answered through the research. Initially, I will present the findings of Study 1, which concentrated on the *diagnostician's* perspective. I will then present the findings of Study 2, which explored the experiences of people who had been *diagnosed.* In addition I will report on findings that cross over into each study as well as presenting the unique perspective of the person who had been diagnosed. This does not have a bearing on the diagnostician's perspective and is outside the shared process and is similarly outwith the diagnosticians unique experience. The section is structured in terms of the actual research questions that were formulated in Chapter 2, and looks at each question in turn.

It is important to acknowledge that the summary and overview of research findings that are presented in this section are necessarily tentative, and need to be read in the context of an appreciation of the limitations of the study. This research was carried out on a specific group of patients and doctors, in a specific setting. Any generalisation for these findings needs to be made with appropriate caution. So, while the findings are described in a straightforward way, in an attempt to be as clear as possible about the yield of the study, they are put forward as only a preliminary and tentative attempt to map out an area of inquiry in which a great deal more research is required.

### *7.1.1. How do doctors (GPs and Old Age Psychiatrists) construct the meaning of early dementia? What are the linguistic and cultural resources and practices that they utilise in making sense of this illness?*

In line with the social constructionist stance adopted within this study, a central research question concerned the cultural, personal and linguistic resources and practices that doctors used to construct the meaning of early dementia and its diagnosis. This question is of central importance in relation to understanding the process of what happens to people with dementia early on in their illness, because, typically, the medical construction of dementia largely controls the actions that are taken, and the meaning context within which issues are explored. The evidence arising from this PhD in relation to doctors' construction of the meaning of dementia is mainly found in Chapter 4 (Study 1), with some supplementary findings in Chapters 5 and 6 (Study 2). In Chapter 4 it was found that doctors primarily constructed the meaning of early dementia by relying on professional, scientific knowledge which they had gleaned from training and continued professional development (Chapter 4 Section 1.2). However, their understanding of this concept was not confined to a purely medical meaning. They were also influenced by a historical perspective, being aware of how the process of diagnosis had changed over the years since Alzheimer first described this syndrome one hundred years ago (Chapter 4 Section 1.4). Another sphere of influence was through their own personal experiences and social interactions with people with early dementia over a period of years, and whether these social relationships were with relatives, friends or patients, each had an influence on how the doctors co-constructed their meaning of early dementia (Chapter 4 Section 1.5). The negative stereotypical images and fantasies of dementia that doctors saw as being portrayed by society also informed how they constructed their meanings (Chapter 4 Section 1.7). Their understanding of working in the field of early dementia was that it was a difficult and complex area (Chapter 4 Section 3), which was under-resourced (Chapter 4 Section 3.1), with a lack of support for the emotional impact (Chapter 4 Section 3.3) that this work engendered, with difficult decisions to be made and dilemmas (Chapter 4 Section 3.4) to wrestle with in the face of a fragmented health care system (Chapter 4 Section 2). Further evidence relating to doctors' constructions of dementia was reported in Chapters 5 and 6.

In Chapter 5 (Section 3.1) there was evidence to show that GPs seemed to give greater import to third parties rather than the subjective reporting of symptoms of dementia – one participant had to ask three times for a referral to the specialist services when he consulted the GP by himself. The other four participants, who were all accompanied by relatives, were referred to the specialist after their first visit to the GP. Finally, taking the evidence as a whole, it appeared that there existed a large degree of diversity among doctors. To some extent, the way that early dementia was constructed by GPs was different from psychiatrists, reflecting their complementary professional roles and responsibilities. However, even within each of these groups, a range of discursive practices was found from a collaborative and inclusive stance which was patient focused through to a distant, objective, scientific stance which did little to engage the clinician in a meaningful encounter for the patient, but was more focused on symptoms to be managed rather than people to be listened to. This will be explained in more depth in the following section.

### *7.1.2 How do doctors (GPs and Old Age Psychiatrists) understand their role in relation to their management and approach of patients presenting with probable early dementia?*

How doctors understand their role is of fundamental importance and will dictate how they act in relation to the presenting patient and their family/supporter. The time of diagnosis is a crucial point in the patients' journey and what the doctor does and says at this time has the potential to shape how the patient begins to construct their own meaning of being diagnosed with early dementia. As with the previous section, the evidence pertaining to the role of the doctor is found mainly in Chapter 4 of this thesis (from Study 1), with additional references made to Chapters 5 and 6. This section will be divided into three segments dealing with different, but nevertheless connected points in the patients' journey, these being the *pre-diagnosis, diagnosis* and *post-diagnosis* phases.

In Chapter 5 (Section 5.3.1) it was established that GPs were the first point of contact in the *pre-diagnosis* phase, with most patients being accompanied to the consultation by a relative. GPs viewed their function at this juncture as assessing the patient by taking a history of symptoms, performing basic cognitive testing and physical examination including taking routine blood samples. Some GPs would also see their role as offering a tentative diagnosis in discussion with the patient (Chapter 4 Section 4.1) with referral for confirmation of diagnosis being made to the Consultant (Chapter 4 Section 2.1.4). Consultants understood their function as ordering radiological examinations that GPs could not access, taking a more detailed history and further cognitive testing (Chapter 4 Section 4.1). These were the functions that doctors understood as their tasks in the pre-*diagnostic* period.

At the time of *diagnosis* the task of the doctor seemed to take on greater magnitude which was reflected by evidence in Chapter 4. Diagnosis of early dementia was a diagnosis of exclusion (Chapter 4 Section 1.3), seen as a difficult and complex task and was viewed as one of the major challenges by the medical practitioners in this study. Making the diagnosis was seen as a shared enterprise between patient, supporter, GP and Consultant. However, giving the diagnosis was a task usually undertaken by the Consultant. Some GPs saw the giving of the diagnosis as a task they would like to perform as they felt that the doctor-patient relationship had a longer history (Chapter 4 Section 4.2 and 6.6). Doctors reported that telling someone they had a diagnosis of dementia was one of the most difficult tasks undertaken by them (Chapter 4 Section 4.6). It was found that the language utilised in 'telling' was a contentious issue with no real consensus as to what to tell. Arguments about truth telling versus the use of euphemism and metaphor, and the avoidance of the term 'dementia' was common practice. The word 'Alzheimer's' was used because it could be attached to the hope given by pharmacological treatments (Chapter 4 Section 6.1); however, it was prefixed by the word 'probable' or 'possible' in order to avoid litigious proceedings and to denote the lack of any scientific test to confirm diagnosis. Some practitioners used a standard format for disclosing the diagnosis, while others tailored their approach to the individual patient (Chapter 4 Section 6.3).

The study showed that it was rare for doctors to ask the patient's permission to invite the relative into the diagnosis giving interview; there seemed to be a taken for granted notion that this would be acceptable to the patient (Chapter 4 Section 6.2). It was found that GPs favoured telling the patient the diagnosis over a series of appointments while Consultants told in one interview. The timing of appointments may be an important factor in this decision as GP appointments last for ten minutes while the duration of the Consultant appointments can be as long as an hour (Chapter 4 Section 6.5). Doctors felt that the best time for diagnosis disclosure was at the beginning of the disease trajectory, but then only when the patient was ready. There is no scientific measurement of patients' readiness and doctors used their intuition, skill and knowledge to decide the best time (Chapter 4 Section 6.5). Doctors were aware of a sense of stigma which pervaded the time of diagnosis and acknowledge the stigmatising power of the doctor when giving the diagnosis (Chapter 4 Section 6.8). Consultants witnessed the reaction to the diagnosis differently from the GPs. Consultants reported that patients were observed as being relieved, not often shocked or surprised, and exhibited little emotional reaction at the time of diagnosis (Chapter 4 Section 6.9.1). The experience of GPs was different and patients expressed strong negative feelings more readily including anger, anxiety, fearfulness, depression, devastation, shock, unhappiness, and suicidal thoughts which could lead to clinical depression (Chapter 4

Section 6.9.2). GPs also reported that patients acted on these feelings, some setting affairs in order, some experiencing a grief like reaction, with others socially withdrawing. This would seem to be, in part, because there was a longer time lapse between patients consulting their GPs and patients had time to process and react to their feelings and emotions (Chapter 4 Section 6.9.3). Doctors again reflected their individuality as practitioners. However, there was a very clear distinction between how Consultants and GPs experienced the patients reaction to the diagnosis. These were the key findings concerning the time of diagnosis which were mainly reported in Study 1.

A wealth of material was collected around how the doctors understood their function in the *post-diagnosis* period. Doctors concentrated their thoughts primarily on pharmacological treatments and perceived their task as prescribing and monitoring the effects of medication. Most Consultants monitored the effects of medication on people who had a diagnosis of Alzheimer's disease but it was rare that patients with other types of dementia were monitored to the same extent. They were mainly referred back to the GP for prescribing medication to treat vascular disease (Chapter 4 Section 4.3) and GPs recognised that people with Alzheimer's disease seemed to get the most intensive follow up from Psychiatric Services (Chapter 4 Section 5). GPs in particular noted that patients required emotional support following diagnosis, identifying strongly negative emotional responses experienced by patients. Although Consultants were aware of a need for emotional support, they rarely witnessed these strong emotional responses, as patients behaved differently towards Consultants and GPs (Chapter 4 Section 5.1). The lack of appropriate emotional support was seen by Consultants as limited by resources, nevertheless the need for immediate post-diagnostic supportive follow up was highlighted as a gap in the service by both GPs and Consultants (Chapter 4 Section 5.1). They both put forward ideas for how this gap should be filled, with a resource akin to 'family type therapy' being favoured with a debate around who should deliver this service: CPNs with more counselling training or a specialist dementia counsellor trained in different aspects of the illness (Chapter 4 Section 5.2).

Doctors also understood their function as being referral agents. However, there were few services to which they could refer and across the area there were inconsistencies and no referral protocols, with some doctors referring everyone to CPN Services while others referred few patients and viewed this as a luxury service for people with early dementia due to scarce resources (Chapter 4 Section 4.4). Having to deal with this situation within the limited resources took its toll on doctors.

Doctors in this study recognised, and spoke freely about the emotional impact of working with people with an early diagnosis of dementia (Chapter 4 Section 3.2), with both personal and professional elements involved. They also recognised a lack of formal provision of professional supervision and support. Many doctors had derived their own system of dealing with the stress of the job but most would have welcomed support and supervision on a regular basis to help combat some of the stress.

These were the key findings from Study 1, in which 7 Consultants and 12 GPs were interviewed. The evidence of how doctors understood their role showed that there were certain tasks which were particular to Consultants and others which were particular to GPs, with some being neither the province of one or the other but could be seen as interchangeable reflecting their shared medical background. The language used, or not used, when giving the diagnosis seemed to be similar, with most doctors avoiding the use of the word dementia. The most dramatic difference was their observation of patients' reactions to the diagnosis, where Consultants saw little evidence of raw emotion while GPs reported strong negative emotional reactions.

The question of how the person receiving the diagnosis (the patient in the reporting of the doctors' study) experiences the role of the doctor and understands what is meant by their early diagnosis of dementia will now be reviewed.

### *7.1.3 What is the patient's pathway, into and through an early diagnosis of dementia?*

The significance of this question is in relation to reaching an understanding about what happens to people seeking a diagnosis of early dementia. The question is of paramount importance in understanding the patient's pathway and it is imperative that we trace its beginnings and contextualise the pathway, that has influenced how participants in this study begin to form their identity as someone with Alzheimer's disease. The evidence pertaining to this question can be found mainly in Chapter 5.

It was found that four of the five participants in this study did not seek a diagnosis by their own volition; rather it was pursued on their behalf by their relatives (Chapter 5 Section 2.3). Prior to seeking a diagnosis, evidence suggested that changes in memory function had to be acknowledged by the participants (Chapter 5 Section 2.2). This acceptance seemed to allow relatives to instigate medical investigations. Evidence of acknowledgement of change was presented in different ways. Specific events reported by three of the participants highlighted their changes, while other less dramatic realisations of change were apportioned to the remaining participants (Chapter 5 Section

5.2.3). Findings indicated that negotiating the healthcare system was complex, geographically, psychologically and physically (Chapter 5 Section 3 and 3.2) with each person entering the system via the same route which was the GP, but arriving at the specialist Consultant via diverse routes, with different waiting times (Chapter 5 Section 3.1). It was clear that initial contact with Psychiatric Services was an anxiety provoking experience (Chapter 5 Section 3.2). Follow-up appointments also evoked strong emotional feelings, as people waited in anticipation to receive their diagnosis. Waiting times for diagnosis varied from a few weeks to several months, whilst the diagnosis of one participant changed over a two year period (Chapter 5 Section 3.3). Evidence in this thesis suggested that there were several key issues pertaining to receiving the diagnosis: how the diagnosis was delivered; doctor-patient interaction; length of diagnostic appointment (Chapter 5 Section 4.1); and the reaction to the diagnosis (Chapter 5 Section 4.2). Four out of the five participants with dementia did not seek the diagnosis but were persuaded to consult their doctor by a relative in order that a diagnosis could be offered (Chapter 5 Section 5). Four out of the five participants were shocked by their diagnosis (Chapter 5 Section 4.2), with the predominant feeling being fear (Chapter 5 Section 4.2).

Overall, evidence from this thesis suggested that the pathway into and through an early diagnosis of dementia was clearly a unique experience for patients. Whilst there were some similarities, there were no two cases exactly the same and each embraced their own individual encounter with Alzheimer's disease along the pathway that led to their diagnosis.

### *7.1.4 How do people who have received a diagnosis of dementia integrate this knowledge into their lives and relationships? What are the issues that face people who have received a diagnosis, and what strategies do they use to address these issues?*

How people integrate their diagnosis into their daily lives and relationships has not yet been fully understood. The importance of understanding such a process could have potential benefits to service providers to help them design services to meet the needs of people with a new diagnosis. It could also have a benefit to the people with dementia themselves to inform them of what was happening to them within their relationship context. The evidence which informs this question is mainly reported in Chapter 6 of this thesis with some supplementary evidence being reported in Chapter 5.

Integrating the diagnosis into their daily lives and relationships was a complex process that all participants were involved in but not all had completed by the end of their six month involvement in the study. Integration meant more than just acceptance in this study, it also meant that Alzheimer's disease had become interwoven into the identity of the person with the diagnosis.

Integration seemed to begin following a formal diagnosis of Alzheimer's disease by a doctor. Four out of the five participants were shocked by what the doctor said despite having acknowledged changes, and even although one person had expected this diagnosis, it was nevertheless a traumatic event in all of their lives to which they had to respond in some way (Chapter 5 Section 4.1). There was evidence to suggest that this diagnosis led initially to emotional turmoil and was influenced by participants' previous knowledge and personal experience of Alzheimer's disease which in turn influenced their expectations of their future experience of having the illness (Chapter 6 Section 1.1).

Fearfulness was the most strongly and frequently experienced emotion, centring primarily on fear of the future and fear of the judgement of others. Other feelings expressed were of uncertainty, bitterness, loss and relief (Chapter 6 Section 1). Expressing emotions and being able to discuss the diagnosis with others was part of the integration process but there were few opportunities to have conversations that focused on their diagnosis (Chapter 6 Section 2.4); and at times people struggled trying to process emotions internally, when speaking to others was not possible or not their preferred option (Chapter 6 Section 2.4). Being able to speak to friends and family about the diagnosis was very challenging and demanding, indeed telling anyone was difficult. Telling others appeared to be a crucial factor in the integration process and this was instrumental in people moving from a secretive stance to being more open and at ease with their diagnosis (Chapter 6 Section 3.1).

There were different components of the telling and the question of whether to tell or not (Chapter 6 Section 3.2) addressed one of the dilemmas people faced about their diagnosis, and various reasons were offered for each side of the argument. Another dilemma was who should tell, the person to whom the diagnosis belonged or the relative who was with them at the time of diagnosis. There is evidence to suggest that the process of telling or disclosing the diagnosis to others may hold the key to the integration process, and it was only when people started to tell their own story about their diagnosis that integration became more than a possibility (Chapter 6 Section 3.3).

The study suggested that a selection of people within the person with dementia's social network was informed of the diagnosis and not everyone should be, or was told about it – only a selected audience heard the 'telling' from those who wanted their story heard. There were both positive and negative implications of telling (Chapter 6 Section 3.4), but it was the reactions to the telling that helped to shape the new identity of the person with Alzheimer's disease. Some felt that their diagnosis had been minimised and this in turn led to a barrier to integration (Chapter 6 Section 3.6) while others felt affirmed which encouraged them to tell their story again, which led to a greater sense of integration. Despite the affirmation that people gave, there was only one occasion where someone was prepared to discuss the implications of the diagnosis with the person (Chapter 6 Section 3.6). All of the people within the study recognised and acknowledged their need to discuss the diagnosis and their thoughts and feelings about this and be able to raise difficult issues, which their family were not prepared to do (Chapter 6 Section 3.7). This was seen as pivotal to the integration process, while not being able to talk openly about the illness was acknowledged as hindering the process.

The process of the telling or re-authoring of the story had a temporal element in which were woven stories from the past and projections for the future into the experienced present (Chapter 6 Section 4), encompassing horror stories and fantasies as well as different realities, in which people with dementia had a different view of what was real to their spouse. For example, one person felt the presence of her parents but her husband did not share the experience. The process of re-authoring was central to the act of making meaning of current reality (Chapter 6 Section 4.1). Evidence from this study suggests that learning to live with the diagnosis was an active choice by participants and the work they had to do to achieve this incorporated acknowledging and accepting changes, pragmatic planning taking into account these changes, and taking a positive philosophical stance (Chapter 6 Section 4.2). It led to adjusting lifestyle to accommodate the changes and adapting to a life that was different but could incorporate and continue many aspects of life as they knew it, and could still be lived to its full potential within a limited freedom (Chapter 6 Section 4.2).

Facing a future with Alzheimer's disease was an important facet in the integration process despite fears of a diminishing sense of self and anxieties around an inability to know who they would become; fearful of not even recognising themselves or significant others in their lives. Once they had worked through this fear, they came to a feeling of deep resignation about their inability to change the path of the disease.

They also recognised that how they lived with it was their choice to some degree (Chapter 6 Section 4.3), coupled with hopefulness that in the future science would find a cure.

The impact of the diagnosis integrated into relationships often in a covert, tacit manner because of the inability of family members and friends to discuss the diagnosis and its implications. As a result people took over tasks that the person with the diagnosis could still do, but negotiation was not part of this process (Chapter 6 Section 5). This led to relationships being threatened and people's autonomy being undermined and again it was not until there was discussion about these issues that the implications of the diagnosis could begin to be integrated into the relationship. Friends seemed to factor in the diagnosis to relationships and make the necessary adjustments without discussion, but there was an avoidance of the subject with people who accepted the diagnosis, accommodated it into their relationship but continued to refuse to have open discussion (Chapter 6 Section 5.1 and 5.2). There were also threats to the relationship which will be addressed in the next section on issues that people face once they have a diagnosis.

#### *7.1.4.1 Issues to be faced following diagnosis*

It was evident from this thesis that people had to face many issues in the post-diagnostic period, the most prominent of these being the stigma associated with Alzheimer's disease and any type of dementia. Within this study people feared being stigmatised by their family, friends and wider society, with the fear of being treated differently once their diagnosis was disclosed (Chapter 6 Section 2.2). It was clear there were also issues about stigmatising themselves from their own personal perspective about how they perceived Alzheimer's disease (Chapter 6 Section 1). Other issues highlighted within the study were: a difficulty in expressing emotions about the diagnosis (Chapter 6 Section 2.4); the ownership of and sharing information about the diagnosis (the telling) (Chapter 6 Section 3.3); dealing with loss of autonomy and independence accompanied by a diminishing sense of self (Chapter 6 Section 2.3); the lack of willingness of anyone to enter into discussion about the diagnosis (Chapter 6 Section 3); and the changing balance of power and position within relationships (Chapter 6. 5).

This study claims that many of the negative issues experienced by the person with the diagnosis hinder the integration process.

#### *7.1.4.2 Coping strategies used by people who have received a diagnosis*

The development of strategies to cope with the issues arising following diagnosis was reported by the participants in this study as both practical and cognitive and they were devised either by themselves or in conjunction with their close relatives and friends. Stigmatisation was dealt with in two different ways and was felt to be caused by the thought of other people knowing about their diagnosis. This led either to being secretive (Chapter 6 Section 2.2) so that the negative feedback they expected was avoided, or to being open about the diagnosis and its limiting factors (Chapter 6 Section 3.2), thus embracing the external social stigma. The stigma within was dealt with again in a similar manner, by either choosing to ignore the diagnosis and feelings associated with it (Chapter 6 Section 2.4) and trying to live as if everything was the same as before (Chapter 6 Section 3.3), or by expression of their emotions during the research project which then enabled the emotional processing in order to deal with their sense of inner stigma (Chapter 6 Section 2.4).

It was found in this study that one of the difficulties that inhibited the expression of feelings and emotions about the diagnosis was because other people did not want to listen or engage in dialogue about the diagnosis. This led to a lack of opportunity for people to discuss feelings (Chapter 6 Section 3.7), and the research project again became a vehicle to allow such discussion to take place.

Issues around the ownership and sharing of the diagnosis were worked out tacitly within the family, with little discussion. People with a new diagnosis of Alzheimer's disease do not always get the opportunity to make the decisions about how or even whether this information should be disseminated. There is evidence in this study to suggest that the strategy adopted by most people is collusion with what their spouse/family think is best, with examples of this being relatives of James and Maggie, who moved their position to accommodate others within the family (Chapter 6 Section 3.3).

Loss of autonomy and independence (Chapter 6 Section 5.2) were coupled with many pragmatic strategies which enabled decision making skills and 'limited independence'. These were finding new and diverse ways of solving potential problems and included enlisting the help of family and friends in reminding people of appointments made, asking friends to drive to meetings, building a routine and using a diary for all engagements. Maximising skills and recording in writing different steps of procedures and following these steps in a methodical way were all ways of pragmatic planning in order to prolong the feeling of independence. Exploring alternatives such as eating out instead of cooking, taking a taxi or buying a bicycle instead of driving were just some examples of how practical solutions were being explored (Chapter 6 Section 4.2). These strategies were also practical ways in which a diminishing sense of self was overcome. Cognitive strategies utilised included relating the cause of the disease process to external factors, at times existing in a different reality, by accepting the diagnosis but actively choosing to ignore the inherent changes and by exploring such questions as 'who will I be when I die?'(Chapter 6 Section 4.1 and 4.2). Embracing the fears of the future was balanced out by the tentative hopefulness and investment in science to find a cure (Chapter 6 Section 4.3).

Issues within relationships relating to the balance of power and changing position were dealt with in several different ways. There was evidence of acquiescence as all of the participants accepted different positions assigned to them. There was also evidence of people circumventing these positions by finding ways of continuing to be independent when the supporting relative was absent. The other method of dealing with this was to confront and refuse to be positioned in a negative way (Chapter 6 Section 5.2). Through the discussions within the research project many of these issues were resolved because there was a third party present, however, these discussions were rare and most of the issues were dealt with in a covert and tacit manner, with negotiation being very rare.

## 7.2. Integrating findings with previous theory and research

The purpose of this section of the thesis is to discuss and integrate the findings from this study in relation to previous theory and research. There are a number of places that the findings make a contribution to the debates and therefore this section may appear repetitive in nature.

### *7.2.1 Doctors' construction of meaning*

Within the medical literature, the meaning of early dementia has been studied around three or four main topics, with the predominant focus on the debate centring on whether the diagnosis of dementia should be disclosed to the patient or not. In Chapter Two of this thesis, the literature on this subject was reviewed and the key conclusions were that there were multiple causes of this syndrome (Jacques and Jackson 2000) with questions over whether or not it was an extension of normal aging (Brayne and Calloway 1988), and that it was difficult to diagnose and differentiate between early dementia and Mild Cognitive Impairment (Chertkow 2002). And a diagnosis can only be certain at post-mortem (Ballard 2000). Early diagnosis meant early on in the disease trajectory (Kelly 1995) and the imperative of making an early diagnosis was highlighted by many (Bond Chapman, et al. 2002, Bryans, et al. 2003, DeKosky 2003, Gustavo 2003, Hamilton 2001, LoGuidice 2002, Manthorpe, Iliffe and Eden 2003, Rait, Walters and Iliffe 1999, Wackerbarth and Johnson 2002). These findings are in keeping with those reported earlier in this thesis.

However, doctors' constructions of early dementia in this study were also influenced by their own personal encounters with people with dementia, whether in personal relationships or social interactions and not confined to purely scientific knowledge. This could account, in some part, for the great diversity between the doctors in the study regarding how they constructed early dementia. The scientific knowledge that they gained from training and continuing professional development would be similar in both groups of doctors. If they were constructing their meaning purely on scientific knowledge then there would have been much more of a similarity in how doctors viewed early dementia and responded to patients. However, since they have all had very different personal encounters and experiences of early dementia, whether with relatives, friends or patients, this could go some way to explaining the diverse practice which was witnessed in this research project. This has not been previously reported.

The debate around the disclosure of a diagnosis highlights and reflects many different aspects of how doctors construct early dementia. Disclosing a diagnosis of early dementia had an ethical stance (Drickamer and Lachs 1992, Erde, Nadal and Scholl 1988, Pinner 2000) and was likened to the discussion around diagnosis disclosure to that of earlier attitudes to cancer (Novack, et al. 1979, Oken 1961). It was thought each individual case should be evaluated but as a rule most people should be told their diagnosis of dementia (Drickamer and Lachs 1992, Vassilas and Donaldson 1998). However, this was not a view held by all (Hesketh 2001, Markle 1993) and fewer than 50% of doctors informed their patients about the diagnosis according to later studies (Clafferty, Brown and McCabe 1998, Johnson, Bouman and Pinner 2000), and the patient's perspective was much less in evidence although some studies have asked if people liked the idea of having a copy of their diagnosis in writing (Eaton 2002, Jha, Tabet and Orrell 2001, Smith, et al. 2001, Smith and Beattie 2001). Whilst this information was moderated by patients' relatives many felt that it would be beneficial to have a written diagnosis. However, rarely was the patient consulted and more normally it was their families who were asked for their views (McGuire, et al. 1996, Pucci, et al. 2003).

In this study there was little debate around whether people should be told or not. It was expected that patients would be told their diagnosis unless there were exceptional circumstances cited such as the person with dementia having a concurrent terminal illness. For this group of doctors involved in the study the debate around whether to tell has moved on, although it seems from the literature still to be an ongoing discussion (De Lepeleire, Buntinx and Aertgeerts 2004) in various parts of the world. None of the doctors in this study offered a written diagnosis to the patient or family. However, the study opened up some new topics like who was the best placed to give the diagnosis, the GP or the Consultant, thereby challenging the taken for granted assumption that it should be the Consultant, with some GPs arguing that they should be the ones to give it to the patients with whom they already have a well established relationship. It also highlighted the question about who should receive the diagnosis, should it be the patient alone or should the relatives automatically be included in the diagnosis giving interview with the Consultant? Again this is something that happens automatically and it was stated that only one of the nineteen doctors interviewed sought permission from the patient to include the relative. This was similar to the findings of Connel et al. (2004).

A reluctance to tell had also been noted in the literature which found many different reasons why people should not be told, including stigmatization, harm, protectiveness, degree of dementia, embarrassment at using the word dementia, provisional diagnosis, uncertainty, fear of causing psychological distress, loss of hope or risk of suicide (Boise, et al. 1999, Brodaty, et al. 1994, Fortinsky, Leighton and Wasson 1995, Johnson, Bouman and Pinner 2000, Rice and Warner 1994, Rohde, Peskind and Raskind 1995, Van Hout, et al. 2000).

Doctors in this study were aware of these barriers to giving a diagnosis but they did not give them as reasons why people should not be informed of their diagnosis, although some of these issues were mentioned in discussion as potential problems for the patient. They all agreed that it was a difficult and complex task. However, they were more focused on the language that they used when giving the diagnosis and debated whether it was acceptable to use metaphor and euphemism rather than saying the word dementia. Many doctors, although not shying away from giving a diagnosis, did not want to use the word dementia for many of the reasons noted in the literature reported above. The difference was that they were all convinced that people should be given a diagnosis, but not sure just how much information, or what type of information patients should have. Some doctors seemed to tailor the diagnosis to suit the individual patient while others used a similar approach for all.

### *7.2.2 The doctors' understanding of their role in early diagnosis*

The literature reported in Chapter 2 Section 2.3 relates to the role of the doctor. This section of the thesis will argue that doctors co-construct meaning from the tasks that they undertake in conjunction with how they see their role. Many of the tasks undertaken by both groups of doctors in this study are similar, with assessment, diagnosis, management and treatment cited as the main duties (Draper 2003, Van Hout, et al. 2000), with GPs concerned more about the pre-diagnosis phase of the disease, and normally referring on to Consultants in Old Age Psychiatry for formal diagnosis (Van Hout, et al. 2000, Wattis 1996). Although GPs were referred to in the literature as holding a pivotal position (Downs 1996, Downs, et al. 2000, Wilkinson and Milne 2003), there was no evidence in this study to suggest that GPs perceived themselves in this light, and differing attitudes as to the importance of early diagnosis prevailed in keeping with studies reported (Eefsting, et al. 1996, Vassilas 1999, Wind, et al. 1994).

One of the differences between GPs and Consultants in this study was the disclosure of the diagnosis and although it has been reported above, the taken for granted role of the Consultant appears to incorporate the disclosure and most of the GPs too saw this as part of the task of the Consultant (Draper 2003), although some GPs would have wanted to give the diagnosis themselves.

Another difference was that GPs seemed to be more aware of the emotional response to receiving the diagnosis (De Lepeleire, Buntinx and Aertgeerts 2004), whereas Consultants found that people felt relief and rarely were shocked or surprised by their diagnosis and it was noted that patients seemed to present differently in clinic situations to that of the GP surgery.

Doctors saw themselves as referral agents (Van Hout, et al. 2000). However, apart from GPs referring to Consultants and vice versa, there were few agencies that were available for them to refer to especially when it came to emotional support for patients and families, and the lack of psychological support services was a gap that was identified by both groups and recommended in HDL 44 (2004).

There is also evidence in this study that suggests there is an emotional impact on the doctors who describe a feeling of sadness for the patients and also felt that they had to present a positive image on what they perceived to be a particularly negative prognosis. There is evidence of this in a study by McWilliams (1998) who also recommended that Consultants should have access to professional support. Doctors in this study also expressed a need for support.

The resultant stress incurred as part of their role was acknowledged (McIntosh, et al. 1999) as was the lack of support and supervision provided (Benbow and Jolley 1999).

### *7.2.3 The patients' pathway*

The patient's pathway towards diagnosis has not been reported to any great extent in the literature because it is by its very nature retrospective, but anecdotal evidence tells us that it is rarely patients themselves who seek a diagnosis, but their relatives who normally prompt them to seek a diagnosis. This is evidenced implicitly in studies such as Fortinsky, Leighton and Wasson (1995) and Hanson (1989). This was also the case in this study, where four out of five participants sought diagnosis as the result of prompting from family members. They followed the pathway of being seen by the GP and referred by the GP to the Consultant (Van Hout, et al. 2000), with the diagnosis being made in all cases at an early period in the trajectory (Kelly 1995). Different times for the diagnosis to be clarified resulted because of the lack of definitive testing (Kawas 2003) and the change between Mild Cognitive Impairment (MCI) and dementia (Visser 2002). The pathway continued with histories being taken from the person and their family member, along with formal cognitive testing, physical and neuropsychological testing and neuro-imaging (Santacruz 2001). Following results from these tests, diagnosis was given to the person and their family together (Connel 2004). There was no dilemma about whether people should get the diagnosis or not, unlike much of the literature (Biernacki 2003, Fahy, et al. 2003), although the language used was, in some cases, couched in euphemism and metaphor (Johnson, Bouman and Pinner 2000, De Lepeleire, Buntinx and Aertgeerts 2004). Whilst Consultants felt that patients and families accepted the diagnosis and did not seem surprised, this was actually in contrast to how they felt, as described when four out of five of them reported that they were shocked by the diagnosis (Connel 2004) with the predominant feeling being fear (Husband 2000).

What stands out as different from earlier literature reports is the dearth of information about the patients' journey towards diagnosis and the actual diagnosis, but this has to be anecdotal and retrospective. There have been no studies reported that have engaged people with a diagnosis as early in the post-diagnostic phase as this study, which had all participants recruited within 15 days of the diagnosis. This study therefore gives a unique perspective on the person's experience and how they integrated their new diagnosis of Alzheimer's disease into their lives.

### *7.2.4 The integration process – learning to live with a diagnosis of dementia*

Learning to live with a diagnosis of early dementia is a difficult and complex process as has been seen throughout Chapter 6 of this thesis. It would seem that there is a process taking place that leads to the integration of such a diagnosis into the people's daily life. This process takes different lengths of time for different people and in some cases it does not happen. It has been evident, particularly in the case of James, that once it does happen, as relatively normal a life as possible can be enjoyed, but this can be something of a delicate balancing act between the need to continue as before and having to construct a different identity (Pearce, Clare and Pistrang, 2002).

This thesis increases our understanding of the processes which are experienced by people who are newly diagnosed with early dementia.

In common with the study of Husband (2000), following the diagnosis the initial feelings were predominantly of fear and other negative emotions connected with fear, which were fear of being judged, fear of others finding out, fear of future dependence most of which was shaped to some extent by previous experiences of dementia. This process is complex and unique.

A crucial part of the integration process is telling others but there has been little reference to importance of this in the literature with the exception of Phinney (2002) who questions the ownership of the diagnosis story believing it to be a shared narrative rather than just belonging to one person. There was a reluctance to tell the diagnosis to others for fear of how they would be evaluated by others and how they would be treated. Without being able to tell others there was no possibility of knowing how others would react. Scant reference was made to the telling, although for the purposes of integration it was found to be a crucial part of the process in this study and it was in the telling that people began to form a different sense of self. This different sense of self was achieved through the processing of thoughts, beliefs and feelings centred on the impact of the diagnosis and the projected future. There was a need for maintaining much of the old self alongside knowing that a co-construction of a different self was required (Pearce, Clare and Pistrang, 2002; Menne, Kinney and Morhardt, 2002). This time in the integration process is classified as being in a state of flux (Harris and Sterin, 1999) with a need to confront fears of the future. Facing these fears and naming them were found to be necessary to move on (Husband 2000).

### *7.2.5 The importance of 'the other' in relationship*

Sabat's (2001) exposition on the self[3] personae leads us to believe that we are dependant on the cooperation of others for jointly constructing a social identity. Hanson (1989) offers a model of how families construct either positive or negative social identity for people with dementia either as definitional deficit or definitional equality. The deficit families indulge in malignantly positioning the person with dementia and make decisions without consulting them and generally exclude them from decision making processes, while the equality families are much more inclusive and positive. Within this study it was not quite as clear as an 'either or' position. James belonged for the most part to what Hanson (1989) would describe as a definitional equality family; although he did not discuss his diagnosis with his family, he discussed everything with his wife. His family were not living within the family home. Ian was part of an equality/deficit split family because sometimes he was consulted and at other times ignored. This was similar for Jenny although her family had moved from being a deficit to more of an equality family. Beth and Maggie both belonged to definitional deficit families where they were usually given instruction rather than being consulted about what was happening, and being the recipients of malignant positioning, although their families had their welfare at the centre of all they did, and thought that they were doing well by not burdening them with decisions to make or discussions to have about their diagnosis. Family relationships were paramount in how people learned to live with their new diagnosis.

Couples' reactions to the diagnosis had both positive and negative effects according to Robinson, Clare, and Evans (2005), with feelings of relief, and understanding while others felt differently with no alleviation of their uncertainties.

They also describe a process of adjustment and loss akin to models of grief, with the process of acknowledging loss an important part in the overall process. Losses included: previous lifestyle; roles; independence; while changes in the relationship resulted in inequality of power, and their role within the relationship also changed. For the most part the couples in this study were mostly shocked; initially, none expressed relief at their diagnosis. They did experience changes in roles within the relationship with Ian giving up driving and financial management and his wife taking on these roles, while Maggie struggled to be allowed to do the cooking which she used to do for a job, and had to do things behind her daughter's back because her daughter was fearful of her doing too much. Mary and James continued with their separate roles although adjustment had to take place and Mary felt that her role had extended rather than changed because she was always the organiser and manager. Jenny and Ron had changed roles with Ron trying to be over protective and thereby stifling Jenny's autonomy. Du Vugt (2001) reported changes in the marital relationship with a decline in happiness, sexual expression and equality. In this study the subject of the sexual activities was never discussed and no-one reported a change in happiness but the equality of the relationship was affected as reported earlier. Some partners experienced deterioration in the relationship although at the same time felt much closer. This would be true for only Ron (Jenny's husband) and Mary (James's wife), who described being more open about the situation they were in than they had ever been in all their married lives.

Others played a considerable part in shaping a different self and this could be both affirmative and negative (Harris and Sterin, 1999), but was always was achieved through social interaction (Pearce, Clare and Pistrang 2002, Sabat 2001). The negative reaction of others was mainly seen as a result of stigma which had an effect on self-esteem (Sabat 2001) and people in this study tried to avoid this stigma by being secretive about their diagnosis, and this was the main reason they would not share their diagnosis. On the other hand, once someone had integrated their diagnosis this fear of telling was less likely to be avoided and the person would be more likely to develop a sense of agency sharing their diagnosis.

There was no doubt that within the relationships, reciprocity and mutuality had diminished to a greater or lesser extent as was shown by Baikie (2002). Although they were diminished, there was an increase in shared activities (Hellstrom, Nolan and Lundh 2005). This had little to do with reciprocity and mutuality and more to do with an increased sense of appreciation of the relationship where in one instance, Jenny's daughter made a point of meeting her mother for coffee every week which is something that she had not done before. On the other hand spouses had become more protective and encouraging of dependency and less likely to encourage autonomy such as Jenny's husband wanting to be with her all the time. Maggie's daughter now included her mother in the annual holiday abroad and this did not happen before. James and Mary now both played bowls because Mary was anxious about James making his own way to the bowling alley so she decided to take up the same hobby. These are all instances within the study of increased shared activities.

The importance of relationships cannot be over emphasised. The extent to which the person with dementia is supported positively or not depends very much on the quality of the relationships they experience. How a person learns to live with dementia is very much dependent on their social relationships. However, it is difficult to encourage supportive positive relationships in a climate of secrecy and silence when some of the participants were not willing to share their diagnosis even within their own families. Those who did want to share their diagnosis found that people would not allow them to express raw emotion, but closed them down whenever they decided to tell the diagnosis, and that inhibited the process. These were common not only with friends and family, but with the health care professionals too as people were malignantly positioned as dysfunctional patients, or cognitively impaired patients. This complex process will now be theoretically analysed.

### *7.2.6 The process of constructing a valued social identity with Alzheimer's disease: the interaction between negative self*$^2$ *and positive self*$^3$

The aim of this section is to offer a tentative theoretical formulation that seeks to make sense of how people who have been given a diagnosis of dementia engage with others in their life to make meaning out of this life event. From the material presented in chapters 4, 5 and 6, it is clear that a complex set of processes and interpersonal interactions take place at the time of diagnosis and during the subsequent six months. The person diagnosed with dementia is influenced by broader social attitudes; by the way that people around him or her understand and talk about the condition, and by their own characteristic ways of coping. Without wishing to deny the complexity of what happens during this period, I would wish to argue that there is one critical process that stands at the centre of the challenge faced by the person at this period in their life. The findings of this study suggest that:

**The key to the formation of a valued social identity in early dementia is linked to the capacity to tell others about the diagnosis. However, the significance of this act does not only lie in the 'telling' but in who is listening, how they listen and whether they are prepared to respond with compassion and love and are able to respond in a way that meets the needs of a person expressing the emotional meaning that the condition holds for them.**

The remainder of this section comprises an attempt to articulate this statement more fully, back it up with evidence from the study, and explain where and how it connects with existing theory.

The social constructionist notion of self and selfhood that was introduced earlier in this thesis comprises three aspects to selfhood: self$^1$, self$^2$, and self$^3$ (Sabat 2001, 2005) which affects how a person is positioned (Harré and van Langenhove 1999, Sabat and Harré 1992, 1999) . Self$^1$ is the self of personal identity, and expressed through the use of personal pronouns, self$^2$ is the self of physical and mental attributes, past and present and self$^3$ is the social personae constructed with the necessary help of others. Within this study there is evidence to suggest that when this theory is applied to people with a new diagnosis it gives a fresh understanding of the emotional process of the person. Essentially, when someone receives a diagnosis of early dementia, this means that a new self$^2$ attribute has been added to that person's attribute system. This new attribute can be seen to consist, at one level, of a self-statement along the lines of "I have Alzheimer's disease". At a less overt level, however, the diagnosis activates what can be understood as a set of latent attributes, arising from stigmatising and negative social images of and attitudes toward a person who has "dementia". This cluster of negative and frightening attributes poses a threat to the stability of that self$^2$ attribute system as a whole, as the person struggles to accept this latest attribute assigned to them by their doctor (in this study, the Consultant in Old Age Psychiatry).

In trying to assimilate the implications of this new attribute, the person relies on their previous experience of what dementia means to them, which may be a pretty negative and frightening picture, described in this thesis by the theme 'horror stories and fantasies' (Chapter 6 Section 4.1). This negative image means that they will have a strong tendency position themselves (reflexive positioning) according to that set of undesirable attributes, as a person who is worthless or has a "spoiled identity". In other situations where a person is assigned an undesirable attribute (e.g. receiving news that one has not been successful in a job application), it may often be possible for the person to engage in an internal dialogue in which they are able to place the bad news "in perspective", for example, by using readily available forms of accounting such as "I never wanted the job anyway, I'm happy with what I've got", and not allow it to have any major impact on their sense of self. In the case of a diagnosis of dementia, however, the implications of the new attribute are so total and overwhelming, and the likelihood of remedial self-dialogue so low (given the unwillingness of members of our culture to speak positively about dementia), that the person in the post-diagnostic period is locked into a new sense of self that is frightening, undermining and immovable.

In order to move on from that image, the diagnosed person must rely on at least one other person in order to co-construct a valued social identity (self$^3$). For the person with a new diagnosis this is difficult to achieve. Findings from this study reveal that people are loathe to become involved in any exchange of dialogue that will support the formation of a positive self$^3$. Of the 5 participants who were involved in the study, only one instance is recorded of someone being prepared to have open dialogue that embraced the emotional state of the person. Participants in the study found that doctors treated emotions as symptoms, e.g. possible depression to be treated by drug therapy or a visit from a nurse. Doctor used euphemisms to avoid speaking directly about the condition. Friends and families just would not engage in discussion about how the diagnosis affected the feelings of the participant. Interactions with doctors, and with family and friends, were largely characterised by information exchange rather than dialogue and meeting. The result of all this was that emotions had to be suppressed and internalised, with no opportunity to externalise them. The attribute system therefore remained in an unstable state, because of the conflict within the participant of trying to come to terms with, and assimilate the new attribute of being a person with dementia.

Any conversation or interaction that would allow the person openly to discuss the real personal meaning of the diagnosis would inevitably involve the expression of emotion, for two reasons. First, to imagine being a person with end-state dementia is in itself a terrifying proposition. Second, all of the new self$^2$ attributes associated with the disease set up conflict with the pre-existing self$^2$ attributes that had previously guided the participant's life as a healthy person. For example, a feeling of loss could be understood as the effect of dementia-dominated "bleak future" attributes obliterating previously-held hopeful future attributes. All of the participants in this study (and in other studies) reported feeling strong emotions of fear, anxiety, loss and frustration in the post-diagnostic period. However, there were very few reports or observations of interactions with other people in which emotion was openly expressed. Without expression there was no resolution and no moving on to positive positioning. The emotional process was not being allowed to flow, therefore there was no resolution of inner self[2] conflict.

In order for a positive positioning experience to take place there had to be opportunity to tell people about their diagnosis (not merely inform them), and how they felt about it. Only then were they able to regain their personal agency and reposition themselves. The process that is being described looks something like this:

Diagnosis of early dementia received → position self negatively → given opportunity by a significant and trusted other to express emotions about diagnosis → affirmation given → beginning of formation of a valued social identity → regain personal agency and be able take control of life again → learn to live within a limited freedom.

I will now illustrate this new theory utilising two of the case study individuals, one who had this experience and the other who did not.

James was a 68 year old retired pharmacist. He was normally of a jovial nature and very active in his church and in his community, had lots of friends, hobbies and was a member of various clubs. He received a diagnosis of early Alzheimer's disease from the Consultant.

James became very depressed and distressed following his diagnosis. He felt that his world had come to an end, and envisaged his future as very quickly deteriorating (negative views of the new attribute of having Alzheimer's disease) and he shared this with me on our second meeting: "the thing that worries me is that this is going to go on deteriorating, and I won't know who I am…what I really dread is if it gets worse and worse and I forget who you [wife] are" (James 2: 415). Here, he is clearly positioning himself negatively (malignant positioning): "this is a degenerative condition for which there is no cure" (James 2: 508). He views himself as deteriorating into oblivion. This was the picture of dementia that he was living by and this was how he attributed dementia to himself (self$^2$). It was difficult for him to leave that position without expressing his feelings. His wife, while very supportive and reassuring, did not discuss the emotional impact of the diagnosis. This was not their usual way of interacting. He told (informed) two people, one his insurance man and one of his fellow choir members, both of whom said they were sorry but did not engage in any meaningful discussion about how this would affect him. It was not until he decided to share his feelings about his diagnosis with his minister that he was able to begin constructing a positive self$^3$. What happened between him and his minister was a very intimate exchange. He was able to share the news of his diagnosis with him, and to tell him that he felt that his world was coming to an end. His account of his visit to the minister is as follows

> "He was exceedingly good, he knelt down and prayed with me and I felt that was a very good thing. I think it released, I don't know, a feeling of tension you know, that I had actually told somebody and they were sympathetic...I felt a sense of relief at that point that I had told somebody and got it off my chest...it wasn't a shut out process, [he didn't say] you can't come back to church or anything like that...nobody else has talked about how I felt about it" (James 3: 35 & 47 6: 320).

In enabling James to express his emotions the minister was doing something very precious that James had not experienced anywhere else. He was listened to, embraced, valued, affirmed and reassured of his continuing place in the church and in his ongoing relationship with the minister. It was not just in the act of sharing information that James was able to co-construct his valued social identity, because he had informed two other people. It was only in the expression of his emotion through the telling of his story that he was able to diminish the negative self$^2$ attribute and allow a positive self$^3$ to form. From that time James, went on to tell many other people, but by then he had reclaimed his own power and therefore was able to position himself in relation to these others. He would tell people he had a diagnosis of early Alzheimer's disease and he told them that he hoped that it would not diminish their relationship. He went on to integrate his self$^2$ attribute of Alzheimer's disease as something he could learn to live with and adapted his life to what he called 'learning to live within a limited freedom'. With the help of his minister initially, he progressed to being able to form a valued social identity. The minister had not positioned James malignantly, but affirmed him as a person.

This reluctance of the person with dementia to risk telling the diagnosis, which was also a finding in this study, gave few opportunities for this kind of exchange to be offered. However, even if participants were willing to tell their diagnosis, there were very few people who are willing to facilitate and witness the expression of such raw emotion. Although all of the participants were able to discuss their emotional reaction to their diagnosis within the context of the study, with me as researcher, the incident between James and his pastor was somehow very different. It occurred with someone who held a respected position in James's community and whom he trusted. This twenty minute exchange allowed James to co-construct a positive meaning that allowed him to move from a position of being stuck with a negative self$^2$ attribute to a positive self$^3$ persona.

Sabat (2001) contends that "there can be a relationship between the process of positioning certain self$^2$ attributes and the construction and manifestation of self$^3$ personae" (p. 20). The relationship described above leaves little doubt that there is a definite relationship between the self$^2$ and the self$^3$, possibly one that is more visible at the beginning of the trajectory than later in the disease process. Later in the disease process, the pattern of self$^2$ attributes of the person will have formed into a more static pattern. Also, at a later stage the cognitive and linguistic effects of the disease will both make it harder for the person to engage in the kind of episode that James described, and at the same time reinforce the set of negative self$^2$ attributes that lead to malignant self-positioning.

The antithesis of James's experience is that of Maggie. Maggie was 69 years of age when she entered the study. She was a retired chef, who had been widowed four years earlier. She was a quiet reserved lady, who shared her home with her daughter and grand-daughter. She had a limited network of social relationships, with very few contacts outside her family. Her main pastime was watching the television. Maggie received a diagnosis of probable Alzheimer's disease from a Consultant. She did not seek this diagnosis for herself but was encouraged to go to the doctor by her daughter. Maggie was quite shocked by the diagnosis and could not understand how she got Alzheimer's disease. She was a very private individual and did not even want her sons to know. Her daughter knew because she had accompanied her to her appointment. Although she was questioning her identity and had worries about who she would be following her diagnosis, "after that I still don't know who I am" (Maggie 2: 473 ). She positioned herself negatively, being fearful about saying the wrong thing in front of people. She worried about her deterioration too, although her only experience of people with dementia was limited to what she had gleaned from television. Maggie's daughter also positioned her malignantly, although not deliberately so, by comparing her to people with dementia in residential care, and by taking over tasks that she could easily still manage. Maggie was therefore stuck in a set of negative self$^2$ attributes of Alzheimer's disease, with little hope of moving on because she would not allow others to be told of her diagnosis and therefore denied herself the possibility of a valued social identity. Her reluctance around telling trapped her in a malignant position. It is difficult to anticipate how Maggie might cope with her diagnosis as time passes, since she had no-one else with whom to share her thoughts and fears. Although she had been allocated a community nurse, they did not discuss the diagnosis or how she felt about it, but instead engaged in pleasant social exchange with the nurse checking how she was reacting to the medication she was taking.

There is evidence (Fratiglioni, et al. 2000) that the strength of a person's social network is predictive of how vulnerable the person is liable to be following a diagnosis of dementia, but there is no evidence yet as to how an active social network would sustain the person once that diagnosis was given. The case material presented here suggests that the significance of an active social network may lie in the fact that it provides the person with dementia a wider range of people with whom to have the kind of emotionally honest conversation that James had with his pastor.

The importance of positioning following an early diagnosis of dementia cannot be overestimated. It can influence the pathway that is taken by the person and his/her family and social network. The negative picture painted of dementia by many people has its roots firmly entrenched in the latter end of the disease trajectory. The opportunities afforded by positive positioning at the time of diagnosis have major implications for how the pathway of the entire process is lived and managed, both by the person and their family. It also has major implications for the professionals serving this group of people.

There are still many questions around this theory that need to be answered perhaps by further research. How fixed is a negative self$^2$ attribute? What can dislodge it? Can positive positioning do this? Can inviting the expression of emotion do this? When is the meaning ascribed to a self$^2$ attribute – when is it laid down? What activates it? There are also practice oriented questions around the potential role of health professionals in promoting "telling" and both accepting and facilitating the expression of emotion.

### *7.2.7 Therapeutic Tasks*

The findings of this thesis have [raised] a number of possible implications in the development of counselling services for people diagnosed with early dementia. One way of beginning to make sense of the role of counselling in dementia is to identify the distinctive therapeutic tasks that are most relevant to working with people with early dementia.

A model of therapeutic tasks can operate as a set of guidelines for people in the helping professions in their efforts to support and enable people to come to terms with their diagnosis of early dementia. A therapeutic task is a goal-focused activity that is seen as something that therapist and client can work on together. Once a goal has been agreed, it is possible to break that goal down into much smaller steps or tasks. Some tasks may be self-directed while others may be engaged in collectively.

The idea that there is a set of tasks that need to be carried out also gives a very useful and straightforward explanation to clients and others of what therapists can do in this situation. These tasks listed below are derived both from the findings of the present study, and a reading of the wider literature.

The tasks appear below in no particular order, as there is no hierarchical structure to them. It is envisaged that some patients may require to explore one or two tasks in depth, while others may need help to engage with all of the tasks.

These tasks are offered as a tentative guide for therapists working with people with dementia and may be added to over time as more research in this area is undertaken.

#### *1. Exploring the possibility of life as normal*

Studies conducted by Phinney (1998) and Menne, Kinney and Morhardt (2002) both reveal the need of people with a diagnosis of dementia to continue with their normal pattern of life despite the challenge and struggle to maintain this. This has also been evident from this study, "we just do away as we did previously, more or less…as long as we can keep going the way we are I have no complaints" (Beth 3: 162 & 4: 57). The task of exploring what 'life as normal' has been for them and enabling and empowering them to continue with as much of that lifestyle as possible if they choose, is a crucial element of the counselling process. The use of problem solving skills to explore new ways of continuing would be useful in this task of continuing life as near normal as possible.

### *2. Evaluating the usefulness of different sources of information*

People all have their own picture of what dementia means to them. In exploring what people think dementia is, there is an opportunity to dispel any myths and to help contextualise their own experience. This is also a time to evaluate and offer sources of useful information such as books or the internet and also to give information in a form that will be useful and meaningful to the person. Putting them and their families in touch with organisations such as Alzheimer's Scotland and giving pertinent local information can be useful. For example, the Alzheimer Scotland 24 hour helpline, which operates a freephone service and received 5785 calls last year, and is accessed mainly by carers and families but is becoming an increasingly utilised resource for people with a diagnosis of dementia. 49% of these callers were seeking emotional help and this is increasing. (Helpline Report 2004/5). Other forms of help may come from psycho-educational resources and personal experience of working with people with dementia.

### *3. Understanding changing roles and relationships*

Many people, at this stage in their lives, have well established relationships which undergo changes as an inevitable consequence of this diagnosis. Taken for granted roles, whether physical or emotional within relationships are under threat (Wright 1993, Pearlin et al. 2001) and mutuality and reciprocity is challenged (Baikie 2002). Not only do the people with the diagnosis have their own picture of what dementia is, but people with whom they have social relationships also have their own perceptions. These changes occur, as people position themselves and others differently, often in a tacit way, and frequently a slow erosion of power and autonomy takes place within meaningful relationships as people tend to take over tasks and roles once held by the person with dementia although they may still be able to complete these tasks. An understanding of these changes has important implications for members of the social network both now and in the future as Jenny explains: "if somebody has been compos mentis enough in the past you expect that to continue, you know instead that it is not going to, not by any manner of means" (5: 129), and her husband states why the relationship is changing, "I know that she has got a problem and I am more protective of her" (Ron 5: 251). Ideally counselling would be offered to partners and families, as well as people with the diagnosis, so that both parties would have an understanding of the process, and therefore more chance of preventing this erosion of power and autonomy.

### *4. Understanding the emotional process*

Much of what characterises the strong emotional response to a diagnosis of dementia is the feeling of fearfulness, especially about the future, as was found in this study: "I feel worried that this is going to progress and I'm going to get worse and I feel distressed about that" (James 1: 379). When someone receives a devastating diagnosis like dementia it is understandable that they would experience emotional turmoil as they try to make sense of what is happening to them. There is a threat to their personhood and it is important that there is someone there for them to discuss this with as it is often too painful for the relatives and friends to discuss with them. Studies by Husband (1999, 2000) Moniz-Cook et al. (1998) and Brierly et al. (2003) have shown that different forms of counselling can help to facilitate the emotional process and provide support.

### *5. Addressing deep philosophical questions around personal identity*

"The thing that worries me is that this is going to go on deteriorating and I won't know who I am" (James 2:415). In the normal day to day lives we lead we rarely think that we will be different people when we die (Boden 1997), or indeed that we will be struggling with and trying to protect our sense of self (Sabat 2001). For someone with a progressive degenerative brain disease such as dementia, there is the question of how much of themselves will be lost in the process, and fears such as who they will be and will they remember their partners name are questions which frequently occupy the thoughts of people with dementia. Few opportunities arise to discuss this fully with someone who has the necessary listening skills and it is not something that people readily engage with. However, these issues are very real and occupy the thoughts of how the disease process will affect them. These are very difficult issues both to come to terms with and to share with people and the worries and fears of the future can be seen as part of the counselling agenda.

### *6. Facing up to and embracing stigma*

Stigma associated with a diagnosis of dementia was a common phenomenon experienced in this study: "it is a stigma…I wouldn't like to broadcast it …I would never think of telling the lady next door" (Jenny 5:61), and was the biggest single barrier to disclosing the diagnosis. The fear of what people would think of them following the diagnosis was powerful: "they look at you in a different light now and they begin to watch what they say and what you say…they would put you in a category and think there is not a lot of point in saying much…anybody who knows would think less of you (Jenny 4: 205 65 & 81). People with dementia are stigmatised by society, by their families and by their friends, because they are portrayed as 'other and different' but sometimes the stigma comes from within. They stigmatise themselves and present themselves as having a spoiled identity (Goffman 1963), are stigmatised by association (Blum 1991), or are humiliated during assessment that highlights their deficits (Sabat 2001).

### *7. Creating a modified personal and social identity*

As people coming to terms with any type of debilitating diagnosis can experience, it is difficult to accept and then think of life never being the same following that diagnosis. Creating a different identity which incorporates that diagnosis is quite a complex process. This process is explored by Werezak and Stewart (2002) and Clare (2002). Sabat (2001) offers a social constructionist perspective which implicates the place of others in the co-construction of a different identity. This notion of co-construction is dependent on how others react to the person with dementia and whether they position them in a positive or negative way, and whether the diagnosed person accepts or rejects their positioning. From this study it is also seen as dependent on how the person positions themselves. The therapist has two main tasks here. First to explore identity that the person has assigned to themselves in relation to their diagnosis and second, to co-construct a positive position that can lead to a valued social identity.

### *8. Telling and retelling their story*

The telling of their story in order that they are heard and their diagnosis becomes integrated into their lives and becomes part of them is a necessary part of the process of integration. Arthur Frank (1995) believes that ill people have to learn to think differently and the telling of the story is part of forming a different self. Telling a friend or family member that you have been given a diagnosis of Alzheimer's disease or other type of dementia is a very difficult task and is something that people rarely discuss. A task of the counsellor would be to discuss this with the person and to help them formulate the words and phrases, to rehearse how they are going to tell and provide a safe space for them to practice the telling before they do this on their own. It is in the telling and the retelling of their story that it becomes both real to them and part of who they are. This could also become part of 'family type therapy' as according to Phinney (2002) this story is not only affecting the person but the family and it is a story which is jointly lived and therefore jointly told. It is in the joining in of telling the story that it becomes a shared experience.

### *9. Find a way through the health system*

Finding your way through the health care system can be a challenge at the best of times when people are young and relatively fit. However, when the person trying to make sense of it all is older, and can at times become overwhelmed by details, then it is useful to have someone who would guide them through the process. It is therefore ideal if there is the offer of pre- and post-diagnostic counselling in order to provide support for the person and their family. One participant described her first visit to the clinic as "a bit of a nightmare" (Beth 1: 348), and to have someone explain what could be expected would go some way to addressing this 'nightmare'. It would also help to make this process less Byzantine.

The tasks that have been identified here are useful for the training of dementia counsellors and health professionals using counselling skills in their work with patients, because they map out the training agenda. They are also neutral from the perspective of the psychotherapeutic models and are easily transferable through the different theoretical models of working. The existence of these tasks may hopefully go some way to offering a way of implementing aspects of the new knowledge that has been generated by this research study.

This list is not exhaustive. There are other helping activities that counsellors could provide such as psycho-educational counselling, and informing people of other helping bodies, such as Alzheimer's Scotland, or the Alzheimer's Society. There are also many issues that need to be raised regarding counselling people with dementia, such as the issue of who is best placed to do it. Should counselling be provided by CPNs with counselling training, or by counsellors with specialist knowledge of dementia? There are also important issues around the appropriate training and supervision of dementia counsellors. These are questions for further research.

## 7.3 Methodological issues raised by the study

This section of the thesis concentrates on the methodological issues highlighted by the study, such as the strengths and limitations of the research design, and possible changes that would be made in future studies.

### *7.3.1 Limitations of the research*

At the outset of this study there was a only a restricted literature available which addressed the methodological issues pertaining to engaging the two different groups of people whose experiences I wished to explore. Writers on methodologies within this field were only beginning to call for inclusive and collaborative research design (Wilkinson 2002), and highlighting the potential benefits for research partnerships with people with dementia (Sabat 2003). To gain the perspectives of both groups, a decision was made to adopt different methods of data collection in Study 1 and Study 2. This strategy represents one possible limitation of the study, since it restricted the opportunity directly to bring together observations from doctors and patients. The other main limitation of the study lies in the relatively small sample size. It may well be that a larger sample size, reflecting a diversity of Health Board areas, might yield further themes and categories in relation to the experiences of both doctors and people with dementia.

### *7.3.2 Strengths of the research*

The main strength of this study was that it allowed the voice of the doctors and the voice of people with dementia to be listened to within one study. Methodologies engaging doctors in most previous studies have been quantitative and have not addressed many of the issues highlighted in this study. Rarely are doctors' feelings reported, and rarely have they accepted the invitation to express their views in interview format. Similarly, people with dementia had rarely been invited to collaborate in the research design and most previous studies have not been ethnographic, but more frequently employed interviews. By utilising an ethnographic methodology it has been possible to include not only the person with dementia and their carer, but to incorporate the wider social network of relationships. Spending time sharing the lives of people with a new diagnosis of dementia has allowed deeper understanding of their experiences and perspectives. My own background as a health professional working within the region in which data were collected has, on balance, been advantageous, because it has allowed me access to informants that might have been denied to a researcher who was more of an 'outsider'.

### *7.3.3 How the study might have been improved*

Much has been learned from the people who have participated in this study and by the inclusive, collaborative research design. With hindsight, changes that may have benefited this study would have been to design it as one fully inclusive ethnographic study rather than adopting two different methods. To incorporate both groups would be a challenge but with the experience, my proposition would be to follow the patient's pathway more closely and include their own GPs in the study, rather than selecting a different group of GPs who had no knowledge of the patients in the study. It would also have been useful to have spent time 'hanging out' with the Consultants for longer and to witness more closely what early dementia meant to them actually in practice. I was able to witness this with only three of the consultants who had enrolled the patients into the study. It would also be useful to follow people up over a longer period than six months to monitor the changes taking place within the social relationships. Despite these suggested changes, I have been privileged in gaining access to researching two groups of people who are rarely available to researchers.

## 7.4 Implications of the findings of this study

The implications of this study are wide ranging and have the potential to influence change in many different spheres. In this section I will discuss separately the implications for different groups: the research community, doctors, health service planners and providers, the policy makers and lastly and most importantly, people who have received a diagnosis of early dementia.

### *7.4.1 Implications for further research*

By adopting a social constructionist perspective it has been possible to challenge taken for granted assumptions that people with dementia should not or could not be active participants and collaborators in such a research endeavour. Without exception the people in this study really wanted to be part of it, even although they were unsure what it entailed initially. The main reason for people wanting to be involved in this project was to help other people who would be diagnosed after them, which was a truly altruistic motive, with only one person thinking that it might be of benefit to them. They also wanted to contribute to the body of knowledge which they saw as important. They saw themselves as being of benefit to others, and in turn felt that their diagnosis would not have been in vain. People with a diagnosis of dementia should not be excluded from research, but offered to be part of the process from the earliest possible moment so that they can become collaborators or partners in such research endeavours. Whilst the research community should be mindful of not exploiting people, it needs to rise to the challenge of finding new ways to be as inclusive as possible when it comes to working with this group of people. Cognitive decline should not be seen as a barrier to including people in all parts of the process of research. When asked the question 'would you think about becoming involved in further research?' there was an unequivocal answer, which was yes. People with a diagnosis of dementia can contribute so much to our knowledge and understanding; they are just waiting to be asked. Furthermore, with notable exceptions of authors such as Gloria Sterin, Steven R. Sabat and Tom Kitwood, the position of the researcher in the research endeavour is largely invisible. Reflexivity is an important methodological issue and one that needs to be considered in view of the emotive element of working with people with dementia.

### *7.4.2 Implications for medical practitioners*

Some doctors viewed their input in the life of the diagnosed following a diagnosis of dementia as minimal. While that may be the case, a relationship with their doctors is nevertheless a crucial part of the patient journey. What is said by doctors and how it is said at the time of diagnosis is highly significant for a person receiving a diagnosis and can have far reaching implications for both the person and their family. From the findings of this study, I would like to suggest the following in relation to this aspect of patient care.

In order to enhance the process of integration of a diagnosis, doctors should first of all offer the diagnosis to the patient on his or her own, rather than include the family without previous consultation. It is taken for granted that relatives being present will support the patient through the receiving of the bad news; however, it could impede the integration process as the person with the diagnosis no longer has ownership of the diagnosis, as it is usually shared from the very outset and denies the person the opportunity to tell their own diagnosis story.

There is also a stigma felt by the medical profession around the word dementia and most practitioners in the study avoid the use of this word. If the profession is serious about tackling such stigma, and literature suggests that this is the case, doctors need to be much more at ease with the use of the terminology. Patients can detect when there is a hesitance on the part of the doctor and this only serves to increase the stigma felt by the patient and can compound their own difficulties about feeling unable to use the word in discussion with friends and family.

When a diagnosis has been given it is important to check out the picture that people have in their minds of Alzheimer's disease or other forms of dementia. There is evidence in this study to suggest that people think of the end stage of the disease trajectory. Doctors could influence a different co-construction of meaning for the person receiving an early diagnosis. The emotional impact of a diagnosis should not be underestimated or neglected and doctors could refer patients for psychological therapies that could address this, with each patient having their own unique interventions designed with them rather than doctors perhaps prescribing short term post-diagnostic follow up, making it much more patient led.

There does not appear to be a consistent model of practice in Old Age Psychiatry throughout Tayside, and it would seem timely as a Managed Care Network develops that the fragmentation of the service could be addressed to work towards greater uniformity and cohesion while enhancing the patient journey, and sharing of good practice. The support offered to people with an early diagnosis requires urgent review in the light of these findings.

### *7.4.3 Implications for people with an early diagnosis of dementia*

People with early diagnosis for the most part are struggling with negative images of dementia and learning to live with this diagnosis can be problematic. This study has shown that this does not have to be the case and things can be different if there is professional support for them in the immediate post-diagnostic period.

There is an emotional process to go through in order to integrate this diagnosis into the daily lives of people with dementia. This process can be facilitated by professional workers who can engage people in that emotional process to help make meaning out of the emotional turmoil to show people that it is not just a set of symptoms to be managed but emotions to be processed and in the process people find their own limited freedom within which they can live life to the full.

People with a diagnosis of early dementia still have the ability to make choices and have some control over how they live with dementia, providing they have someone there to guide them through their initial emotional process. However, it is not just the person receiving the diagnosis who has to process emotions pertaining to the diagnosis. It is also true for family members and it is important for families to be willing to share their feelings openly with the person who has the diagnosis. Although this is a painful process for all concerned it is nevertheless a necessary part of the coming to terms with, and learning to live with dementia. This is difficult to achieve without the facilitation of this process by a third party who is trained and has experience of the therapeutic process.

### *7.4.4 Implications for health service planners and providers*

Services for people with an early diagnosis are very limited. The NHS HDL (2004) 44 sets out clearly that people with a new diagnosis and their families should have access to support to assist with forward planning. However, there is work to be done before people can think of planning a future. There is a need for someone to facilitate them through the emotional trauma of receiving a diagnosis and coming to terms with it. The psychological wellbeing of the person is of paramount importance and little is suggested in the way of counselling or psychotherapeutic interventions. It is at the time of diagnosis that there is an opportunity to make a difference. By offering a counselling/psychotherapeutic input at this time, it will not only enhance the patient journey but will help to shape it into a more positive experience in learning to live with the diagnosis. When someone is diagnosed with cancer or AIDS, there is a multiplicity of services offered and available to the newly diagnosed person. However, this study shows that this is not the case for people being diagnosed with dementia. Analysis of the data has shown nine therapeutic tasks which will have implications for practice.

Early intervention models of care have been largely dominated by a biomedical model in which treatment equals medication. Whilst this model is effective in many ways, it should not be the only perspective that is employed. This study has highlighted the need for psychological support at the time of diagnosis and has identified nine different therapeutic tasks that could be a useful guide to the therapist undertaking this work (Weaks, McLeod and Wilkinson 2006).

People who are diagnosed with dementia are very frequently older and have perhaps been in a loving relationship for many years. A diagnosis of dementia threatens that relationship as it brings a different ending from that which might have been perceived. This thesis has increased the evidence base around the importance of relationships within the context of an early diagnosis of dementia. Many of these relationships have endured over fifty years. The challenge to health service planners and professionals alike is to design a service that would find a way forward to protect and sustain these valued and enduring relationships and to help create valued social identities within the limited freedom that people with a new diagnosis of early dementia have to learn to live by.

## 7.5 Final reflections

This thesis has sought to bring a deeper understanding of how people with a new diagnosis of dementia learned to accept, adapt and integrate what it meant to them, and how they began the journey of this new and frightening chapter of their lives in which they had to ***'learn to live within a limited freedom'*** that the diagnosis of Alzheimer's disease had imposed on them. One of the prime objectives of the study was to hear the voice of the people involved in the diagnostic process of dementia. This has been achieved by employing in-depth qualitative methodologies that have sought to allow the experiences of participants to permeate throughout the research process. By engaging the doctors in qualitative interviews, it has been possible to gain a comprehensive insight into their practice, something which has rarely been accessed before. This has deepened our understanding of the process of the disclosure of diagnosis and the doctors' role. The voice of the person with early dementia also has been heard. By engaging participants in the design process of Study 2, and by adopting an inclusive, collaborative ethnographic methodology, it has been possible to gain access to the emotional process which follows the diagnosis and the impact of the diagnosis on relationships within the social context in which people live.

From the findings of these two studies it has been possible to apply the theoretical perspectives of Sabat to people with a new diagnosis. His concept of a 'valued social identity' has been elaborated to encompass the time of early diagnosis, which expands our understanding of how a valued social identity is developed or not from the outset. This concept embodies the key message of this thesis, that of the significance of 'telling' the story of the person with dementia and of the importance of it 'being heard' and enacted upon.

Having completed this study, there are many fresh challenges that demand further attention. For example, the development of the theoretical perspective outlined in Chapter 7 Section 2.6 invites further research and elaboration. In addition, as an experienced practitioner I am very aware of the gap between research and practice. A major challenge that faces me is to publish work from this thesis in a way that will affect practice and encourage practitioners to adopt ways of co-constructing valued social identities among those diagnosed with early dementia. I believe that publications that convey the similarities found in the way both professionals and people with dementia co-construct their own meanings of the concept of early dementia may represent an important way forward, one that might lead to more of a possibility of partnership between patients and professionals and may help to counteract the propensity of professionals from treating people with dementia as 'other'.

I also believe that the opportunities offered in a counselling relationship have the potential to encourage the development of the valued social identity and to offer ways of sustaining and supporting enduring relationships in those with dementia and their wider social networks. There are many issues to confront in this area around who would deliver counselling, and the need for training and evaluation in this field. No-one to date has developed a model of counselling specifically designed to meet the needs of people with dementia. Instead, studies that have reported on the use of counselling in early dementia have attempted to adapt theories and methods that are already available, without giving due consideration to whether or not new ways of counselling may require to be developed. Working together with colleagues to devise methods of offering counselling that are of maximum benefit to people with dementia, and which integrate with existing patterns of service delivery, is a substantial task for the future.

***I would like to close this thesis by offering some final reflections on its meaning for me.*** This thesis opened with a preamble which took the reader through a potted history of how my career had developed to date, following the changing patterns of how people with dementia were treated within the health service. This personal journey has travelled from long term wards within mental hospitals in the mid-1970s to being involved in seeking further counselling training in order to offer more appropriate interventions to people with an early diagnosis of dementia, then to the decision to undertake further study. This career development found me turning to the research process in order to gain answers to some of the questions that were developing within me from a practice perspective. At the outset of this research endeavour I was a pragmatic practitioner seeking a way of coming to a better understanding of how the patients I had been working with constructed and made meaning from their experience of having been given a diagnosis of early dementia.

Throughout this journey into a new chapter of my own life, which involved embracing the relatively unknown world of academia, I could relate to the fearfulness of the people in this study. Metamorphosis is an uncomfortable state and I struggled at times to come to terms with the change from pragmatic practitioner to my new self[2] attribute of academic researcher. Now as I write the concluding phrases of this thesis I ponder the future. Reaching a new understanding is not an end in itself but rather the beginning of an opportunity, not just to follow trends in health service practice but to co-construct new practice and policies. From that new understanding, my hope is of being able to influence the future research, practice, policy and planning of how people with a new diagnosis are treated within the health service. My personal challenge is to tell the story of the people in this thesis who are learning to live within their limited freedom, in a form that can be heard by those who can make these changes possible.

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# Appendix A

Invitation Letters to Doctors (GPs and Consultants)

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Dear Doctor,

**"Psychosocial impact on patients and medical practitioners of diagnosis of patients presenting with changes in memory function**

I write to invite you to take part in this qualitative study, which is being carried out within Tayside and is funded by Tayside Primary Care Trust.

You would be required to agree to an audio-recorded semi-structured interview, which would last for approximately 60-90minutes of your time. The purpose of this interview is to map current general practice thinking within Tayside on the subject of early diagnosis of dementia and how that impacts on patients and medical practitioners within the first 6 months of a diagnosis
The information from the interviews will be coded and stored in a secure cabinet and you can be assured of anonymity and confidentiality. When the study is completed the tapes will be wiped. Around 12 of your colleagues will also be invited to take part.
If you are interested in being interviewed please return the tear off slip at the bottom of the page and return it to me in the stamped addressed envelope supplied. I will then contact you to arrange a suitable time and venue for us to meet and discuss this research topic.
If you would like to know more about this research, please do not hesitate to contact me: Telephone 01382 308000 ext 7321 or e-mail 0014279@abertay.ac.uk

Yours sincerely

Dot Weaks
PhD Student

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NAME.......................................................................................................
ADDRESS..................................................................................................
CONTACT TELEPHONE NUMBER..........................................................
E-MAIL.....................................................................................................

**Thank you for taking the time and interest in this study and for agreeing to be interviewed.**

### The Aims and Objectives of the Study

1. To explore the patients' experience over the first six months following an early diagnosis of dementia, in conjunction with the family member.
2. To discover what the subjective view of the patients' support needs are over that period, in conjunction with the family member.
3. To analyse factors which facilitate/inhibit specialist consultants in old age psychiatry communicating an early diagnosis of dementia and ascertaining how they see their role within the first six months of patient contact.
4. To analyse how GPs see their role with patients who have been given an early diagnosis of dementia and during the following six-month period.

### Design of the Study

This study will be divided into two phases:
1] Mapping current practice of GPs and Consultants in Old Age Psychiatry
2] Exploring personal experience of people who have received an early diagnosis of dementia

### Phase 1: Mapping current practice (July—December 2003)

Phase one will be a qualitative study. Data will be collected using semi-structured in-depth interview to gather the views and experiences of all the Consultants (n=8) in Old Age Psychiatry in Tayside and a number of General Practitioners in Tayside (approx 10-15 until saturation of data is reached). The interviews will explore current practice and views as well as care offered to people within the first six months of an early diagnosis of dementia. The data will be analysed using the standard qualitative technique of grounded theory analysis (Strauss, A. and Corbin, J. 1990). This method is widely used in health research, and enables systematic categorisation of informants' accounts to produce a structured understanding of the meanings of medical practitioners' experiences of care of people with an early diagnosis of dementia.

## The Sample

The sample for phase one of the study, which is a purposive sample, will be all consultants in Old Age Psychiatry in Tayside and a number of General Practitioners from across Tayside. General Practitioners will be recruited using a snowball sampling method. The number of General Practitioners is as yet unknown but will be approximately 10-15 and will be determined by how many interviews are necessary to reach saturation of the data. Saturation occurs when no new categories appear within the process of analysis.

The reasons for this sample of medical practitioners to be chosen to study is that:

1) General Practitioners and Consultants in Old Age Psychiatry are usually the first and frequently the only contact that people with an early diagnosis of dementia and their families have with the helping professions.

2) They are the only professions equipped and legally entitled to give a medical diagnosis.

3) Few studies have invited medical practitioners' views by the interview method. Frequently, data has been collected from medical practitioners by questionnaire, which rarely allows their voice to be heard in depth or detail.

**Phase 2: Exploring personal experience (October 2003-December 2004)**

Phase two will employ a qualitative methodology using an ethnographic approach to data collection. Initially semi-structured in depth interviews with up to 15 purposively selected people across Tayside who have been given an early diagnosis of dementia by a specialist in Old Age Psychiatry and their families will be invited to participate. Following the initial encounter, negotiation will take place between the patient, family and researcher as to the frequency of contact they will have over the next 6 months. The purpose of employing an ethnographic approach to this study is to enable the collection of rich, descriptive data in order to gain a better understanding and insight of the effects of being given the early diagnosis of dementia, which cannot possibly be obtained in one interview with a stranger. The researcher takes on the role of participant observer and participates in the lives of the researched e.g. accompanying the patient to the clinic, while keeping a professional distance in order to allow recording of data from the observations. Furthermore it will allow a deeper awareness of the process being experienced and the support requirements that patients and their families require at this stage in their lives.

## The Sample

The sample for this phase of the study will be purposive and patients who have been given a diagnosis of early dementia will be invited to participate in the study by the consultant making this diagnosis. It is also anticipated that family members will be invited to be interviewed during the study. It is not known how many families will be taking part and again, as in phase one, it will depend on how many interviews and encounters it will take in order to reach saturation of data during the period of analysis.

Inclusion criteria for people with dementia in this study are:

Interviewed not more than six weeks after being given their diagnosis of dementia; person has been informed of their diagnosis by a consultant in Old Age Psychiatry; sufficient cognitive capacity and memory to contribute verbally to a conversation and be able to discuss issues of daily living; absence of other mental disorders. Inclusion criteria for this study are based on having cognitive capacity, although I am aware of the Adults with Incapacity Act on research.

## Qualitative Research

Due to the nature of qualitative research, changes normally occur over the time of the study, which are not apparent at the design phase, in order to accommodate emerging issues from the participants. I will endeavour to inform the committee of any significant changes that may occur due to the nature of this research method.

# Appendix B

Consent Form for all participants' written consent.

# CONSENT FORM

NB. This form must be completed by the patient and signed in the presence of the Principal Investigator* or his/her deputy who must be a medically qualified co-investigator*.

## Please tick (✓) appropriate box

| | | | |
|---|---|---|---|
| Have you read and understood the Subject Information Sheet? | Yes ☐ | No ☐ | |
| Have you been given an opportunity to ask questions and further discuss this study? | Yes ☐ | No ☐ | |
| Have you received satisfactory answers to all of your questions? | Yes ☐ | No ☐ | |
| Have you now received enough information about this study? | Yes ☐ | No ☐ | |
| Who have you spoken to? Dr/Mr/Mrs/Miss ........................................................... | | | |
| Do you understand that your participation is entirely voluntary? | Yes ☐ | No ☐ | |
| Do you understand that you are free to withdraw from this study: | | | |
| At any time? | Yes ☐ | No ☐ | |
| Without having to give a reason for withdrawing? | Yes☐ | No ☐ | |
| Without this affecting your present or future medical care? | Yes ☐ | No ☐ | |
| Do you agree that your records in this research and supporting medical records be made available for inspection by monitors from: | | | |
| (Name of sponsor company)? | Yes ☐ | No ☐ | |
| NHS Tayside monitors? | Yes ☐ | No ☐ | |
| Regulatory authorities? | Yes ☐ | No ☐ | |
| Do you agree to take part in this study? | Yes ☐ | No ☐ | |
| Do you agree to any tissue (specify) used in this study being retained for use in future research? | Yes ☐ | No ☐ | Not applicable ☐ |

Subject's signature .................................................. Date ................................

Subject's name in block capital letters .......................................................................

Telephone contact (Subject) ..................................(Home) ................................(Work)

Doctor's signature* ........................................... Date ................................

Doctor's name in block capital letters ......................................................................

# Appendix C

Interview Schedule for Doctors

## Doctors Interview Schedule Prompt

1. Check that information was received about the study and ask if they have any questions about it.
2. Explain about confidentiality and audio-taping.
3. Ask for informed consent form to be signed
4. Ask a bit about their practice, how long they have been there etc just as a warm up
5. Discuss issues around in the literature about doctors playing a central/pivotal role in the diagnosis and management of early dementia

### Aide Memoire and Question prompts

### Professional and Practice Issues

When you think of early dementia, what sort of picture comes to mind?

Tell me how you see your role in the diagnosis of early dementia?

What would your management strategy be?

I wonder if you could take me through the most recent patient journey that you experienced with someone with an early diagnosis of dementia. What went well and why? Can you think of a time when things went ‘not so well’?

Who do you think should make a diagnosis of early dementia?

What about giving the diagnosis? would that be something that you would do? Who would you tell? How would you tell? What choice of language would you make?

Is there any fear of getting the diagnosis wrong? Can you tell me about that?

Can you tell me of any time when the family member has asked you to with hold a diagnosis?

What reaction do you observe as most common when people receive a diagnosis of early dementia?

What would be your ideal service for people with early dementia in the initial period following diagnosis? Who do you think would be best placed to deliver this service?

What would you envisage the service should be for the first six months after the diagnosis?

What basic and ongoing education have you had that covers the subject of an early diagnosis of dementia?

## Personal Issues

I want to ask you some personal questions now, but please feel free not to answer them if you would rather not…

Have you ever had a close relative who has had dementia?

How did that affect you at the time? Were you involved in their care?

How do you think that impacts on your present practice?

Do you use the knowledge you have gained from your experience in practice?

Do you ever share that with patients and families?

How do you feel when you begin to suspect that someone coming to your surgery/clinic might have early dementia?

Is it a diagnosis you worry about?

Is there anything else that you would want to discuss with me in relation to the topic of the interview or anything you want to elaborate on or tell me about?

## Last Question

I know that this is something that doctors don't generally get involved in (research interviews) and I just wondered if what your thoughts on the experience are. Is there anything that you would recommend I could change in any way to improve the interview situation?

Thank you very much indeed for taking part in this interview.

# Appendix D

Patient Information Sheet

Family Member Information Sheet

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# PATIENT INFORMATION SHEET

**Psychosocial impact on patients and medical practitioners of a diagnosis of patients presenting with changes in memory function**

I invite you to participate in a research project. I believe it to be of potential importance. However, before you decide whether or not you wish to participate, I need to be sure that you understand firstly why I am doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information. Read it carefully and be sure to ask any questions you have, and, if you want, discuss it with someone you trust. I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision and you can contact me at the above address, Telephone 01382 308000 if you have any questions.

## THE BACKGROUND TO THE STUDY

- This research is about trying to understand what it is like for someone to be given an early diagnosis, following investigation of changes in memory function, and how their daily lives are affected over a 6month period.
- This research is being done to find out what would help and support people best in this situation. The results of this study will help to design future services.
- Tayside Primary Health Care Trust is sponsoring the study.
- You have been chosen to participate in the study because the diagnosis you have been given by the clinic doctor matches the criteria of the study and we feel that you are in the best position to inform us of what that is like for you.
- There will be around 15 other people who will also be invited to take part, all living within Tayside.

## WHAT DOES THE STUDY INVOLVE?

- Once your clinic doctor has advised me that you are willing to take part I will telephone you to arrange a suitable time for us to meet. I will be happy to come to your home for this meeting.

- I would like to interview you and, with your permission, record this on an audio recorder so that I can go over what you have to say. The kind of questions that I am likely to ask are "What was it like to be given a diagnosis?" "What difference has that made to you?" and "what has happened since then?" The interview will last between 30-45 minutes, but you can stop this at any time.
- After the interview I will ask if you are willing for us to meet again to continue to follow your progress over the 6month period.
- I will also seek to interview your close family member with your permission.
- This study may not benefit you personally, but by sharing your experience and having your views heard, you are able increase the knowledge of others and influence what kind of services people who have the same diagnosis as you may benefit from in the future.

## WHAT WILL HAPPEN TO THE INFORMATION COLLECTED IN THE STUDY?

- All information that you give me will be treated as confidential and I will assign a code name or number so that you will not be able to be identified. The only people to have access to the information will be my university supervisors.
- The information, both written records and tape recorded, will be kept in a locked filing cabinet and destroyed following the completion of the research.
- In order that other professionals can learn from the findings of this study, some articles and papers may be published, however your name will not be used and if you wish, a copy of any publication using information you have given can be sent to you.

## WHAT ARE MY RIGHTS?

- Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason.
- This will not affect your future medical care or your relationship with medical staff looking after you in any way.
- You can obtain further information about this study by asking your clinic doctor or by writing/e-mail/ telephoning me at the address/number below.
- Please feel free to discuss this study with friends and relatives or your GP before deciding to take part.
- You can refuse to take part or withdraw from the study at any time, even if you agree to take part now

## THE TAYSIDE COMMITTEE ON MEDICAL RESEARCH ETHICS

- The Tayside Committee on Medical Research Ethics, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics.
- It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside and the Regulatory Authorities.

Thank-you for taking the time to read this information sheet.

**I can be contacted at**

**Dorothy A. Weaks**

TAYSIDE INSTITUTE for HEALTH STUDIES

UNIVERSITY OF ABERTAY DUNDEE
School of Social and Health Sciences
University of Abertay Dundee
Dudhope Castle
DUNDEE
DD3 6HF
**Telephone 01382 308000**

**e-mail 0014279@abertay.ac.uk**

UNIVERSITY
of
ABERTAY DUNDEE

# FAMILY MEMBER INFORMATION SHEET

**Psychosocial impact on patients and medical practitioners of diagnosis of patients presenting with changes in memory function**

I invite you to participate in a research project. I believe it to be of potential importance. However, before you decide whether or not you wish to participate, I need to be sure that you understand firstly why we are doing it, and secondly what it would involve if you agreed. I am therefore providing you with the following information. Read it carefully and be sure to ask any questions you have, and, if you want, discuss it with outsiders. I will do my best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision and you can contact me at the above address, Telephone 01382 308000 if you have any questions.

## THE BACKGROUND TO THE STUDY

- This research is about trying to understand what it is like for someone to be given an early diagnosis, following investigation of changes in memory function, and how their daily lives, and that of their families, are affected over a 6month period.
- This research is being done to find out what would help and support people best in this situation. The results of this study will help to design future services.
- Tayside Primary Health Care Trust is sponsoring the study.
- You have been chosen to participate in the study because the diagnosis your family member has been given by the clinic doctor matches the criteria of the study.
- There will be around 15 other people who will also be invited to take part, all living within Tayside.

## WHAT DOES THE STUDY INVOLVE?

- Once your clinic doctor has advised me that you are willing to take part I will telephone you to arrange a suitable time for us to meet. I will be happy to come to your home for this meeting

- I would like to interview you and, with your permission, record this on an audio recorder so that I can go over what you have to say. The kinds of questions that I am likely to ask are "What was it like for you when your family member was given a diagnosis?" "What difference has that made to you?" and "what has happened since then?". The interview will last between 30-45 minutes, but you can stop this at any time.
- After the interview I will ask if you are willing for us to meet again to continue to follow your progress over the 6month period.
- This study may not benefit you personally, but by sharing your experience and having your views heard, you are able increase the knowledge of others and influence what kind of services people who have the same diagnosis as your family member may benefit from in the future.

## WHAT WILL HAPPEN TO THE INFORMATION COLLECTED IN THE STUDY?

- All information that you give me will be treated as confidential and I will assign a code name or number so that you will not be able to be identified. The only people to have access to the information will be my university supervisors.
- The information, both written records and tape recorded, will be kept in a locked filing cabinet and destroyed following the completion of the research.
- In order that other professionals can learn from the findings of this study, some articles and papers may be published, however your name will not be used and if you wish, a copy of any publication using information you have given can be sent to you.

## WHAT ARE MY RIGHTS?

- Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason.
- This will not affect your future medical care or your relationship with medical staff looking after you in any way.
- You can obtain further information about this study by asking your clinic doctor or by writing/e-mail/ telephoning me at the address/number below.
- Please feel free to discuss this study with friends and relatives or your GP before deciding to take part.
- You can refuse to take part or withdraw from the study at any time, even if you agree to take part now

## THE TAYSIDE COMMITTEE ON MEDICAL RESEARCH ETHICS

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Thank-you for taking the time to read this information sheet.

**I can be contacted at the address below:**

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# Appendix E

List of presentations given from this research project

## Presentations and Publications from this PhD Study

### *Presentations*

The Psychosocial Impact on Patients and Medical Practitioners of an Early Diagnosis of Dementia: *Poster presented at the British Society of Gerontology annual conference in Newcastle, September 2003*

Family Counselling after Diagnosis: *Paper presented at annual Scottish Conference of PSIGE in Edinburgh, November 2003*

The Value of Post Diagnostic Counselling for People with Alzheimer's disease: *Paper presented at 10th International BACP Conference in London, September 2004*

Learning to Live within a Limited Freedom: *Paper presented at COSCA Counselling Research Dialogue Conference in Perth, March 2005*

Living within a Limited Freedom: *Paper presented at NMAPH Scottish Research Conference in Stirling, June 2005*

Living within a Limited Freedom: *Paper presented at the British Society of Gerontology annual conference in Keele University, July 2005*

Dealing with the Aftermath: *Paper presented at the British Association for Counselling and Psychotherapy in Glasgow, May 2006*

### *Publications*

Weaks , D., Wilkinson, H. and Davidson, S. 2005
*Families, relationships and the impact of dementia—insights into the 'ties that bind'* chapter in Families in Society-Boundaries and Relationships: McKie, L and Cunningham-Burley, S. eds.

Weaks, D. A., McLeod, J. and Wilkinson, H. A. 2006.

Dementia. *Therapy Today.* 17(3): pp.12-15.

UNIVERSITY of ABERTAY DUNDEE

# The Psychosocial Impact on Patients and Medical Practitioners of an Early Diagnosis of Dementia

Dot Weaks[1], John McLeod[2] & Heather Wilkinson[3]

NHS Tayside

## Aims of Study

- To **explore** the subjective experience of the person with dementia following diagnosis for a 6 month period
- To **discover** the subjective view of the support needs over that period
- To **analyse** how GP's and consultants in old age psychiatry view their role over the first 6 months following a patient's diagnoses of early dementia

## Background

The importance of an early diagnosis of dementia has been highlighted both in recent research (Audit Commission Update 2002) and in a report from the National Institute for Clinical Excellence (2001), however the subjective experience of early dementia, until fairly recently, has had scant attention from the research community.

The pivotal role of the GP (Wilkinson & Milne 2003) and the Consultant (Pinner 2000;) has been acknowledged especially from the perspective of giving a diagnosis of dementia. Recent research reports that people with dementia want to know the truth about their diagnosis (Pratt & Wilkinson 2001)

Diagnosis usually involves the person with dementia and their family, the GP and the Consultant in Old Age Psychiatry, and according to Cheston and Bender (1999) diagnosis should serve as the beginnings of a collaborative long term relationship.

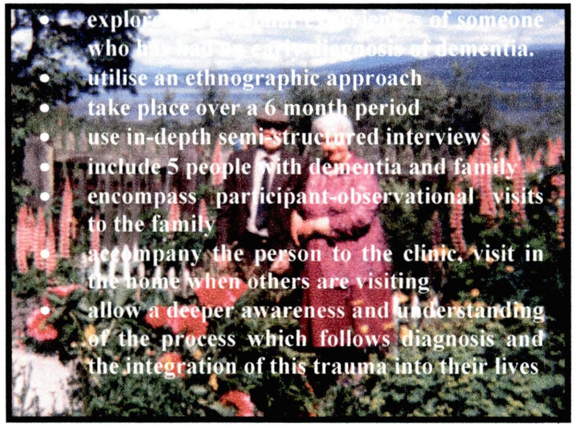
This study has chosen to concentrate on the three key stakeholders in this collaborative relationship; the person with dementia, the GP and the Consultant in Old Age Psychiatry and their experience of the first 6 months following diagnosis.

## Design of the Study

*Phase 1* **of the study will**

- map current practice of GP's and Consultants
- utilise qualitative methods
- collect data via semi-structured interviews
- concentrate on a single area Health Board in Scotland
- use informants' accounts to produce a structured understanding of the meanings of medical practitioners' experiences of care of people with an early diagnosis of dementia.

*Phase 2* **of the study will**



- **explore [illegible] experiences of someone who has had an early diagnosis of dementia.**
- **utilise an ethnographic approach**
- **take place over a 6 month period**
- **use in-depth semi-structured interviews**
- **include 5 people with dementia and family**
- **encompass participant-observational visits to the family**
- **accompany the person to the clinic, visit in the home when others are visiting**
- **allow a deeper awareness and understanding of the process which follows diagnosis and the integration of this trauma into their lives**

### About the Research

Initial analysis of the interview material is already highlighting areas that can have a potential impact on practice within the first six months following an early diagnosis of dementia. Both benefits and barriers to a wide variety of support services have been identified and explored. The research is currently in the midst of the data collection and analysis of phase 1.

## References

Audit Commission (2002) Forget Me Not 2002: Developing mental health services for older people in England. London Audit Commission

Cheston, R., & Bender, M (1999). The Man with the Worried Eyes. London, Kingsley

Pinner, G. (2000). Truth-telling and the diagnosis of dementia. *British Journal of Psychiatry* ***176****: 514-515.*

Pratt, R., & Wilkinson,H. (2001). Tell me the Truth: The effect of being told the diagnosis of dementia from the perspective of the person with dementia, *The Mental Health Foundation.*

Wilkinson H and Milne A (2003) Sharing a diagnosis of dementia – Learning from the patient perspective *Aging and Mental Health. 7 4 300-307*

## Funding

This study is funded by **NHS Tayside**

**If you would like more information about this project please contact:**

Dot Weaks

[redacted]

### About the researcher

**Dot Weaks**[1] is employed by **NHS Tayside** and is currently seconded to Tayside Institute for Health Studies by **NHS Tayside** for 3years on a Research Training Fellowship.

The training and the research project are being supervised by **Professor John McLeod**[2],University of Abertay Dundee and **Dr Heather Wilkinson**[3], Centre for Research on Families and Relationships at Edinburgh University.

**The two published articles cited below have been removed from the e-thesis due to copyright restrictions**

# Appendix F

Weaks, D., Wilkinson, H and Davidson, S. (2005) Families, relationships and the impact of dementia—insights into the 'ties that bind'. In L. McKie and S. Cunningham-Burley (eds) *Families and Society : Boundaries and Relationships*: Bristol. The Policy Press pp. 149-167.

# Appendix G

Weaks, D. A., McLeod, J. and Wilkinson, H. A. 2006. Dementia. *Therapy Today*. 17(3): pp.12-15.