
DEMENTIA AND IDENTITY

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Abstract

This thesis explores the multiple ways identity can be affected by dementia. It primarily concerns how ‘personal identity’ is affected in the early to moderate stages of dementia, and secondarily concerns how ‘personhood’ can be threatened in the late stages of dementia. When a patient’s personal identity or personhood is called into question due to their dementia, there are significant practical implications for their health and moral status. These can include issues involving autonomy, implementation of advanced directives and right to treatment. It is important to consider these issues given the increasing rates of dementia in developed countries and the substantial burden of disease this has on healthcare systems. Descriptive accounts of ‘identity’, ‘memory’ and ‘dementia’ are provided to inform discussion of these issues. Distinctions are drawn between ‘object’ and ‘agency’ theories of identity, ‘archival’ and ‘process’ models of memory, and ‘frontotemporal’ and ‘non-frontotemporal’ dementia subtypes. An agency theory of personal identity, which emphasises a person’s relationships and meaningful actions, is put forward as the more suitable approach to these problems, as it aligns better with the emerging process model of memory and better explains the direct and indirect ways dementia can affect a person’s identity. The findings of a qualitative study interviewing experienced health care professionals about these issues are also reported. This study found clinicians’ approaches to be broadly supportive of conclusions drawn by the theoretical work of this thesis, and helped to clarify where further research is needed.

Dedication

For Nola, because she is still my grandma, and loves me very much.

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To a degree, this thesis is an expression of my own identity and, given my now developed perspective on personal identity, it seems appropriate that I also consider it to have been completed only through the assistance of a great many people. As such, I have a great many people to thank. I owe a tremendous amount of gratitude to my primary supervisor, Simon Walker, who dedicated much effort and many hours to mentoring me in philosophy, ethics, writing and life in general. I also must extend my deepest gratitude to my secondary supervisor, Grant Gillett, who somehow leaves me more informed, excited and confused about the world (all at once) after each conversation I have with him. To my many med school mentors, Nick, Em, and Vimal, who understood my struggles and inspired me to overcome them. To Improsaurus, the HTs of Carrington College Alex and Bruno, for being my Dunedin families. To Rose, for taking me out to dinner, on holiday and to the happiest moments of the year. To the Carringtonians studying HUBS, med students in Histology and the talented young theatre-sports-people I taught this year, for helping me do something truly meaningful to me. To Lorraine Francis Hall and the organisers of her estate, for providing financial support in the form of a scholarship. To Brandon, for helping me choose journey over destination. To the members of Grant's Neuroethics group, for broadening my horizons and allowing me to share my ideas with you. To Angela, the staff at the Bioethics Centre and the many other people who manage the systems that allowed me this opportunity. To Emma and Kelby, for their vital advice on qualitative research. To Ruth, for teaching me clinical skills and interview techniques. To Janine, Susie, Matthew, Maria, Marie, Helen, and the others, for their time, patience and poignant statements. To Evelyn, George, Stuart, and Sarah, who proof-read chapters at very short notice and were so complimentary. To my large group of friends and extended family, for their ongoing love and support. To my father, for worrying, so I didn't have to. To my mother, for her unconditional belief in me. And to my brother, James, for quite simply being the best.

Table of Contents

Title Page.....	i
Abstract	ii
Dedication	iii
Acknowledgements	iv
Table of Contents	v
Introduction	1
Chapter One - Identity.....	7
1.1 Personhood.....	7
1.1.1 Human criterion	8
1.1.2 Cognitive criterion	8
1.1.3 Significance criterion	10
1.1.4 Gradient theory	12
1.1.5 Limitations of personhood tests	12
1.1.6 Social constructivist theory.....	13
1.1.7 Summary	14
1.2 Personal identity.....	14
1.2.1 Object-based theories.....	17
1.2.2 Memory theory.....	19
1.2.3 No-self theories.....	22
1.2.4 Agency-based theories	23
1.2.5 Summary	27
1.3 Conclusion.....	28
Chapter Two – Memory	29
2.1 Memory as an archive	29
2.1.1 Memory systems	30

2.1.2	Encoding, Storage and Retrieval.....	31
2.1.3	Engrams and memory traces.....	31
2.2	Criticism of archival memory	32
2.2.1	Social and Cultural.....	32
2.2.2	Media, Technology and Art	35
2.2.3	Biological and neurocognitive	36
2.3	Conclusion.....	39
Chapter Three – Dementia		40
3.1	Epidemiology of dementia	40
3.2	Clinical course of dementia.....	41
3.3	Dementia subtypes	44
3.3.1	Alzheimer’s disease (AD).....	44
3.3.2	Vascular dementia (VaD)	46
3.3.3	Dementia with Lewy Bodies (DLB)	46
3.3.4	Frontotemporal dementia (FTD).....	47
3.4	Conclusion.....	49
Chapter 4 – Dementia, Memory and Identity.....		50
4.1	Direct and indirect effects	51
4.2	Arguments against an object approach.....	52
4.2.1	Bodily continuity	52
4.2.2	Psychological continuity	54
4.2.3	Locke’s memory theory	55
4.3	Arguments for an agency approach.....	57
4.4	Personhood.....	64
4.5	Conclusion.....	66
Chapter Five - Interviews.....		68
5.1	Method	69

5.2	Findings and analysis	71
5.2.1	Participants' conceptions of identity and dementia	71
5.2.2	Summary discussion of participants' view on dementia and identity.....	81
5.2.3	Personhood.....	82
5.2.4	Advance directives.....	85
5.3	Conclusion.....	88
	Conclusion.....	89
	Bibliography.....	92

Introduction

Dementia refers to a collection of chronic progressive brain diseases that affect cognitive functioning in significant ways. Dementia is most common in elderly populations but is not a normal process of aging. As such, dementia prevalence in New Zealand and other developed countries is rising due to aging populations. Healthcare workers are already faced by ethical challenges that arise with dementia and the occurrence of these will only increase in coming years. It is important to give them thorough consideration in order to approach the care of people living with dementia in an ethically appropriate way. In this thesis I focus on how dementia affects a person's identity and the problems that arise when one's identity comes into question as a result of dementia.

The ethical problems related to identity in dementia can be categorised into two groups. This thesis primarily concerns the first group of problems, centring around the notion of 'personal identity', i.e. the question of what is required for a particular person to remain who they are. It concerns the idea that we remain *ourselves* despite whatever changes we go through in our lives – the idea that *who we are* somehow endures. Issues of personal identity generally concern people in the early to moderate stages of dementia. They are reflected in some of the stigma and fear surrounding dementia, e.g. that dementia brings about 'the loss of one's self', and become especially relevant when considering a person's decision making capacity. They may concern the idea that the self can be lost or diminished, or the more radical notion the self has completely changed through dementia and is replaced by a different self. Such problems typically arise when a person with dementia has abrupt shifts in attitude or behaves in significantly uncharacteristic ways. The challenges that can follow are perhaps most acutely felt by those who live with or are close to the dementia sufferer, but include a range of clinical questions as well, particularly in the use of advanced care plans and directives. The second group of problems centres around the ethical concept of 'personhood'. This is the concept of what qualities or attributes something needs to have in order to hold 'moral status'. It is sometimes suggested that people in late stage dementia, with minimal cognitive functioning, have ceased to be 'persons', and hence no longer have the same moral status as those of us who are persons. Numerous practical problems can be related to this question. In particular, there is debate about what duties we bear to those with advanced dementia, and whether it is morally necessary to continue providing life-sustaining

treatments. These issues are related to identity in the sense that people asking them are often wondering whether a particular person is 'still there'. However, the issues tend to be addressed in terms of what persons *in general* have in common. Due to the limited scope of this thesis and the complexity of the issues surrounding personhood, my arguments will be cursory in nature.

These issues have received considerable attention in bioethical literature, and various cases have been put forward to illustrate what they involve. I will introduce some of these here, and return to them later in my discussion (principally in Chapter Four). The first is from Ronald Dworkin's influential book, *Life's Dominion*. It concerns a woman called 'Margo', as described by a medical student called Firlik:

The apartment had many locks to keep Margo from slipping out at night and wandering in the park in a nightgown, which she had done before. Margo said she knew who Firlik was each time he arrived, but she never used his name, and he suspected that this was just politeness. She said she was reading mysteries, but Firlik "noticed that her place in the book jumps randomly from day to day; dozens of pages are dog eared at any given moment ... Maybe she feels good just sitting and humming to herself, rocking back and forth slowly, nodding off liberally, occasionally turning to a fresh page." Firlik was confused, he said, by the fact that "despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known."¹

Margo's case is in many respects typical of patients with mild to moderate dementia. For some people, the cognitive deficits Margo exhibits – the wandering behaviour and disorganised thinking – amount to a loss of self. In discussion of this case, Dworkin posits the question of what to do if before developing dementia, Margo had written an advanced directive refusing medical treatment if she were to be in such a condition. As Dworkin notes, it is not immediately clear whether this advanced directive should be enforced. Given Margo's apparent happiness, one might well suppose that she still values her life, and so one might think it right to take reasonable measures to preserve her life. However, if we suppose Margo is no longer able to make autonomous decisions (if she is 'not herself' as some would hold), and if respect for autonomy is an important value, then it will seem that we should follow the decision she made prior to falling into this state.

¹ Dworkin, Ronald. *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. 1993.

A different kind of case is described by Agnieszka Jaworska in her article, *Respecting the margins of agency: Alzheimer's patients and the capacity to value*. It concerns a man called 'Mr O'Connor':

Mr. O'Connor was a deeply religious man for whom thoughts of taking his own life or of withholding lifesaving measures for whatever reason were completely unacceptable. In his seventies he developed Alzheimer's disease. He lost his ability to do many of the things he used to enjoy, such as playing the piano; soon he could no longer take care of himself. With the loss of capacity for complex reasoning, most of his religious beliefs gradually faded away. Then came a terrible emotional blow: the death of his wife. He has now begun saying that he does not want to go on, that he does not want to live. His daughters no longer know what would be best for him: Should they make decisions for him based on his earlier life-philosophy or should they respect and take seriously his current wishes?²

This case is an interesting contrast to Margo, as Mr O'Connor's pre-morbid wishes and apparent wishes living with dementia undergo the opposite transition to Margo's, however, the problem is structurally the same. The significant changes in his behaviour and attitude, both regarding his views on treatment and his religious beliefs, could be regarded as evidence that his decision making capacity is impaired by dementia. Yet as with Margo, if this is true then it seems that respect for autonomy requires us to uphold his prior wishes and disregard his current quality of life. This needs some consideration, as it seems unsatisfactory (and perhaps even wrong) to simply 'write-off' the present experiences of both of these people. Jaworska's view is people who are moderately demented, like Margo and Mr O'Connor, can still be regarded as partially autonomous, and that respecting autonomy should include taking account of how they value their current situation. I will provide the detail of Jaworska's argument later in the discussion. My purpose here is to outline the questions that cases of dementia can raise for our understanding of identity.

The third case is from an article written by Tony Hope:

Mr D taught classics at a boy's preparatory school. He loved music and played the piano. He married at 25 years of age and has had two daughters. He retired

²Jaworska, Agnieszka. "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value." *Philosophy Public Affairs* 28, no. 2 (1999): 105-38.

at age 63 because his workload was beginning to become too much for him. Soon after retirement he was diagnosed with Alzheimer's disease. At first he enjoyed retirement, but life gradually became more difficult. After about a year he became less affectionate to his wife. Things deteriorated to the point where, for the first time in their married lives, they slept in separate beds. As time went on he started to do less and less. His indifference to his wife started to become active hostility and this hostility became directed to his daughters as well. About 4 years after retirement he wandered out of the house when his wife was out shopping. The police brought him back after complaints that he was 'molesting little girls'. Apparently he had said some things to a group of schoolgirls in a shop and the shopkeeper was concerned and called the police. His physical aggression has never extended beyond pushing his wife away. He can feed himself and is fully continent. There are times when he appears to know who she is, but for much of the time he does not appear to know her.

His wife's attitude towards him has changed radically over the years. At first she did not see the changes as being the result of an illness – she thought that he had ceased to love her. The second stage was when she accepted he was ill and that he needed her help. But over the last year her attitude has changed again ... She says that he must go into a home permanently. 'I don't see why I should have him in the house at all. It's like living with a stranger. He's not the man I married – that man has been dead for at least two years.'³

This case presents a particular challenge if we accept Jaworska's view that people with mild to moderate dementia retain some autonomy. While Mr D seems cognitively better off than Margo and Mr O'Connor, his wife's view is that he is no longer 'himself'. More precisely, she says he is a completely different person. If we conclude that Margo and Mr O'Connor are still in some respects themselves, but Mr D is not, then this difference needs to be explained. Why would it be that in some cases identity is maintained through dementia, and in other cases it is not? To answer this question, we need some explanation of how personal identity is constituted, and a more detailed account of the ways dementia can affect us.

In this thesis, I bring together classic theories of identity with contemporary clinical and neuroscientific understandings of dementia and its primary symptoms in an effort to provide some answer to the questions raised by these cases. I will argue that theories of identity that centre on the persistence of certain 'objects' are mistaken, and that these

³ Hope, Tony. "Personal Identity and Psychiatric Illness." *Philosophy, Psychology and Psychiatry*, 1994, 131-44.

theories incline us to overstate the extent to which identity is lost through dementia. Within this argument, I highlight how the dominant understanding of memory – currently being overhauled in the contemporary science of memory – has reinforced this mistaken view of identity. I then argue that in place of these ‘object’ theories we should adopt theories that centre on interdependent agency, i.e. theories that view the self as fundamentally an agent endeavouring to maintain an array of meaningful connections. Such theories shift attention from questions of whether the dementia sufferer retains certain thoughts or is still capable of particular functions, and considers instead a person’s ability to act as themselves.

To complement this theoretical discussion of identity, I report on the findings of a qualitative study undertaken as part of the dissertation project. In this study I interviewed seven participants with significant clinical experience in various dementia care settings. The interviews were 50 to 70-minutes, semi-structured and explored the participants’ views on the questions raised by the cases described and also the theoretical responses I was developing. The purpose of this study was to further test the clinical relevance of the problem presented in the literature, and to develop the ideas about identity that I wanted to put forward. Overall, the participants were supportive of the position arrived at in the theoretical discussion, though their views diverged on certain issues, and some participants appeared to vacillate in their positions throughout the interview. This highlights the complexity of the issues discussed and the need for theoretical work.

The thesis is structured as follows: In Chapter One I provide an overview of several major theories of identity, divided into theories of personhood and personal identity, and briefly review arguments for and against each one. The section of personal identity will be further divided into ‘object’ theories which conceive identity as persisting through some object and ‘agency’ theories which consider identity to be formed and expressed through actions and choices. In Chapter Two I address the concept of memory, and outline how the academic understanding of memory is shifting, based on current neuro-physiological and psychological science. As will become clear, the concept of memory is highly relevant to theories of identity and the clinical course of dementia, as it is often maintained that memory provides the psychological continuity necessary for personal identity, and it is also generally regarded as the cognitive function most profoundly affected by the

common forms of dementia. In Chapter Three I describe the current epidemiological data relating to dementia, a typical clinical course, as the symptomology and pathophysiology of different dementia subtypes. Examining the differences in these dementia types will be important when considering how memory, identity and dementia intersect. In Chapter Four I will reconsider the theories of identity described in Chapter One in light of the discussions of Chapters Two and Three. I will explore the likely origins of the ethical problems with identity in a dementia context, and indicate how a change in the ways we think about these key concepts may improve how we care for people living with dementia. This is where I will make my main argument against object theories in favour of agency theories. I will also outline what these theoretical moves mean for the cases described above. In Chapter Five, I will report on the qualitative study, and discuss how the accounts of clinicians align with the ideas of the previous chapters. I will finally conclude by offering closing remarks and indicate areas for further investigation.

Chapter One - Identity

Identity is a difficult concept that philosophers, psychologists and sociologists have debated over for many years. The difficulty is partly due to the fact that the term ‘identity’ is used to refer to a range of different concepts that, while connected, are distinct. In this chapter I will discuss two such concepts, which I will describe as ‘personhood’ and ‘personal identity’. It is important to be aware of the distinction between these concepts, as they are implicated in very separate sets of questions and dilemmas that can arise in cases of dementia. Broadly speaking, personhood involves questions derived from “what we are,” whereas personal identity concerns “who we are.” Discussions of identity can easily conflate these concepts (as indicated by some quotes in Chapter Five). Further difficulty arises from the fact that each of these concepts is ambiguous in its own right. While most people will have some intuitive sense of what they mean, most also find it difficult to provide precise definitions that stand up to critical analysis. The following discussion will help minimise confusion and provide a foundation for arguments made for and against particular theories of identity in Chapter Four.

1.1 Personhood

Considerations of identity often concern what I will refer to here as the concept of personhood. In philosophical and ethical literature, personhood typically refers to the status of being ‘a person’. It is the concept by which we separate persons from non-persons. Being a person is associated with having a certain ‘dignity’, and with that rights and responsibilities. It includes living in a moral community made up of other persons. Questions of personhood usually involve variations of “what are we?”, “at what point do we start being persons?”, “when do we stop being persons?”, and “what makes persons different from non-persons?” These questions make personhood an essential consideration in a wide range of important ethical and legal issues, including abortion, euthanasia, capital punishment, slavery and other human rights. For example, justification for abortion relies heavily on the idea that a foetus is not a person (or at least not a person in the same way that a child is a person). Historically, practices such as slavery have been justified by the notion that those who are enslaved do not hold the same status of the enslavers. For our discussion of dementia, the main question of personhood is whether late stage dementia can destroy the person *qua* person, or whether it can affect personhood in some other profound way. The qualities and criteria required for personhood are widely debated within philosophy and ethics; the following is a brief outline of some of the major arguments.

1.1.1 Human criterion

In building an account of personhood, some theorists infer from the strong intuitive sense that “persons are human” that everything that is a human is also a person. This approach will tend to find the criteria for personhood in that which is biologically distinctive about humans, e.g. human resemblance or human DNA. John Noonan has put forward one version of the view, arguing that to be considered a person, you simply must be human, and this for him means being conceived by human parents.⁴ While this view rules out the possibility of non-human persons e.g. aliens or machines with artificial intelligence, it also ‘rules in’ beings such as unborn foetuses, anencephalic babies, patients in persistent unresponsive states, and perhaps even human cadavers. All of these have been conceived by human parents, and possess human DNA. While the conclusion that a foetus is a person will be agreeable to those who, like John Noonan, hold pro-life views in abortion debates, many view these other kinds of human beings as non-persons, or perhaps as not-yet-persons, or past-persons. It seems clear at least that persons are different from dead bodies, as they receive very different moral consideration.⁵ So, while all these beings are biologically human, there is debate about which of these, if any, should be regarded as persons. To push this argument one step further, all cells within my body contain human DNA, but it seems incorrect to award personhood to a collection of skin cells, or say, a severed toe, even though these examples are undeniably human. So, it seems evident that personhood is about something more than just being genetically human. It is clear that the biological criteria alone will not settle the issue.

1.1.2 Cognitive criterion

A number of classical and contemporary philosophers have maintained that personhood is dependent upon a cognitive criterion, i.e. being capable of a certain set of cognitive functions. For instance, classic British empiricist John Locke said that a person is:

a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that

⁴ Noonan, John Thomas. "An Almost Absolute Value in History." In *The Morality of Abortion; Legal and Historical Perspectives*, 51-59. Cambridge, MA: Harvard University Press, 1970.

⁵ A cadaver is of course generally treated with respect. Moral significance extends beyond just persons, but persons are clearly given more moral consideration and responsibility than dead bodies. Rights to basic needs like food and water are a part of being a person and it would be ridiculous to grant these rights to a dead body.

consciousness which is inseparable from thinking, and, as it seems to me, essential to it.⁶

For Locke, it seems that the essential cognitive function is self-awareness through a continued consciousness so that one can recognise past and future actions as their own.

Another modern proponent of a cognitive criterion is philosopher Mary Anne Warren, who puts forward a similar view to Locke's. She offers an extended list of five traits that she views as most central to the concept of personhood: consciousness, reasoning, self-motivated activity, communication and self-awareness.⁷ She clarifies that any one of these traits is not necessary for personhood, and acknowledges that consciousness, reason and self-motivated activity may indeed be sufficient. However, on her account, if a being is unable to fulfil any of these criteria, they cannot be considered a person. This view appears to exclude fetuses, anencephalic babies and those in varying states of 'brain death', and fits with many people's existing intuitions. However, it may also exclude some beings that are widely regarded as persons. For example, children in the first few months of life do not fulfil many of these criteria, if any at all: they sleep for large portions of the day (minimally conscious) and have not yet developed reasoning, self-motivated activity, communication or self-awareness. Yet we generally include infants in our moral community and treat them as persons. The same could be said for people with severe mental impairments.

An alternative cognitive criterion comes from enlightenment philosopher Immanuel Kant, who emphasises a person's capacity for autonomy. On his account, the actions of non-persons are entirely dependent upon that being's particular nature i.e. they act entirely on their natural desires or inclinations. In contrast, persons are able to choose actions on the basis of moral requirements.⁸ As such, we do not regard non-persons as immoral for acting according to their nature. For example, if a factory worker loses their life due to unfortunately falling into a machine, it would seem ridiculous to 'punish' the machine. However, persons should be punished if they choose to act immorally. For example, if someone pushes our unfortunate factory worker into this dangerous machine, they definitely should be punished.

⁶ Locke, *An Essay Concerning Human Understanding*, b2, c27 ; paragraph 9

⁷ Warren, Mary Anne. "On the Moral and Legal Status of Abortion." *Monist* 57, no. 1 (1973): 43-61.

⁸ See Kant, Immanuel, and Mary J. Gregor. *Groundwork of the Metaphysics of Morals*. Cambridge, U.K.: Cambridge University Press, 1998., and Kant, Immanuel. *Critique of Practical Reason*. New York: Liberal Arts Press, 1956..

Contemporary bioethicist Peter Singer offers a utilitarian perspective, influenced by philosophers such as Jeremy Bentham, John Stuart Mill and Henry Sidgwick. In his view, moral significance arises from a being's capacity to hold preferences and to feel pleasure and pain (where success or failure in achieving those preferences may be critical). As holding preferences requires rationality, autonomy and self-consciousness, Singer draws the conclusion that "only a person could have a right to life"⁹. However, he regards the species of a being as unimportant when considering personhood, and states that "there could be a person who is not a member of our species. There could also be members of our species who are not persons"¹⁰. Singer follows this argument to quite provocative conclusions. Not only does he argue that foetuses should not be regarded as persons, like Warren, but also extends the same regard to infants and profoundly intellectually disabled humans, as these beings also fail to fulfil his criteria for personhood.¹¹ Moreover, he argues that some animals, such as gorillas, appear to fulfil these criteria and thus should be extended the moral consideration of personhood. There is a possible interpretation here that Singer is suggesting the relegation of the rights of infants and intellectually disabled humans to the current standard held by non-human animals. Singer addresses this by maintaining that "the aim of [his] argument is to elevate the status of animals rather than to lower the status of any humans"¹². He also adds a caveat in suggesting that the moral questions about personhood should be regarded as independent of the legal outcomes, stating that "[t]here is some plausibility in the view that, for legal purposes, because birth provides the only sharp, clear and easily understood line, the law of homicide should continue to apply from the moment of birth."¹³

1.1.3 Significance criterion

Contemporary philosopher Charles Taylor has argued that the kinds of criteria put forward by Warren and Locke are not enough to differentiate human agents from non-human agents, such as animals and machines that are able to exhibit complex and adaptive behaviours. This conclusion seems to align with Peter Singer's views, although Singer sees this as a reason to

⁹ Singer, Peter. *Practical Ethics*. 3rd ed. Cambridge: Cambridge University Press, 2011. p82

¹⁰ Singer, *Practical Ethics*, p74

¹¹ A contrasting argument could be that infants and foetuses are indeed conscious, under a definition of consciousness that focuses on a being's ability to respond to environmental stimuli. However, this definition of consciousness is also necessarily extended to animals and indeed plants which are equally capable of responding to stimuli. It seems that this definition of consciousness, is no more helpful in determining personhood if a distinction is to be maintained between the moral status of foetuses and plants.

¹² Singer, *Practical Ethics*, p67

¹³ Singer, *Practical Ethics*, p153

elevate the moral status of animals, rather than reconsider the framework of personhood. In place of a cognitive criterion, Taylor proposes a “significance criterion”, by which persons are understood as creatures that attribute meanings to representations that are “peculiarly human, and have no analogue with animals.”¹⁴ There are certain *motives* behind particular actions that are specific and unique to humans which are not shared by animals or computers, e.g. pride, shame, guilt, love and honour. These motives are dependent upon the meanings that are significant to us. This significance is subjective and informed by our individual representations of the world and influenced by our culture. As Grant Gillett puts it, “the things a culture values are built into and structure the thinking and action of a human being.”¹⁵ This is evident from the fact that certain actions may be considered appropriate in one culture but shameful in another, e.g. killing animals for food vs. worshiping them as gods. These peculiarly human meanings drive us to act in ways that are distinct from how non-humans act (e.g. according to a programme in the case of machines, or by weighing up desires, as is proposed in animals) and so can act as the distinction between person and non-person. To convey the distinctiveness of human meanings, Taylor describes the difference between a fear response and a shame response. With fear, there is objective danger or badness. However, with shame, the badness comes from the very meanings we attribute to the particular shameful action; there is no objective badness. However, it is not clear if this theory truly clears up problem cases. Several examples from popular culture depict non-human beings with *artificial intelligence* who have complex moral thoughts and emotions and as a result exhibit these very ‘peculiarly human behaviours’. Perhaps Taylor would in fact allow that on his account these beings would be considered as persons. Furthermore, it might be argued that his theory excludes infants, humans with severe mental impairments or those who have somehow lost the ability to engage in the relevant types of meaningful behaviours. Taylor attempts to address this concern through the following remark: “those who through some accident or misfortune are deprived of the ability to exercise these capacities [required for personhood] are still understood as belonging to the species defined by this potentiality.”¹⁶ It seems that beings with some potential for these morally significant behaviours are extended the same kind of moral consideration.

¹⁴ Taylor, Charles. *Human Agency and Language*. Cambridge: Cambridge University Press, 1985. p97-114

¹⁵ Gillett, Grant “Is There Anything Wrong with Hitler These Days?” 1997, cited in Elliott, Carl. *A Philosophical Disease: Bioethics, Culture and Identity*. New York: Routledge, 1999. P162

¹⁶ Taylor, Charles. *Human Agency and Language*. Cambridge: Cambridge University Press, 1985. p97-114

1.1.4 Gradient theory

The theories discussed so far describe personhood as something that is ‘all or nothing’, i.e. you can be a person or a non-person. It may be possible to consider personhood as a matter of degree - as a gradient rather than a binary switch. Throughout our lives, we acquire more complex cognitive functions e.g. complex reasoning and communication abilities, and we also develop more nuanced ‘peculiarly human’ motives for our actions through culturally significant interactions. Simply put, as we grow and develop, we begin to fulfil more of the criteria specified in the theories above. It seems sensible that if the acquisition of these qualities is progressive, then personhood is also something that could be developed in gradual degrees. It is difficult by any measure to pinpoint a precise moment in a person’s life where personhood starts,¹⁷ and thinking of personhood as a gradient alleviates the need to draw this line. This approach may also fit with the fact that unimpaired adults have assigned more moral responsibility and freedom to make decisions about their own lives compared to infants and people with severe disabilities. However, this conclusion is problematic in practical application, as considering personhood this way appears to open the possibility of classifying some groups as ‘lesser persons’, such as infants and people with severe disabilities, who are still extended the same moral consideration as unimpaired adults.

1.1.5 Limitations of personhood tests

In most attempts to formulate an account of personhood, there is an implicit assumption that the basic problem can be resolved theoretically. In other words, the theories described above are expected to generate as a sort of ‘personhood test’, where there is a set of criteria which, if met by a being, would mean that being should be included in the moral community as a person. Under such theories, if we settle on a straight definition of ‘person’, we should know what to do in the problem cases such as fetuses, anencephalics and ‘brain-dead’ patients. However, this basic assumption has been challenged by some ethicists and philosophers, who argue that the problem of personhood is not a problem that can be answered in abstract, non-moral terms, because a conception of personhood will inevitably reflect pre-existing and pre-theoretical moral commitments. As contemporary bioethicist Carl Elliot describes:

¹⁷ Unless this is done dogmatically (i.e. arbitrarily), as the Catholic Church does – but even then there is much disagreement on when this precise beginning should occur.

But what is wrong here is the notion that we can somehow define what a person is apart from our moral attitudes towards persons, and that once we get the definition right, this will tell us what our moral attitudes should be. ... But this is not the way our moral grammar works. In fact, just the opposite. Our moral attitudes are not grounded by a theory of persons; they are built into our language. Part of what we mean by the word 'person' entails a certain moral attitude. A 'person' is a type of being about whom we have certain moral attitudes and towards whom we ought to behave in certain ways.¹⁸

The implication here is that instead of arguing over what persons are capable of doing, we should instead examine our moral attitudes towards persons and see if they extend to these problem cases. This perspective would partly explain why there is not unified agreement on what is and is not a person, and why these debates seem to be so intractable. Different parties carry different moral attitudes based on what is significant to them. Elliot's views are substantially influenced by Wittgenstein's radical reframing of how to approach philosophical problems.

1.1.6 Social constructivist theory

Extending on Elliot's views, another Wittgenstenian philosopher and bioethicist, Hilde Lindemann, remarks that personhood may extend beyond the weighty moral arguments about that status of beings and could instead be about normal every-day interactions:

[Personhood] includes taking for granted that persons wear clothes and are given names rather than numbers, or that they are to be referred to as 'who' instead of 'what.' The stance we take toward persons is one we learn, and we learn it so early and so thoroughly that it seems perfectly natural to us.¹⁹

For Lindemann, recognising someone as a person is not about passing a judgement about them and then ascribing them certain moral rights and holding them to certain moral responsibilities; it is rather that through our normal every-day interactions with them, we come to treat them as a person. In this way, we grant others personhood by socially constructing them as *someone*. Furthermore, it is possible to socially construct a being as a person through these natural everyday actions, even if they are unable, or no longer able, to take part in morally significant behaviours. To illustrate, Lindemann describes her sister Carla, who had hydrocephalus and died very young. Though Carla lacked significant cognitive functions required to fulfil the

¹⁸ Elliott, Carl. *A Philosophical Disease*, p158-162

¹⁹ Nelson, Hilde Lindemann. "What Child Is This?" *The Hastings Center Report* 32, no. 6 (2002): 29.

criteria of any personhood test, she was nonetheless treated as a person by her family. However, this is not to say that one may successfully socially construct anything at all as a person. If someone treats a cat like a person, that does not make the cat a person. Lindemann tries to explain the difference in terms of 'sentience' and 'humanness', and she relates these concepts to Wittgenstein's remark that "the human body is the best picture of the human soul." Sentience, she maintains, involves bodily expression of our inner psychological states and others' responses to those expressions. Similarly, humanness is a requirement under the notion that we are only able to appropriately understand beings that are similarly embodied as we are. Therefore, if a being is able to successfully express their inner thoughts and have these interpreted by others, then through these interactions, they may be constructed as a person.

1.1.7 Summary

In this overview of personhood, I have described several different theories which aim to explore what we mean by the term 'person' and how to approach some challenging cases. Some theorists maintain that personhood can be simplified down to a test or criterion, and conclude that whether or not this test is passed will indicate that the being in question bears all the moral rights and responsibilities that go with personhood. Other theorists argue that these views miss the point of personhood, which is about the moral treatment of beings by others. From this they argue that the concept of personhood cannot be defined independently of a particular moral standpoint. These issues are relevant to dementia because people with dementia (particularly advanced dementia) often lose the capacities specified in several theories as necessary to personhood (e.g. they become minimally communicative and heavily dependent upon others). Though my main focus will be on personal identity, I will briefly revisit these issues of personhood in Chapter Four, and consider them in the light of the argument about identity that will have been discussed.

1.2 Personal identity

Personal identity, in contrast to personhood, is about the *who* rather than the *what*. It concerns the things that make me 'uniquely myself' and not someone else. While we tend to have a strong intuitive sense that we are the same being continuing throughout time, i.e. that we remain *ourselves* over the course of our lives, it is also clear that we can change substantially during that time. This seems to present a kind of paradox: how is it that I can be both the same person and not the same person I was, say, ten years ago? In this section, I will describe three broad

approaches of considering personal identity which aim to explain this paradox. The first of these are ‘object-based theories’ which argue that personal identity endures throughout time because there is some enduring substance that contains it, whether it be the body, brain, mind or consciousness.²⁰ The second approach is the use of a ‘no self theory’, which rejects the notion that we have a persistent personal identity and that our selves persist through time. The final approach I will describe uses ‘agency-based theories’, which regard personal identity as something that is expressed and formed in our actions and the reasons behind those actions, and hold that we remain the same person over the course of time through the intentional continuity of our actions and interactions with others. The important distinction here is between object-based and agency-based theories, which conceive of identity in fundamentally different ways. This distinction is vital to understand the arguments I make in Chapter Four for the use of an agency-based approach over an object-based approach in the context of dementia.

Personal identity is an important concept as it is foundational to ethical concepts such as obligation and accountability. If a friend of mine loans me some money, I am obligated to return that money to them at a later date. Implicit in this arrangement is the assumption that I will still be the same person when it is time to repay the debt. If I was somehow not the same person that the friend loaned money to, then I would have no obligation to pay them back. Likewise, if I organise to go out to dinner with a group of friends at a particular time and place, I expect those particular friends to show up at that time and place and not an entirely different group of people. Generally, we hold people in the present accountable for their promises and actions made in the past exactly because we believe that they will continue to be persons they are.

Before discussing theories of personal identity, I will make some general remarks about the nature of the problem they are supposed to address. There is often a similarity drawn between the identity of objects and the identity of persons. Objects can be described as having ‘qualitative identities’ and a ‘numerical identity’. ‘Qualitative identity’ refers to the properties of an object which distinguish it from other objects. For example, a carrot cake and a chocolate

²⁰ Note that what I am describing as ‘object’ theories could be referred to as ‘substance’, or ‘entity’ theories. I prefer ‘object’ for several reasons. Firstly, because it reflects the empiricist conception that generally accompanies such theories (i.e. the presumption – perhaps only implicit – that what is being described could be identified in experience). Secondly, in epistemology and ontology the term ‘object’ is often contrasted with ‘subject’, and this distinction broadly aligns with the distinction I will make between ‘object theories’ and ‘agency theories’. Thirdly, the term ‘substance’ has a broad application, and in ontology can refer to a range of key ontological concepts (including ‘essence’ and ‘nature’), whereas ‘object’ is more focused.

cake are qualitatively similar in the way that they both possess the properties of cakes (sweet taste, eaten as dessert, baked in an oven etc.), but they are qualitatively distinct in the way that they have a different flavour and are made from different ingredients. ‘Numerical identity’ refers to total qualitative identity, the kind an object can share only with itself. While two banana cakes may share many or all of the same qualitative properties, they are not the *same cake*. Whatever else they may share, they necessarily occupy different spaces, and are composed of different ingredients (however similar those ingredients may be). Personal identity most often refers to the unique numerical identity of a person, over the course of their life. It is felt as the sense of ‘self’ we intuitively carry through all the changes in our lives.²¹ Like objects, persons can be described by their unique qualities which distinguish them from other persons but are also only numerically identical to themselves. However, over the course of time, objects and persons can change their qualitative properties and thus their qualitative identity. The challenge here is explaining how the qualitative properties of an object, or person, can change over time while numerical or personal identity must, by definition, endure.

An example often used to illustrate this problem is “The Ship of Theseus” (or one of its many variants).²² In the illustration we are asked to imagine that the ship leaves port from Athens and sails around the world, during which it encounters many dangerous storms. As a result, planks of wood that make up the ship are periodically replaced by new planks. This process proceeds until when the ship returns to Athens it no longer has any planks of wood that it originally had when it left Athens. And so the question arises: “is this the same ship that left?” As the changes are gradual it is not clear when, if ever, the ship stops being the ship that left Athens. If we hold that the ship that returns is not the same ship that left, then it seems that the identity of the ship is dependent upon its constituent parts. This might suggest that the ship ceases to be the same ship when it has its first plank replaced. On the other hand, if we hold that the returning ship is indeed the same ship that left, it follows that the ship’s identity is constituted by something other than an organised structure of wooden planks. Thomas Hobbes further explores this puzzle by asking what would happen if each of the planks that was discarded were somehow

²¹ Throughout this thesis I will use the terms ‘personal identity’ and ‘self’ somewhat interchangeably.

²² Another famous variant of this is “my grandfather’s axe” which over the course of generational inheritance has both its blade and handle replaced several times. This sort of problem can also be extended to the identity of clubs, organisations or nations. For example, rock bands that have periodic roster changes until the current line-up is completely different from the original e.g. Little River Band.

collected and used to reassemble a ship.²³ Would the reassembled ship be “the Ship of Theseus” or would it be the ship that is periodically repaired? Could they both somehow be the same ship? These questions are not easy to answer when regarding objects and matters are complicated further when we begin to consider the identities of persons, which seems to be more complex than that of objects.

1.2.1 Object-based theories

As the Ship of Theseus problem illustrates, there is at least some intuitive connection (which may turn out to be false) between identity and objects. In first considering the puzzle, we tend to suppose that the ship of Theseus is the ‘actual ship’ discernible to our senses. The question that the puzzle then poses is precisely *which* parts of the ship are necessary for this identification to be correct. Several accounts of personal identity carry this assumption, in that they seek to explain personal identity as inhering in some object or collection of objects. The first of these are bodily identity theories.

Bodily identity theories attempt to explain the persistence of personal identity in terms of continuity of a body. In other words, the idea is that we persist over time because we occupy the same physical body. In several ways this seems credible. It appears evident that we never *leave* the physical confines of our body and when, for example, we invite someone out for dinner, we expect their body to turn up. However, similar to the Ship of Theseus, it is the case that many cells in our body are degraded replaced by new cells through a process of growth and repair, and all of the changes involved in these processes are small and gradual. This, however, is not a perfect parallel, as when the cells in our body are replaced it is done so by that very organism, as a growing ‘whole’.²⁴ The Ship of Theseus does not self-produce the planks that replace the old ones. We could perhaps say that the ship is repaired according to a particular *form*, much like our bodies are. However, while this seems an important observation, it does not entirely resolve the problem. There is still a question about how much, or what aspects, of a given form needs to remain the same for the thing to remain what it is. It is evidently possible for people to lose parts of their bodies and still remain themselves. For example, a person who uses an artificial limb following amputation, or a person who undergoes an organ transplant. We will tend to say that such procedures change people, but we are not

²³ Hobbes, Thomas. *Elements of Philosophy: The First Section, concerning Body*. London, 1656. Chapter 11

²⁴ Furthermore, many other cells types in our body are never replaced and some damage cannot be repaired.

likely to say they become new people (or hybrid persons). This is a point that Descartes emphasised in formulating his now infamous mind-body distinction. There is, he observed, a ‘great difference between the mind and the body ... the body is by its very nature always divisible, while the mind is utterly indivisible’. Because of this difference, ‘if a foot or arm or any other part of the body is cut off, nothing has thereby been taken away from the mind’.²⁵ While we may wish to argue with the claim that ‘any’ part of the body can be ‘cut off’ without taking away from the mind (neurological damage seems to demonstrate otherwise), these observations do isolate a key problem that a theory of identity needs to address, *viz.* why changes in the body do not necessarily associate with changes in the mind. Moreover, they reflect a strong sense that what we think of as ‘the person’ is more closely identified with the ‘mind’ than with the body. Given that bodies can grow and change without affecting who the person is, it seems that personal identity must be about something other than the continuity of a bodily substance.

While Descartes’ mind-body dualism has now been widely rejected, the link he draws between the self and the mind has in many respects persisted. In place of bodily identity, various theories maintain that identity is grounded in continuity of a mental substance, or some psychological phenomena. Some versions of these theories conceive the mind as made of a non-physical substance that is somehow separate from the body (just as Descartes did). Others view the mind as ‘contained’ or ‘subsisting’ within the body (generally in the brain), but hold that the mind is in principle ‘separable’ from the body, similar to the way that a computer programme is separable to the hardware through which it operates. Several of these theories will explore hypothetical situations in which one’s mind is somehow transported into the body of another, in order to test where we intuitively identify a person with bodily or psychological continuity. For example, philosopher Bernard Williams has formulated a thought experiment in which two people, A and B, appear to *exchange bodies*. After the exchange the body of person A now bears the mental life of person B, and vice versa.²⁶ Before this process occurred, person A was told that after the exchange, one of the people is to be rewarded and the other tortured and is

²⁵ Descartes, René, John Cottingham, Robert Stoothoff, and Dugald Murdoch. *The Philosophical Writings of Descartes*. Cambridge: Cambridge University Press, 1984. p 59.

²⁶ Williams, Bernard Arthur Owen. *The Self and the Future*. London: Cambridge University Press, 1973. There are also many simplistic versions of this problem in popular media. Indeed, it has become a well-used premise in many comedy films, which turn on the difficulty in appreciating person’s perspective e.g. *Turnabout* (1940), *18 Again!* (1988), *Dating The Enemy* (1996), *Freaky Friday* (2003), *17 Again* (2009), *The Change-Up* (2011), etc.

given the option of deciding which outcome each body receives. Proponents of psychological continuity would argue that person A would want person B's body to receive the reward after the exchange process, whereas proponents of bodily continuity would argue the opposite.

Rather than aligning one's position with either the mind or body theorists, one might reject the question altogether, and maintain that thought experiments like the one just outlined are implausible. It seems inescapable that our minds are intertwined with our bodies, i.e. that the two purported substances are not in fact separable. The perceptions of our mind are derived from sensory stimuli delivered by sensory organs within our bodies and our minds take shape according to the sensory organs available to us. For example, having functional eyes allows us to imagine pictures, but someone born blind does not have access to these visual representations. Conversely, mental sensations drive our bodies to certain tasks e.g. desire for food prompting one to open the fridge. For these reasons, it seems impractical to suggest the transposition of one's self based on the separation of one's mind from their body. Thus, the person is not either the body or the mind; both must exist together for the person to be who they are. Nevertheless, the question of which parts of the combined body and mind comprise the person still needs to be answered.

1.2.2 Memory theory

John Locke's theory of personal identity is an earlier and influential version of the 'psychological continuity' approach. Just as he viewed personhood as dependent on a particular form of consciousness, he also viewed personal identity as dependent on the continuation of a particular individual consciousness. In contrast to Descartes, he argued that one can hold this view and remain agnostic about whether consciousness (i.e. the mind) exists in the body or as a distinct substance. Critical to his account of personal identity is the idea that an individual's consciousness can be 'extended backwards' to 'past actions or thoughts':

as far as [a person's] consciousness can be extended backwards to any past action or thought, so far reaches the identity of that person; it is the same self now it was then; and it is by the same self with this present one that now reflects on it, that that action was done.²⁷

²⁷ Locke, *An Essay Concerning Human Understanding*, b2, c27, paragraph 10

It is possible to debate what Locke meant in his notion of consciousness extending backwards,²⁸ but the standard interpretation, perhaps first formulated by Thomas Reid, is that this is a reference to the operation of memory.

Now, consciousness of what is past can only mean remembering it; so that Locke's principle must be that identity consists in remembering, and consequently a man must lose his personal identity with regard to everything he forgets.²⁹

In other words, the claim is that we persist throughout time because our consciousness persists and connects us to our past actions through our memories. It follows that without memory a person could not exist. This 'memory theory' has endured for three centuries now, and it reflects the commonplace view held by many people today. These people include contemporary neuroscientists such as Daniel Schacter, who describes that "our sense of ourselves depends crucially on the subjective experience of remembering our pasts."³⁰ While this approach may seem to circumvent the problems associated with substance dualism, new problems arise with Locke's memory theory, many of which relate to the pervading but mistaken view that memory is a reliable 'archive' of information.

According to the memory theory of identity, a person's identity consists entirely in what they can remember and as Reid noted, if a person cannot remember something, then it follows that it is not part of who they are. Locke writes:

for, whatsoever any substance has thought or done, which I cannot recollect, and by my consciousness make my own thought and action, it will no more belong to me, whether a part of me thought or did it, than if it had been thought or done by any other immaterial being anywhere existing.³¹

There are some obvious problems with this. Firstly, there are important parts of our identity that memory does not capture. People usually have no memories of their early infancy, yet likely consider their infant self to be continuous with their present self. Similarly, there are some events for which we are not conscious, and so are unable to remember e.g. anything that

²⁸ See Schechtman, Marya. *The Constitution of Selves*. Ithaca, NY: Cornell University Press, 1996. p27

²⁹ Reid, Thomas, and Derek R. Brookes. *Thomas Reid, an Inquiry into the Human Mind: On the Principles of Common Sense*. University Park, PA: Pennsylvania State University Press, 1997. p9

³⁰ Schacter, Daniel L. *Searching for Memory: The Brain, the Mind, and the past*. New York, NY: BasicBooks, 1996. cited in Hydén, Lars-Christer, Hilde Lindemann, and Jens Brockmeier. *Beyond Loss: Dementia, Identity, Personhood*. Oxford: Oxford University Press, 2014. Chapter 5, Questions of meaning

³¹ Locke, *An Essay Concerning Human Understanding*, b2, c27, paragraph 24

happens to you while you are asleep. Yet, these events are still considered to be happening to the same person as the conscious self; we generally consider things that happen to us when we are asleep as indeed happening to *us*. We are likely concerned for the beings we are in infancy or when asleep in the same way that we are concerned for our present selves. Furthermore, sometimes we forget things that we did, yet they are still our actions. This is reflected in the fact that, in most cases, we are held accountable for actions even if we do not remember taking them. If Locke's theory were correct, then it seems that if he were to accept an invitation to come to dinner with you and then later forgot to attend, he would feel no remorse, and indeed would argue that he cannot be the same person that you invited. This would be a very strange position to maintain, and it contradicts many of the ways we think about identity and accountability. Suppose again that a number of other friends who also received invitations could attest to the fact that you had invited Locke. It seems on Locke's view their testimony would count for nothing. Of course, if Locke had forgotten then this may constitute an explanation of why he did not attend, but it would remain the case that *he* had forgotten a promise that *he* had made. As such, he may be asked to account for his forgetting, rather than the failure to show up; the point is that he is still himself and he is held accountable. Similarly, consider a person who committed a crime and was sentenced to imprisonment based on sufficient evidence. Suppose that on the way to prison this person suffered a head trauma and could no longer remember the crime, nor the court proceedings following it. This would not make the crime any less theirs. However, under a Lockean view this person would have to be acquitted of their crimes.

Secondly, it is common for people to remember things *incorrectly* as memory is also mutable and suggestible in addition to being inconsistent. We can become convinced that things happened when they did not, and can be made to feel differently about past events through the use of leading questions and re-negotiation. Indeed, these false memories can affect people's actions in significant ways and has caused considerable controversy in cases of eye-witness testimony, which have later been revealed to be incorrect based on DNA evidence.³² Under a

³² This claim is based upon work done by Elizabeth Loftus, who has conducted many studies on the malleability of memory and existence of implantable false memories. See Loftus, Elizabeth F. "Leading Questions and the Eyewitness Report." *Cognitive Psychology* 7, no. 4 (1975): 560-72.; Loftus, Elizabeth F. "The Malleability of Human Memory: Information Introduced after We View an Incident Can Transform Memory." *American Scientist* 67, no. 3 (May 01, 1979): 312-20.; and Bernstein, D. M., C. Laney, E. K. Morris, and E. F. Loftus. "False Beliefs about Fattening Foods Can Have Healthy Consequences." *Proceedings of the National Academy of Sciences* 102, no. 39 (2005): 13724-3731. doi:10.1073/pnas.0504869102.

memory theory of personal identity, the existence of false and mutable memories suggests that our personal identities would be unstable or even fictitious.

These arguments suggest that while memory is an important factor in determining our actions, in many cases it does not behave as a stable archive of information and also fails to capture several important parts of our identity. In the following chapter, I will explore the nature of memory in more detail, as it is the cognitive function most commonly affected by dementia.

1.2.3 No-self theories

An alternative way of addressing the problem of personal identity is to conclude that the notion of a persistent self is in fact an illusion. An early proponent of this view is classical empiricist philosopher David Hume, who reported that when he looked for the self in his experience he could not find it: there was no object in his field of perception to which this idea could be applied. He concluded that what we regard as our 'self' is simply a bundle of perceptions; a collection of 'impressions' that exist in the mind like a play in a theatre. The bundle that is present at one time could be very different from the bundles at earlier or later times, and so there is no real basis to speak of a persisting identity.

Expanding on Hume's thinking, contemporary philosopher Derek Parfit calls for a shift of focus away from identity (which is an all or none quality) towards relation and survival.³³ Like Hume, Parfit argues that there is no one self that endures throughout all of life, but rather a myriad of past and future 'selves' comprised of variable degrees of psychological connectedness in the operation of a particular mind. This notion of psychological connectedness differs from the notion of psychological continuity described previously in two important ways. The first is that psychological connectedness comes in degrees as opposed to continuity, which is binary. That is to say, an individual could be psychologically connected to a recent part self to a greater degree than a distant past self. The second is that psychological connectedness it is not transitive while continuity is transitive. This means that while a 'person' at time Y may be psychologically connected to both a person at time X and a person at time Z, the persons at time X and time Z need not be connected. If all these 'people' at time X, Y and Z are psychologically continuous, then under a theory of psychological continuity, they must be the same person. Parfit encourages us to focus more on the degree of connection there is

³³ Parfit, Derek. "Personal Identity." *The Philosophical Review* 80, no. 1 (1971): 3.

between to past and future selves, rather than being concerned about whether they are the same. On Hume and Parfit's accounts, persistence is a non-issue because they abandon the notion of anything persisting.

While Hume and Parfit's view may be theoretically simple, the implications are far-reaching and likely unacceptable to most people's functional understanding of personal identity. As Marya Schechtman describes, "[t]here is a strong pre-philosophical sense that facts about identity underlie facts about four basic features of personal existence: survival, moral responsibility, self-interested concern, and compensation."³⁴ To abandon a notion of a persistent personal identity, as no-self theories appear to do, is to undermine these four features, which seem an unacceptable conclusion for a coherent life and society. As such, I will not return to these theories in my discussions in Chapter Four. To utilise a no-self theory when considering the problematic cases in dementia would be to short-sightedly dismiss them as completely unproblematic.

1.2.4 Agency-based theories

The approaches to personal identity discussed so far, including the no-self view, largely turn on the idea that personal identity (if it exists) consists in some object or 'thing' that persists. In the Lockean view it is the persistence of certain ideas contained in one continuous consciousness, whereas for Hume it is expected to be the persistence of some entity discernible in experience (in the same way that other objects, like trees, dog, buildings, bodies, and so on persist in experience). Another approach is to view personal identity as grounded in the persisting activity that generates experience, i.e. in agency. On this view, we are *who we are* – or perhaps become who we are – through what we do and the reasons we act upon. So, on this approach, the ontology of a 'person' is not conceived in terms of a bounded object persisting in space and through time, but rather as an agent: an entity that expresses its nature through action (or more precisely, through the actualisation of power).

Immanuel Kant formulated a version of this approach when he argued that for experience to be possible, there must exist a unified mind that brings together and interprets the 'raw material' given by our perceptions.³⁵ He then extended this work in his moral philosophy, by arguing

³⁴ Schechtman, 1996, *The Constitution of Selves* p2

³⁵ Kant, Immanuel. *Critique of Pure Reason*. Translated by Paul Guyer. Edited by Allen W. Wood. Cambridge: Cambridge University Press, 1998..

that the unified self operates in the world through intentional action, and ultimately through acting on what he called the ‘moral law’ (which he held to be given through pure reason, and not experience).³⁶ Though few now accept Kant’s radical separation of ‘pure’ universal reason and experience, the link he draws between intentional action and personal identity has been widely implicated in modern theories of identity. An influential contemporary exponent of the idea is Christine Korsgaard. She argues that the self-reflective structure of human consciousness requires us to form a conception of ourselves, out of which we select reasons as the basis of our actions.³⁷ This self-conception is established and developed through the ongoing process of self-reflection and decision. In this way, says Korsgaard, personal identity is self-constituted. The persistence of an identity, on this view, depends not on physiological or psychological continuity, but is achieved through the person’s ongoing commitment to a particular set of reasons and corresponding patterns of activity – what one might call *moral* continuity.

In Korsgaard’s theory, the processes of reflection and deliberation are arranged around our ideas about what is important, i.e. our values. When we act on a given reason we are implicitly acknowledging that that reason represents something significant to us.³⁸ This means that values have a central place in her conception of identity. A critical question that follows from this is how our values are identified and determined, or, in other words, what is it that brings us to act on some reasons and not others. I will not attempt a complete response to this question here, but will outline three perspectives that have a particular relevance to our view of dementia.

The first is from the legal and moral philosopher Ronald Dworkin. Unlike Korsgaard, Dworkin does not directly attribute his views to Kant, but his ideas seem in many respects to fit with the Kantian tradition. He maintains that a person’s core, identity determining values are associated with what he calls the person’s ‘critical interests’.³⁹ Critical interests are things that people consider vitally important to their sense of self and what makes their lives ‘successful as a whole’. He contrasts them with ‘experiential interests’, which are interests worth meeting for the fulfilment of pleasure and happiness but are not vital to one’s sense of self. For instance, a

³⁶ Kant, Immanuel. *Critique of Practical Reason*. Translated by Lewis White Beck. New Jersey: Prentice Hall, 1993.

³⁷ Korsgaard, Christine M., and Onora O’Neill. *The Sources of Normativity*. Cambridge: Cambridge University Press, 1996. p100

³⁸ See the definition of ‘practical identity’ (Korsgaard term for a self-conception) in *The Sources of Normativity*, p 101.

³⁹ Dworkin, *Life's Dominion*, 1993.

person might choose to stay up late to finish an assignment, and thereby spurn the experiential interests of a good night's sleep, in order to satisfy the critical interest of getting a good grade at university and thereby improve future job aspirations. Our commitment to certain relationships is often similar. For example, many parents will attest that the price of parenthood is high when it comes to satisfying experiential interests; parents will often put their own interests aside in order to provide better lives for their children. Dworkin suggest that this is because being a parent is a core element of their identity. He further notes that these 'critical interests' tend to be reasonably stable throughout someone's life, whereas experiential interests more easily come and go. Importantly, Dworkin holds that critical interests are formed from rational reflection on what makes one's life worth living.⁴⁰

Dworkin's account of critical interests has been challenged by psychiatrist Agnieszka Jaworska. She accepts the basic notion that there are some values that are 'identity defining' and others which are not, but rejects Dworkin's claims that identity determining interests can only be formed and upheld through a rational appraisal of one's life as a whole. Instead, she argues that such interests can be identified through the sense of obligation that a person attaches to such interests, the impact they have on that person's sense of self-respect, and connection that these interests have to something independent of the person's experience. In other words, for Jaworska, a person is expressing critical interests when they hold themselves obliged to act on a particular reason that is not solely about themselves, and where successfully or unsuccessfully acting on that reason affects their self-respect. An important implication of this view is that the persistence of autonomous agency is not dependent on those rational capacities that enable a person to reflect on their life as a whole, and so a person may retain the ability to express their identity in mild to moderate dementia.

The third perspective that I wish to outline involves the role of relationships in forming our personal identities. The theories mentioned thus far generally present personal identity as something that is contained within the person. However, these views may ignore the fact that humans exist in relationships with the world and other people. Relational accounts of identity argue that a person's identity is constituted in their interactions with other persons, places and things. This idea fits with the observations that many people will regard a sense of belonging to a place or community to be critical to their sense of self. This can range from being a citizen

⁴⁰Dworkin, *Life's Dominion*, 1993, p213

of a nation, a member of a particular family, or a person who has lived and worked in a certain area. Some people consider connections to particular geographical structures to be vital to their identity. This kind of thinking is evident in Māori culture in New Zealand, where the traditional introduction (*mihimihi*) includes a person's relationships with a river, a mountain and a tribe, all before the person's name. Others consider particular objects to be critical to their identity for example if someone takes extreme pride in their car, they might claim that this car constitutes a significant part of who they are. Furthermore, the objects we own, clothes we wear and things that we surround ourselves with in our homes can also be considered constitutive of our identities.

It is worth noting that a relational account of identity does not easily fit with an object theory, as it is not obvious what it would mean to say that an object (e.g. a collection of memories) was constituted by existing in relation to other objects. There is a much better fit with agency-based accounts, as it makes sense to think of a person's agencies as enabled or supported by other 'agencies' (whether it is the regular operation of an environment, or the understanding and help given in a family).

An aspect of relational theory that needs special consideration is the role of society in 'constructing' a person's identity. Theorists who emphasize this aspect may be said to be putting forward a 'social-constructivist' account of identity. Hilde Lindemann, for example, defines personal identity as "the interaction of a person's self-conception with how others conceive her: identities are the understandings we have of ourselves and others."⁴¹ This view argues that a person's identity is held partly in other peoples' conception of them, instead of purely within the person themselves. Obviously the relationships we have to others are complex, and vary in degrees of significance. It follows that the relationships we consider more important contribute to our identity to a greater degree. Our conceptions of other people are based on many factors, and are in certain respects mutually determined, but to a large degree are derived from a person's actions.⁴² If someone acts in a way that does not fit with my

⁴¹ Lindemann, Hilde. *Damaged Identities, Narrative Repair*. Ithaca: Cornell University Press, 2001. Cited in Schechtman, Marya. *Staying Alive: Personal Identity, Practical Concerns, and the Unity of a Life*. Oxford, UK: Oxford University Press, 2014.

⁴² Our conceptions of others are clearly not *entirely* dependent on their actions. For example, when meeting someone new, there are very few actions that you can draw upon as 'data' to form a concept of them and so most of your concept must be derived from something else. I believe that these *first impressions* are largely based on things about you, rather than the person you are meeting, specifically your previous experience with people you

conception of who they are, I am forced to adjust my conception. For example, if someone who I had always thought was a nasty person does something kind for me, I am forced to at least consider that my notion that they are a nasty person is wrong. Similarly, our conceptions of others can affect their actions. Most people will feel social pressure to alter their actions in order to conform to the expectations held by others e.g. if a person is treated as a soldier – they are given orders by a superior and are expected to wear a military uniform – they will be inclined to act as a soldier. This interaction between actions and conception of others is the basis for ‘social roles’. These can include, but are not limited to, someone’s occupation and their role in a family or social group. On this view, a person’s identity is constructed by their actions, by the language that is applied to them, in their thoughts, and also in the thoughts of others. This person persists as the same person through time not only because they consistently act as themselves, but also because others consider them as the same person through time and hold them to the expectation that they act ‘as themselves’. An implication of this view is that a person will have only limited control over their identity. This is evident in the influence that early learning and experiences have on who a person later becomes. When babies are first born, we tell stories about them and so construct who they are, while the babies themselves have very little control over this; at this stage their identity consists mostly of third person accounts.⁴³ As we grow older, we begin to take more ownership over our actions and contribute more to our identities, while the second and third person factors are still pertinent to our identity.

1.2.5 Summary

In this section, I have outlined how personal identity has been variously explained in terms of bodily continuity, psychological continuity, as an illusion, and as grounded in agency. The last of these approaches the concept of personal identity in a fundamentally different way from the previous theories, in that it conceives identity as being expressed in actions and choices, rather than as a persistent object. The differences in these approaches can impact our understanding of dementia and its effect on personal identity. A clear example of this is the link that is commonly drawn between memory and identity, and the loss of self that is associated with dementia. As suggested earlier, this ‘commonsense’ thinking indicates the widespread

consider to be *like* this new person. This could be a basis for prejudices like racism and a reason to be critical of our first impressions of others and be wary of jumping to conclusions when considering new people.

⁴³ Another example is Carla, Hildemann’s sister who was born with hydrocephalus mentioned earlier towards the end of section 1.1.6

influence of the Lockean view that the self persists through the extension of consciousness via memory. I have also indicated how agency may be linked to our values and how there are different perspectives on how identity-defining values are formed, which will become important for the discussions in Chapter Four where I will re-examine the cases described in the introduction.

1.3 Conclusion

In this chapter I have described several classical and contemporary theories exploring the concepts of personhood and personal identity. In light of Locke's pervasive theory, which holds that memory is the object of a person's identity, in the next chapter I will more closely examine what exactly 'memory' is and describe how the traditional archival model of memory is being superseded. In Chapter Three I will provide some informative descriptions of dementia, to provide context to the ethical problems. In Chapter Four, I will revisit several of the theories outlined in this chapter and discuss how they fit with the emerging view of memory and a clinical context of dementia. I will argue that agency-based theories provide the best framework for understanding how dementia affects identity and for addressing the kinds of ethical problems outlined in the introduction.

Chapter Two – Memory

We know much about human memory. Yet as it is with memory itself, we do not know very much for sure. And, what is more, we only have a vague idea about memory as a whole. We cannot even say if there is such a thing as memory (or a memory, or specific memory systems) at all, and I am afraid that the view of memory that I put forward will intensify this doubt.⁴⁴

Memory, as a concept, has long referred to a collection of measurable cognitive processes involved in storing information in an archival fashion in an individual's brain. This view of memory has been pervasive and unchallenged in multiple disciplines involved in 'memory studies' (including psychology, neuroscience, social sciences, history and many others) for hundreds of years. It has been accepted by mainstream western society because it corresponds with many intuitive, well-engrained assumptions and is reinforced by comfortable metaphors that place memory as something akin to a stone tablet, history book or computer hard drive. However, only very recently, this definition of memory as an archive and its associated assumptions are dissolving under a weight of new thinking across research disciplines.

Our understanding of memory is relevant to my broader question about the relationship between identity and dementia for two reasons. Firstly, memory is integral to several of the philosophical theories of personal identity described in the previous chapter and is indeed the central feature of John Locke's pervasive memory theory. These theories have been based on an archival model of memory and so an analysis of that model and whatever might replace it is needed as we consider how they apply to dementia. Secondly, memory deficits are key in the diagnosis and experience of people with dementia. In fact, dementias are often defined as 'memory disorders', so an understanding of the basic assumptions of this model will also help in elucidating some of the clinical and ethical problems that accompany dementia.

In this chapter I will briefly outline the change in understanding that is occurring in memory studies. I will first explain what the archival model involves and then discuss some of the limitations with it. As I do this, I will indicate the new understanding that is emerging. Throughout this chapter I will draw heavily on work by Jens Brockmeier and the PhD thesis of Ian O'Loughlin.

2.1 Memory as an archive

⁴⁴ Brockmeier, J. "After the Archive: Remapping Memory." *Culture & Psychology* 16, no. 1 (2010): 5-35.

The archival model describes memory as a distinct process of the brain that stores information of past events for future retrieval. This model is also sometimes called a storage or computational model, but all of these names are variations of the same basic structural process and have similar downfalls. In this section I will reiterate the three main features of this model as identified by Ian O’Loughlin in his PhD.⁴⁵ These features are: (1) that memory is divided into several memory systems or different ways of remembering, (2) the tripartite model of the remembering process (encoding, storage, retrieval) and (3) the existence of a memory trace, or engram. In the next section, I will explain how this model is currently dissolving.

2.1.1 Memory systems

Memory theorists have long divided memory into different memory systems divided by the kind of information that is remembered and the cognitive (and supposedly neural) processes that are employed in order to remember that information. These distinctions have undergone a multitude of iterations, although the systems detailed below have arrived at somewhat of a settled framework in many research disciplines investigating memory as well as mainstream accounts.

The first distinction that O’Loughlin describes is between declarative and non-declarative memory. Declarative memories are those that are easily expressed verbally. This type of memory is further divided into semantic memory (the memory of facts, e.g. the date of someone’s birthday) and episodic memory (the memory of past events, e.g. what happened at that person’s birthday party last year). In contrast, non-declarative memory is primarily expressed non-verbally and does not easily lend itself to verbal expression. Non-declarative memory is the memory of skills, competences or procedures, e.g. how to play the guitar, perform CPR, conduct one’s self at a funeral, and perhaps the ability to understand the meaning of the word ‘birthday’). This type of memory is more commonly referred to as procedural memory. While these classifications of memory systems may seem distinct enough in most cases, there is clear overlap in their actual expression. For example, how someone behaves at a funeral (procedural memory) depends on their previous experience with funerals (episodic memory) and their understanding of what a funeral is (semantic memory). Autobiographical

⁴⁵ O’Loughlin, Ian. Remembering without Storing: Beyond Archival Models in the Science and Philosophy of Human Memory. PhD thesis, University of Iowa, 2014. <http://ir.uiowa.edu/etd/1374/>.

memory is typically regarded as a combination of episodic and semantic memories of an individual's past.⁴⁶

A second distinction that O'Loughlin mentions is between working memory (aka short-term) and long-term memory. Working memory is concerned with holding and manipulating several pieces of information at the same time and is employed in problem solving tasks. Long-term memory involves the storage of memories for extended periods of time and is employed to answer fact-based questions.⁴⁷ These systems are theorised to involve separate but related neural processes in the brain. The way these systems overlap with the declarative and non-declarative memory is controversial and ambiguous.

2.1.2 Encoding, Storage and Retrieval

Under the archival model, memory researchers have traditionally identified three stages involved in memory which are present across memory systems. These stages are: encoding (the stage where the present event, skill or fact is encoded into the brain as a memory 'trace'), storage (the stage where this encoded memory trace lies dormant for some time) and retrieval (the stage where this memory trace is reactivated and the event, skill or fact is reproduced). While modern accounts have added nuance to this process, attempting to describe some of the more dynamic features of human memory, many do not deviate from the basic assumption that memory works via this three-step process. Metaphors that describe human memory as a computer hard drive (or some similar metaphors such as a filing cabinet or notebook, etc.) have helped to reinforce this tripartite model and establish it as a strong foundation in all disciplines of memory research and mainstream accounts. In fact, several memory problems are often categorised as problems with one of these stages and neuroscientists have long been looking for neural and chemical bases for memory traces and patterns of brain physiology associated with encoding and retrieval processes.

2.1.3 Engrams and memory traces

An engram, or memory trace, is the object of memory processes viz. it is what is supposedly encoded, stored and retrieved. As we are aiming to describe memory, it is unacceptably circular

⁴⁶ This category concerns the memories central to Locke's theory of personal identity.

⁴⁷ Note that 'long-term memory' of recent events (of the last few days) is often conflated with short-term/working memory. This conflation is prevalent in descriptive accounts of dementia, due to the most common early symptoms of dementia being problems recalling recent events - often wrongly described as a 'short-term memory problems'.

to use the term ‘memory’ as what is encoded, stored or retrieved and so the term ‘memory trace’ or ‘engram’ is substituted. A popular definition of these terms comes from Endel Tulving, who describes memory traces as the sum of physical changes that result from an event which is necessary to remember that event at a later time.⁴⁸ Some theorists describe engrams as neural while others will describe them as cognitive, and often these terms are used indiscriminately or the link between them is not detailed. A theory of a neural engram is the hypothetical ‘grandmother cell’. This is the idea that there are specific neurons that respond to specific stimuli and are reactivated when we remember that stimulus. The historical example from Jerry Lettvin in 1969 gave the theory its name as the example he used was the visual representation of a grandmother’s face.⁴⁹ Believing in the existence of grandmother cells fits with the idea that memory disorders could destroy the very cells holding someone’s representations of their grandmother, and so render them unable to remember or recognise her. Nevertheless, an engram is most commonly thought of as the physical manifestation of a memory – it is what is encoded, then lies dormant and retrieved at a later time.

2.2 Criticism of archival memory

In this section, I will detail several shifts away from the archival model of memory across memory research disciplines by drawing on work written by Jens Brockmeier. In his 2010 publication, Brockmeier describes how the archival model of memory that has been pervasive in “Western common sense, both in everyday life, and in science” from ancient through to recent times, is now being dismantled by new ideas and evidence from multiple areas of memory research.⁵⁰ Brockmeier uses the phrase ‘memory crisis’ to refer to these changes in thinking, which have been developing since the early 1990s. He then reviews some of these changes from different disciplines under the headings of: social and cultural, media and technology, literary and art, and biological and neurocognitive.

2.2.1 Social and Cultural

The first area Brockmeier describes is the social and cultural field of research, which include various studies of history and social sciences. Brockmeier describes how societies and nations

⁴⁸ From O’Loughlin, 2014: “A memory trace is the neural change that accompanies a mental experience at one time (time 1) whose retention, modified or otherwise, allows the individual later (at time 2) to have mental experiences of the kind that would not have been possible in the absence of the trace.”

⁴⁹ Gross, Charles G. "Genealogy of the ‘Grandmother Cell’ " *The Neuroscientist* 8, no. 5 (2002): 512-18.

⁵⁰ Brockmeier, J. "After the Archive: Remapping Memory." *Culture & Psychology* 16, no. 1 (2010): 5-35.

have several strategies to reshape the relationship between the past and the present. Typically, these groups will come to regard some events as ‘in the past’ and no longer important, while holding others as ‘still alive’ and relevant. These strategies are processes of collaboratively renegotiating inter-subjective meaning constructions of the past for particular purposes. This renegotiation of meanings is especially evident in large events that affect many people in the world – events sometimes referred to as ‘cultural memories’. However, the analysis can be extended to autobiographical memories and indeed any type of remembering.

Firstly, memories of an event are subjective. Different people will remember the same event in different ways because a single event can be experienced, perceived and interpreted in different ways. For example, first-hand experience of an event is very different to hearing about that same event from someone who experienced it first-hand, and different again from hearing about the event from someone who did not experience it first-hand. For example, the way I remembered the 2001 attacks on the World Trade Centre shortly after they occurred was very simplistic (i.e., as some strange but seemingly important thing that happened to some buildings on the other side of the world – which is an unsurprising account from a six-year-old New Zealander). Obviously people who experienced the attacks first hand will have a profoundly different memory from mine. Moreover, the subjective cultural context that an event fits into will greatly influence how we experience and thus remember it. A six-year old American who experienced the attacks in a similar fashion to how I did (through television screens, as opposed to first hand) would still remember the event differently to me because of the profound affect that this event had on American culture.

While there may be endless ways that an event may be experienced and interpreted, it does not follow that any interpretation could be correct. It may be that some interpretations are ‘more correct’ than others, and there are always certain interpretations that are obviously incorrect. To illustrate, imagine you are driving down the road and arrive at an area being re-worked. There is a road-worker holding a STOP/GO sign with the STOP side facing you. Your perspective of the road worker holding the STOP/GO sign is different to that of the people driving the opposite direction to you (and thankfully so). It is different again to that of pedestrians walking by, not taking much notice of the road-works. However, it would be incorrect to interpret this situation as the road-worker instructing you to drive through. A person could mistakenly take this view, but such an interpretation would either indicate a misperception of the event or a failure to understand what the STOP/GO sign means. This basic idea that there are correct and incorrect ways of remembering events is reflected in the fact that

we will often ‘test’ our memories against those of others.⁵¹ That said, the extent to which a correct or ‘true’ account of a given event is possible will depend on the nature of the event being described, and the meanings involved.⁵²

Memories of events are often changed by how and why we remember them each time we do. When you experience an event you will have an in-the-moment emotional response to it. Shortly after that event, your recollection of it will most likely evoke a similar emotional response. However, when you recall the same event sometime later, your emotional response may be somewhat different, or you may come to revise your initial feelings in the light of more recent experiences, and from then on remember it in a considerably different way. For example, imagine having an eccentric haircut in high school; at the time it may have seemed like a great idea but later you may come to regret it. This kind of emotional transition can also happen in reverse, or other subtler ways. Regardless, it seems evident that the *purpose* for remembering an event will have significant effects on the nature of that memory. To illustrate, imagine going on a fishing trip with your Grandfather for hours as an 8-year-old with a very short attention span and not catching any fish. When recounting your fishing experience to your parents, you may describe the experience as boring with the purpose of not having to go fishing again. However, many years later after your Grandfather has long passed away, you may come to regard this memory in a much fonder light as a way of remembering the care and precious time spent with your now deceased relative. This process of re-visiting, re-evaluating and re-shaping memories of an event incorporates more than just emotional states and purpose for remembering; it involves many features of the person remembering (including updated knowledge and experiences) and collaboration with the experience and thoughts of other people remembering the same event. To return again to the example of the September 11th attacks, as I have grown older my memory of these has significantly matured through discussing it many times with others and learning their thoughts on the matter, as well as having a better understanding of how events like this affect the world as a whole.

In summary, while the emerging social and cultural view of memory outlined here retains a critical notion of truth, it presents memories as much less stable than the archival model

⁵¹ For example, when people compare their remembered version of an event against other peoples’ accounts such as discussing the details of a lecture in a study group.

⁵² For further discussion of the multiple ways in which events can be described and interpreted see Gillett, Grant. *Subjectivity and Being Somebody: Human Identity and Neuroethics*. Exeter, UK: Imprint Academic, 2008. p36-38

suggests. The intersubjective and reconstructive view of memory, which has growing empirical support, is at odds with the archival model of encoding, storage and retrieval of stable traces or engrams. It also blurs the distinction of memory types, as memories of events synthesise episodic and semantic information together. It shows that memories are not fixed representations of particular experiences, or stable traces in a person's brain that lie dormant and unaffected for some time. Rather, memories are meaning constructions involving ongoing renegotiation of the past through various cultural processes.

2.2.2 Media, Technology and Art

The second area Brockmeier discusses is media and technology. Here, he reinforces the mutable and collaborative nature of memory by describing how memories are framed and structured by the ways that they are exchanged and presented e.g. through television, photographs, books, stories, artefacts, and so on. He also describes how the increasing daily reliance on digital media is leading to what he terms the 'digitalisation of memory'.

It is clear that the ability to remember an event (or any other piece of information) can often be improved by the use of media. For example, when recounting a holiday from many years ago you may be able to recall some basic details, but when you look through photos or journal entries from that holiday many more details and stories will appear to come 'rushing' back to you. This is not dissimilar to how one's ability to solve complex mathematical problems is enhanced through the use of tools like an abacus or calculator. While such 'tools' can serve to improve one's ability to remember, they can also alter or modify the ways that events are remembered. A truly tumultuous family Christmas where two of your aunts had a long drawn out argument may be reinterpreted as a wonderfully happy occasion if only pleasant photos are taken and are latterly made into a slide show with an up-beat sound-track. Indeed, when viewing this slide show many years later, perhaps no one will remember that the fight even happened. As Brockmeier puts it, "such digitalized mementos deeply affect people's later remembrance of things past. Over time they may turn into 'true' memories that gain more and more 'documented' authenticity."⁵³

The recent shift toward 'digitalization of memory' further reinforces the idea that memories are processes of collaborative negotiation of past events. Today, the contexts in which

⁵³ Brockmeier, *After the Archive*, p15

memories are being negotiated have become increasingly widespread through integration of online networks like social media websites. In these networks memories depicted in media are shared and mixed in with other peoples' memory 'documents', blurring the lines between personal and public realms of memory. Photos, videos and stories that 'document' an event are continually remixed and edited by many collaborators as they are reimagined or customised for particular purposes. These actions have become so commonplace in the practice of remembering that perhaps we should now regard memory as a 'mental-technical-cultural process.'

These reflections on the ways digital media are changing memory may be related to a broader and longstanding discussion within theories of literature and art about what constitutes a 'true' account of any feature of human life, and how different modalities influence our understanding. Brockmeier briefly explores this connection in a discussion of autobiographical memory and the role it has in forming someone's personal identity. He describes how this role has come into question in modern literature and art. Several authors and artists have raised questions about the reliability, and indeed existence of, memory as a storage of past events. Brockmeier notes that these ideas arose in literature and art long before they were discussed in psychological research on memory.⁵⁴

2.2.3 Biological and neurocognitive

Finally, Brockmeier sketches out the biological and neurocognitive evidence against the archival model of memory from scientific disciplines including molecular biology, neurology, psychiatry, psychology and clinical research. He notes that although there has been a paradigm shift away from an archival model in the disciplines of memory research already discussed, the realm of scientific research still clings to the traditional model, even in the face of new findings within these disciplines that contradict it. It seems that this recent evidence is not yet sufficient to disrupt the deeply ingrained assumptions about the functioning of memory. Nevertheless, the evidential case that has been established seems compelling.

To begin with, Brockmeier discusses how the neurological events that occur in perception, memory and imagination are physiologically indistinct:

⁵⁴ Brockmeier, *After the Archive*, p18

Now considering matters on a neurological level, we have learned that there is no evident distinction between brain processes operative in remembering and in perceiving. That is, there is no biological correlate that allows us to distinguish between what we traditionally call acts of remembering the past from acts of perceiving the present, whether in a visual, acoustical, or tactile mode. Nor are there any indicators that separate the content of a perception in the here and now from the content of a perception that we had at some point in the past. For the neuronal circuits involved there is no difference between perceiving, say, a face here and now and having perceived this face a few days or years ago... Other studies have shown that the same holds true for the distinction, unverifiable on neurological grounds, between a present perception or thought and an imagined future perception or thought.⁵⁵

What this means is that there is no discernible neurological difference between you imagining driving down a road currently being re-worked (as in the earlier illustration), and *remembering* a time when you experienced this. Similarly, if asked to *remember* the guests who were at a dinner party you attended recently, it is likely that you would *imagine* yourself back around that dinner table *perceiving* the other guests. These neurobiological facts about memory go some way in explaining many of the short-comings of the archival model. The notorious unreliability of memory and evidence of false memories make much more sense when we abandon the computational model of the archive in favour of looking at memory as a re-imagining of past events.⁵⁶

Brockmeier argues that if the differences between these neurological processes (remembering, perceiving and imagining) are not biological, then they must instead be discursive and contextual. That is, it must be the meanings that we attribute to each process that differentiates them.⁵⁷ A significant context for dividing these processes is temporal organisation. Memories are contextualised as in the past, whereas perceptions are contextualised as in the present and an imaginings are contextualised as possible futures. However, temporal context is not the only context available. Indeed, there are multitudes of cultural practices, unique to different societies, which give contextual relevance to things being remembered. These are often interwoven with everyday activities, mnemonic tools and social institutions like schools which significantly affect how and what information is remembered.

⁵⁵ Brockmeier, *After the Archive*, p20, 21

⁵⁶ The neurological equivalence of perceiving, imagining and remembering is also discussed by Damasio in *Descartes Error*, 1994. See especially pages 100-108.

⁵⁷ Brockmeier, *After the Archive*, p21-23

Regarding remembering as active neurological processes occurring in the present, akin to imagining and perceiving, fits with updated models of thinking about the brain, sometimes referred to as the ‘21st-century brain.’ This model is based upon neuroplasticity – continuous changes in the brain throughout life – in contrast to the ‘20th-century brain’ that was thought to be reasonably stable once adulthood was reached. Brockmeier describes how every act of remembering fuses elements from the past, present and imagination:

All new experiences, that is, new neuronal input, encounter neuronal networks that have already been shaped by previous encounters with the world. This pre-existing ‘neuronal knowledge’ powerfully influences the way new experiences are integrated, shaping the content, texture, and emotional quality of what we ‘recall’ of the moment.⁵⁸

This updated model of the ‘21st-century brain’ gives a biological basis for how our memories change over time and are affected by our purposes for remembering them (as described in section 2.2.1). Furthermore, it abandons any neurological basis for the archival model, disregarding the theory of ‘grandmother cells’ and also the purported process of encoding, storing and retrieving, as there is no neurological evidence for either. Brockmeier remarks that this new understanding of brain function is “the very opposite of anything resembling an archive” and goes on to describe it as:

a highly fluctuating excitation pattern formed by continuously changing connections of nerve cells, a fickle and unreplicable circuit that in manifold ways is interlaced with other circuits that are also in permanent flux. Nowhere and at no moment in time we can identify here a spot—that is, some molecular or cellular processes, or neuroanatomical substrate—where something could be stored, preserved, and kept over time.⁵⁹

Understanding the process of remembering as a novel cognitive process, involving the reconstruction of a past event in the present moment and attribution of culture-specific meanings, that results in new changes within a constantly changing brain structure, provides a biological explanation for the mutability of memory described in the previous sub-sections. As such, every act of remembering an event will modify the memories of that event by mixing together current perceptions and new meanings with previous constructions of that event.

⁵⁸ Brockmeier, *After the Archive*, p24

⁵⁹ Brockmeier, *After the Archive*, p24

2.3 Conclusion

In this chapter I have summarised the work of Jens Brockmeier and Ian O’Loughlin in describing how the longstanding ‘archival’ model of memory is being dismantled in the contemporary study of memory. I have indicated why memory should instead be understood as a complex process of reconstructing mental connections to re-perceive an event. This process can involve mental, technical and cultural practices which help form and also alter those connections. Under this model, remembering is an active and learned technique that improves as it is practiced – more connections are made and you get better at making them. Likewise, a person’s proficiency for remembering can also be diminished through age or pathology if, for example, fewer new connections are made or fewer environmental prompts surround you. This model frames memory as something *we do*, i.e. as an agentive exercise. This helps to explain how different parties can remember the same event differently, how a person can remember the same event very differently at different times, and how people are better at remembering the things that are important to them. These features of memory will become important in the discussions of the various theories of identity in a dementia context, which will be discussed in Chapter Four. To provide context to this discussion, in the next chapter, I will provide some descriptive details of dementia.

Chapter Three – Dementia

Dementia is a syndrome of many different brain diseases that involve a progressive decline in cognitive functioning. Like ‘identity’, it is a term used to refer to several distinct but related things. Although dementia predominantly affects older people (over the age of 65), it is not a normal process of aging and in rarer cases, it can affect younger people. In the previous chapter I described the archival model of memory and how this is being challenged in contemporary memory studies. I sketched the case for viewing *remembering* as an inter-subjective process that involves the unstable ‘reimagining’ of the past. However, much of our understanding of dementia is built upon an archival model of memory and is indeed supportive of it. For example, the finding that people with dementia (or other brain diseases) are better able to remember certain types of information than other types is taken as evidence for the existence of different ‘memory systems’ in the brain. As a result, descriptions of dementia will often use language from archival models. I will return to the relationship between memory, dementia and identity in the following chapter where I will revisit the theories of identity described in Chapter One and the cases described in the introduction. However, before reengaging with those problems it is necessary to have a working understanding of the common types of dementia, its societal and personal impact, and the standard clinical management. In this chapter, I will briefly detail some descriptive epidemiological data for dementia in New Zealand and worldwide, provide an overview of a typical clinical course of dementia, and then describe the most common dementia subtypes.

3.1 Epidemiology of dementia

Dementia prevalence and the associated economic burden are high and rising, both in New Zealand and around the world. According to reports from the WHO, it is estimated that in 2010 there were 35.6 million people living with dementia worldwide and the total global societal costs of dementia were \$604 billion USD.⁶⁰ This corresponds to 1.0% of the worldwide GDP. In 2012, Alzheimer’s New Zealand published the *Economic Impact of Dementia in New Zealand Executive Summary* which estimated prevalence statistics as well as the financial

⁶⁰ Alzheimer's Disease International, and World Health Organisation. *Dementia: A Public Health Priority*. Geneva, 2012.

burden of dementia in New Zealand.⁶¹ This summary reported that in 2011, there were an estimated 48,182 New Zealanders living with dementia (1.1% of the total population), an 18% increase from 2008 (40,746 in 2008).⁶² It also reported a projected increase to 147,359 people by 2050 (to over 2.6% of the population). The total financial cost of dementia in 2011 in New Zealand was estimated as \$954.8 million, the highest contributing factor being the cost of residential aged care facilities.

These large increases in projected prevalence and economic burden, in New Zealand and worldwide, are largely due to the aging demographic of populations in developed countries, but may also be partly due to inefficiencies in management. Prevalence rates are higher in females (60%) compared to males (40%), primarily because females tend to live longer than males. Dementia is also a difficult disease to measure in populations for multiple reasons due to its insidious onset and the limited accuracy of diagnostic tools.

3.2 Clinical course of dementia

All forms of dementia emerge as a result of pathological changes in the brain and present with changes in cognitive function. Cognitive capacities that can be affected include: memory, attention, orientation, comprehension, calculation, language, judgement, etc., with memory deficits being present in most cases. Though there are multiple different pathologies that contribute to these changes, most dementia subtypes are progressive and incurable⁶³. While symptoms may be transient and variable from hour to hour and day to day, the overall trend of symptoms is one of declining cognitive function. The progressive nature of symptomology is commonly divided into early, middle and late stages (detailed below), but more complex

⁶¹ Alzheimer's New Zealand. Updated Dementia Economic Impact Report. Report. January 2012. http://www.alzheimers.org.nz/getmedia/557692aa-2ccd-4f38-8fdc-db440706fd05/Updated_Dementia_Economic_Impact_Report_2012_New_Zealand.pdf.aspx.

⁶² Note that there was no descriptive epidemiological data for dementia in the New Zealand population that could be identified by this study and so the estimates are based upon worldwide systematic reviews and then applied to New Zealand populations. It would certainly be beneficial to have descriptive epidemiological studies of dementia in New Zealand.

⁶³ All of the dementia subtypes described in this thesis are currently incurable and irreversible, however there are some conditions that are referred to as 'reversible dementias'. Many of these conditions present with behavioural or cognitive symptoms similar to other dementias, but may not fulfil sufficient criteria for dementia. These include: depression, adverse effects of drugs, drug or alcohol abuse, space-occupying lesions, normal pressure hydrocephalus, hypothyroidism and B-12 deficiency. Further reading: Tripathi, Manjari, and Deepti Vibha. "Reversible Dementias." *Indian Journal of Psychiatry*, 52-55, 51.Suppl1 (January 2009); Philpot, Michael. "Reversible Dementias." *Principles and Practice of Geriatric Psychiatry*, 2010, 383-88.

divisions for clinical assessment and management also exist, such as the Global Deterioration Scale (GDS).⁶⁴

- Early: There is significant cognitive impairment that cannot be explained by normal aging processes. The most common symptom is memory difficulties surrounding recent events. Independence is mostly unhindered.
- Middle: Cognitive capacities decline to the point of hindering independence by impairing individuals' ability to complete their activities of daily life (ADLs).
- Late: Individuals become nearly completely dependent upon caregivers, unable to feed themselves independently and lose most of their ability to communicate.

In drawing an outline of the typical clinical course of dementia, it is necessary to keep in mind that dementia can be caused by a range of pathologies and so the clinical presentation and experience of those affected can differ greatly. Furthermore, the experience of dementia is highly intersubjective and dependent upon a myriad of psychosocial factors unique to each individual. That said, a typical case could take the following course: an elderly person presents to their primary care physician because they have noticed some 'early warning signs of dementia.' According to Alzheimer's New Zealand, these symptoms could include difficulty in recalling recent events, difficulty performing regular tasks, language difficulties, disorientation to time and place, poor judgement, difficulty with abstract thinking, misplacing things, changes in mood or behaviour, changes in personality and loss of initiative.⁶⁵ If symptoms are mild, it is likely that they would receive a diagnosis of mild cognitive impairment (MCI). MCI is where cognitive impairment is beyond what is expected from age and level of education, but does not significantly interfere with activities of daily life. This often functions as a pre-diagnosis syndrome for different dementia types, similar to the way prolonged adult hyperglycaemia, sometimes called pre-diabetes, often goes on to a diagnosis of diabetes type II.

From this initial presentation, it is likely that the patient would undergo several investigations with their primary care physician, aiming to identify the cause of their cognitive impairment. This would involve identifying a dementia type as well as ruling out other diseases of old age that can present with a cognitive component. If the case is complicated or symptoms more severe, the primary care physician may refer on to a psychiatrist of old age or memory clinic

⁶⁴ Reisberg B, Ferris SH, de Leon MJ, Crook T. "The Global Deterioration Scale for Assessment of Primary Degenerative Dementia." *American Journal of Psychiatry* 139, no. 9 (1982): 1136-139.

⁶⁵ Alzheimer's New Zealand. "Alzheimers The 10 Warning Signs." Accessed October 20, 2016. <http://www.alzheimers.org.nz/about-dementia/the-10-warning-signs>.

for more thorough investigations, as well as a needs assessment so that available supports could be put in place. Investigations carried out by clinicians could include:

- Thorough medical history including: investigation of the current cognitive symptoms, details of previous medical conditions, family history of dementia and corroborative history from family members
- Cognitive assessment: use of one of many tests designed to assess cognitive functions e.g. the Montreal Cognitive Assessment (MOCA) which assesses memory, visuospatial abilities, attention, concentration, language and orientation⁶⁶
- Clinical neurological examination: physical tests within the clinic which can identify any particular brain lesions – includes assessment of motor and sensory functions
- Medical neuroimaging: likely an MRI or CT scan to assist in subtyping and rule-out reversible conditions
- ADL assessment: investigating the person's capacity to independently perform their daily activities – serves as a needs assessment for any care supports
- Routine blood tests to rule out treatable diseases which may be presenting with a cognitive component. Stroke and infections can often cause cognitive impairment in elderly and this can be misdiagnosed as early dementia symptoms
- Psychological screening and mood assessment to assess the need for any mental health intervention. For example, depression can cause cognitive impairment.

Following investigation, patients will schedule on-going appointments with clinicians to assess the progression of their dementia and receive treatments corresponding with their particular type of dementia. This should include a psychosocial component. Psychosocial supports will vary widely based on the services available and the patient's particular needs, ranging from dementia support groups that share coping strategies for altered cognition, to in-depth counselling for the unique challenges that arise from dementia. Patients and their families will generally require more support as their dementia progresses as they will have increasing difficulty independently carrying out their ADLs. This need will often be met by close friends and family members taking up a greater caring role, by the implementation of home help services, and eventually by moving the patient into full-time residential care. Clinicians will counsel people with dementia through these changes and continuously assess if their current needs are being met. Clinicians will often be consulted for capacity assessments linked to specific complex and important life decisions about issues of finance, living situation and end of life care.

⁶⁶ A copy of the Montreal Cognitive Assessment (MOCA) can be found here: http://dementia.ie/images/uploads/site-images/MoCA-Test-English_7_1.pdf

As the vast majority of dementias are currently incurable, current treatments mostly aim to improve management of symptoms, rather than treating underlying pathologies. As such, dementia is a terminal illness and the mortality rate in advanced dementia is very high.⁶⁷ In spite of this, dementia is often not regarded as a terminal illness, and people living with dementia often receive burdensome non-palliative interventions such as tube feeding, laboratory tests, restraints and IV therapy.⁶⁸ Recent research efforts have aimed to redirect focus in advanced dementia towards palliative care.⁶⁹

3.3 Dementia subtypes

Multiple different brain pathologies can result in the cognitive symptoms present in dementia. These different pathologies give rise to different ‘dementia subtypes’, which present with different symptoms and require different treatments. Alzheimer’s Disease is the most common pathology, present in 50-70% of cases of dementia. Other significant contributors include: Vascular Dementia, Lewy Body Dementia and Frontotemporal Dementia.⁷⁰ Boundaries between these pathologies are often blurred and multiple pathologies often co-exist in the brains of people with dementia. In the following subsections, I will discuss current theories of pathophysiology, any unique symptomologies, the processes of diagnosis, and current management strategies for each of these major subtypes.

3.3.1 Alzheimer’s disease (AD)

Alzheimer’s disease is the most common type of dementia. The exact cause of the disease is poorly understood but several compelling theories exist based on pathological changes observed in the brain tissue of deceased patients with an AD diagnosis. Currently, the most widely accepted theory involves the gradual loss of function and death of neurons due to two pathological processes: extracellular build-up of β -amyloid protein forming senile plaques, and

⁶⁷ Mitchell, Susan L., Joan M. Teno, Dan K. Kiely, Michele L. Shaffer, Richard N. Jones, Holly G. Prigerson, Ladislav Volicer, Jane L. Givens, and Mary Beth Hamel. "The Clinical Course of Advanced Dementia." *New England Journal of Medicine* 361, no. 16 (2009): 1529-538.

⁶⁸ Mitchell, Susan L., Dan K. Kiely, and Mary Beth Hamel. "Dying With Advanced Dementia in the Nursing Home." *Archives of Internal Medicine* 164, no. 3 (2004): 321.

⁶⁹ Mitchell, Susan L., Betty S. Black, Mary Ersek, Laura C. Hanson, Susan C. Miller, Greg A. Sachs, Joan M. Teno, and R. Sean Morrison. "Advanced Dementia: State of the Art and Priorities for the Next Decade." *Annals of Internal Medicine* 156, no. 1_Part_1 (2012): 45.

⁷⁰ There are other neurological disorders that can be categorised as dementia, such as prion disease, encephalopathy and the reversible types mentioned in footnote 4, that are not discussed here. These types are less appropriate for the ethical discussion in following chapters, due to their rapid progression or reversibility which distinguish them from other types of dementia.

intracellular accumulation of tau proteins forming neurofibrillary tangles (findings only identifiable in post-mortem histology).⁷¹ According to the “amyloid hypothesis”, some causative process results in an imbalance between production and clearance of β -amyloid fragments, which are formed by the breakdown of a neuronal transmembrane protein (amyloid precursor protein – APP) causing a build-up of toxic oligomers and insoluble fibrils of these fragments to form. These fragments accumulate outside neurons as insoluble plaques or as toxic oligomers which block neuron-neuron synapses and eventually lead to the death of neurons. The “tau hypothesis” involves the formation of intracellular neurofibrillary tangles due to the hyper-phosphorylation of tau proteins. Tau is normally an abundant, soluble protein involved in assembly and stability of the intracellular microtubule framework within neurons. When tau becomes hyperphosphorylated, it becomes insoluble and cytotoxic, disrupting the neuron’s intracellular transport system, displacing organelles and eventually resulting in cell death. These microscopically evident changes result in macroscopic brain atrophy. This pathology seems to firstly affect the neurons in the entorhinal cortex and hippocampus, primarily active in memory processing, and latterly spread to other areas of the cerebral cortex including the temporal and parietal lobes, as well as parts of the frontal cortex and cingulate gyrus.

The most common early symptom is a noticeable memory deficit in recalling recent events. As the disease develops, memory problems become more pronounced and other cognitive capacities can be affected including: perception, execution of movements and language difficulties. It appears that not all memory systems are equally affected: in the early stage of AD, episodic memory of events from the distant past, semantic memory and procedural memory appear to be mostly spared when compared to recall of recent events. However, as the disease progresses through to the moderate stage, other memory systems can also become impaired. At this stage, unexpected behaviours can begin to manifest, e.g. wandering, unprompted agitation/aggression/crying, increased confusion, etc. People with late stage AD become completely dependent upon caregivers in order to carry out their ADLs and their language capabilities are often reduced to a few simple phrases or are sometimes completely absent.

⁷¹ Querfurth, Henry W., and Frank M. Laferla. "Alzheimer's Disease." *New England Journal of Medicine* 362, no. 4 (2010): 329-44.

Diagnosis of AD is based upon medical history and exclusion of other causes. A definitive diagnosis can only be made from post-mortem histology. Medical imaging can be supportive of this diagnosis as brain atrophy can be observed, however it is not sufficient for diagnosis as the extent of atrophy is highly variable in different cases and it is also unlikely that patients have historical scans for comparison.

Pharmacological treatment for AD is of limited benefit and management has a strong psychosocial emphasis. Most medications for AD are acetylcholinesterase inhibitors e.g. donepezil, which prevent the degradation of acetylcholine (ACh), the most common central nervous system neurotransmitter. ACh has the effect of increasing the concentration and duration of action of the neurotransmitter within synapses. This causes some improvement in cognition and behaviour, however, it does not slow the progression of the disease as it only treats the symptoms and does not affect the underlying pathology.

3.3.2 Vascular dementia (VaD)

Vascular dementia, also known as multiple infarct dementia, is the second most common cause of dementia, contributing to between 20% and 50% of cases. VaD often co-occurs with Alzheimer's disease.⁷² It involves progressive decline in cognitive function due to a series of cerebrovascular events, i.e. multiple minor strokes causing hypoxic damage to brain tissue. Symptomology is similar to AD (involving memory impairment sufficient to interfere with daily life) but may also have specific neurological signs dependent upon the particular location of the vascular damage, i.e. patients may have specific motor or sensory deficits corresponding to certain areas of brain damage. Progressive decline occurs due to multiple small injuries, while abrupt decline can be caused by a specific severe injury. Diagnosis requires a temporal relationship between cerebrovascular injury (which can be identified through medical imaging) and cognitive deficits. Like in AD, treatment is largely psychosocial with modest alleviation of symptoms from acetylcholinesterase inhibitors but should include medications that reduce stroke risk such as anticoagulants, antihypertensives, antiarrhythmics, and antihyperlipidemics.

3.3.3 Dementia with Lewy Bodies (DLB)

Dementia with Lewy Bodies contributes to 10-15% of dementias and is defined by the presence of Lewy bodies (a post-mortem histological feature seen in affected neurons) and often

⁷² Karantzoulis, Stella, and James E. Galvin. "Distinguishing Alzheimer's Disease from Other Major Forms of Dementia." *Expert Review of Neurotherapeutics* 11, no. 11 (2011): 1579-591.

characterised by fluctuating cognition, motor symptoms of Parkinson's disease and recurrent visual hallucinations.⁷³ Lewy bodies are collections of alpha-synuclein and ubiquitin proteins that aggregate within the cytoplasm of neurons. In DLB, Lewy bodies develop in both cholinergic cortical neurons and dopaminergic neurons of the substantia nigra (within the brainstem). This results in Parkinson's-like motor deficits in addition to the cognitive deficits present with other dementias.⁷⁴ Like vascular dementia, DLB can co-occur with AD where both histological findings will be present on autopsy. Because the symptoms of DLB overlap with both AD and Parkinson's disease it is often misdiagnosed as one or the other. However, while AD has a slow insidious onset, DLB often has a rapid and acute onset within the first few months, and as just mentioned, includes the development of motor deficits. Motor symptoms are managed by the same medications used to treat Parkinson's (levodopa), while cognitive symptoms are sometimes improved by medications for Alzheimer's (donepezil) which act to increase the synaptic concentration of deficient neurotransmitters. Like in Parkinson's disease, DLB makes patients hypersensitive to antipsychotic medications which suppress the dopamine pathway, such as haloperidol and can result in "neuroleptic malignant syndrome," a life-threatening disorder characterised by muscle rigidity, fever, and autonomic instability.

3.3.4 Frontotemporal dementia (FTD)

FTD is the most common clinical presentation of frontotemporal lobar degeneration (FTLD), which comprises a range of pathological processes involving loss of neurons in the frontal and temporal lobes of the cerebral cortex. FTD has an earlier onset than other types of dementia, affecting people most commonly between the ages of 55 and 65, where other forms of dementia are most common in those older than 65. There are several variants of FTLD, which correspond with different versions of FTD, the most common being behavioural variant FTD (bvFTD) as it involves significant changes in behaviour. These behavioural symptoms could include: disinhibition, apathy, loss of empathy, compulsive behaviours, hyperorality, perseveration, aggression and inappropriate sexual behaviours. All these symptoms have dramatic

⁷³ Including shuffling gait, reduce facial expression, stiff movement, tremor, difficulty swallowing.

⁷⁴ Parkinson's disease is considered a 'motor disorder' where the dopaminergic neurons of the substantia nigra are affected by the same pathology described for DLB. These neurons are involved in the initiation and termination of motor pathways. In DLB, both substantia nigra and cortical neurons are affected. DLB is sometimes categorised as a 'Parkinson's plus syndrome' which include neurodegenerative diseases with classical Parkinson's motor deficits as well as disorders of some other system; in this case, cognition.

consequences for social functioning. There are also less common clinical presentations for FTLD, including speech difficulties without significant changes to behaviour. These are described as progressive non-fluent aphasia (PNFA), involving difficulty in speech production, and semantic dementia (SD), involving loss of word meaning, impaired naming and comprehension. The clinical presentation is related to the distribution of pathology in the frontal and temporal lobes and as the disease progresses, these symptomologies may overlap. While the symptoms of FTD include significant behaviour changes and language impairments, other cognitive functions that are commonly affected by other dementia types remain unaffected, such as memory, perception, spatial awareness and motor function.

A range of different pathologies contribute to FTLD. 40% of FTLD cases involve a pathology of tau proteins and are classified as FTLD-tau pathologies. As explained earlier, Tau is a protein associated with microtubule stabilisation, and several mutations can lead to the build-up of toxic tau aggregates that inhibit neuronal function.⁷⁵ The majority of tau-negative cases involve pathological post-translational modifications of TAR DNA-binding protein (TDP-43). This protein is involved in multiple DNA and RNA processes within neurons and becomes non-functional when hyper-phosphorylated, ubiquitinated and cleaved. Mutations in the gene that codes for this protein are present not only in cases of FTLD, but also cases of amyotrophic lateral sclerosis (ALS). Most cases of FTLD which are negative for both tau and TDP-43 have been identified as having FUS pathology (FTLD-FUS). FUS is similar to TDP-43, as it is a DNA and RNA binding protein and is also pathological in some cases of ALS. A minority of cases do not fit into any of the above classifications and these are termed FTLD with no inclusions (FTLD-ni). However, as diagnostic techniques develop, these cases are becoming re-classified.⁷⁶

Progression of FTD is gradual and insidious, making diagnosis difficult, but this is usually done by taking into account a full history as well as being supported by medical imaging and neuropsychological testing. Management focuses on supporting the patient, their family and

⁷⁵ Genes identified as causing mutation in this protein include microtubule-associated protein tau (MAPT), progranulin (GRN), and charged multivesicular body protein 2B (CHMP2B) genes. Tau bodies are sometimes referred to as Pick bodies found in Pick's disease, a specific type of FTD.

⁷⁶ Data throughout this paragraph drew upon: Urwin, Hazel, Keith A. Josephs, Jonathan D. Rohrer, et. al. "FUS Pathology Defines the Majority of Tau- and TDP-43-negative Frontotemporal Lobar Degeneration." *Acta Neuropathologica* 120, no. 1 (2010): 33-41 and Mackenzie, Ian R. A., Manuela Neumann, Eileen H. Bigio, et al. "Nomenclature and Nosology for Neuropathologic Subtypes of Frontotemporal Lobar Degeneration: An Update." *Acta Neuropathologica* 119, no. 1 (2009): 1-4.

caregivers to adjust to the behavioural changes but can include some pharmacological treatments, such as SSRIs, which may be helpful in alleviating some behavioural symptoms.⁷⁷

3.4 Conclusion

In this chapter I have outlined a typical clinical course of dementia and described different types of dementia. Each of these types has some unique pathophysiology, symptomology and management, although, it appears that there is a clear distinction between the experience of people with FTD and those with non-FTD types. Nonetheless, all types of dementia profoundly affect peoples' lives by the progressive impairment of cognition in correlation with pathological processes in the brain. This direct cognitive impairment, however, is only one cause of suffering in dementia; there are many other indirect effects of dementia that can be similarly profound. These include how people with dementia uniquely respond to their adjusted set of cognitive skills and also how other people respond to them now that they have dementia. Dementia is a complex disease that affects *persons*, rather than just brains. In the next chapter I will discuss these indirect effects in more detail, and relate them and the other effects of dementias described here to the theories of identity discussed in Chapter One. As I do this, I will indicate how the different theoretical approaches might inform our responses to the kinds of ethical problems described at the beginning of this thesis.

⁷⁷ Cardarelli, Roberto, Andrew Kertesz, and Janice A. Knebl. "Frontotemporal Dementia: A Review for Primary Care Physicians." *Am Fam Physician*, 2010 Dec 1;82(11):1372-7.

Chapter 4 – Dementia, Memory and Identity

This thesis aims to develop an account of how identity is affected by the changes that come with various forms of dementia, and to use this account to outline a response to some of the identity-related ethical problems that arise in caring for people with dementia. In the previous three chapters I have discussed the topics of identity, memory and dementia individually. In this chapter I will bring these topics together in an integrated response to the ethical problems I described in the introduction to this thesis. In this response, I will argue for a shift away from object-based theories, in favour of agency-based theories.

Before going further, it is worth reviewing the key ethical problems relating to dementia and identity. Problems of identity in dementia can arise in various ways. In one set of cases, there is uncertainty about what it means to respect a person's autonomy. These problems become clinically salient when considering the practical implications of past and present decisions about treatment. The 'Margo' case presented by Dworkin⁷⁸, in which it is unclear whether or not an advanced directive refusing treatment should be applied, is an example of this kind of problem. Underlying this question is uncertainty about what makes Margo who she is and what it means for her to make an autonomous (i.e. 'self' determined) decision. In this chapter I will discuss the limitations of an object-based account and the advantages of an agency-based account of identity. In brief, object theories focus too much on the direct, non-modifiable, neuropathological effects of dementia and ignore the indirect, modifiable, psychosocial factors of dementia. They also do not fit with the process model of memory. Although an agency approach does not eliminate all the difficulties associated with dementia, it allows us to take proper account of the complex array of direct and indirect effects dementia can have on a person's identity and as a result offers more optimistic conclusions regarding the persistence of personal identity through dementia.

A more radical kind of problem is the suggestion that a person's identity can be significantly *changed* by dementia. Family members might express this concern when they describe the person with dementia as 'no longer themselves'. This problem typically arises when people with more advanced dementia, or frontotemporal dementia (FTD), behave in grossly uncharacteristic ways. An illustrative case is Mr D⁷⁹. I will again argue that these problems are

⁷⁸ Dworkin, *Life's Dominion*. Also described in the introduction to this thesis, p2

⁷⁹ Hope, *Personal Identity and Psychiatric Illness*. Also in the introduction to this thesis, p4

poorly explained by object theories, especially Locke's memory theory, and that an agency approach is much more suitable. In non-FTD dementia types, such changes can often be explained by an in depth appraisal and understanding of the person's unique situation and difficulties associated with their dementia, meaning that they do not reflect a radical change in personal identity. However, it must be acknowledged that there are cases (particularly with people with FTD) where it is difficult to explain the behavioural changes in this way as they seem to be directly caused by the dementia pathology. Nevertheless, while these cases *do* present a substantial threat to personal identity, I will argue that we should understand them not as indicating a radical *change* in identity, but rather that the person's capacity as an agent has been significantly impaired, and as such they are less able to hold themselves together as themselves.

The possibility of a person's identity being impaired, such that they cannot act 'as themselves', links to a third kind of problem concerning the relationship between identity and dementia: the question of whether personhood can be lost altogether. This problem generally relates to later-stage dementia. Though this problem is not the central focus of this thesis, the concepts of personhood and personal identity are intertwined, and so what is said about one necessarily affects what is said about the other. I will briefly address personhood directly in section 4.4 after discussing personal identity. I will argue that this problem likely arises due to accounts of personhood that favour 'personhood tests', and suggest that we may better engage with people in late stage dementia if we instead adopt an agency-based, socially constructivist account of personhood.

4.1 Direct and indirect effects

Apparent changes in identity for a person with dementia can be attributed to a complex blend of factors. Throughout this chapter, I will refer to non-modifiable, neuropathological effects that dementia has on personal identity as 'direct effects', and the modifiable, psychosocial effects as 'indirect effects'. Though this distinction does blur at certain points, it is useful in helping us to delineate two kinds of causes generating apparent changes in identity. In general, indirect effects tend to involve complex changes in the social and physical environment of the person with dementia, independent of their cognitive impairment, while direct effects can be causally linked to the person's dementia pathology.⁸⁰ To illustrate, imagine a person becomes

⁸⁰ The distinction I am making here is similar to the difference between 'medical' and 'social' models of disability.

incontinent as a result of their dementia pathology. Their incontinence is an example of what I am calling a direct effect. It is non-modifiable and causally linked to their brain pathology. However, the way that others respond to that person's incontinence, and the changes that these responses bring, would be examples of what I am calling indirect effects. For instance, if the person with dementia is scorned and demeaned for their incontinence, this would likely increase their social anxiety and negatively affect their sense of self-worth. Alternatively, if those around them take on a supportive and caring stance, and regard the incontinence as a small challenge to overcome, the person's anxiety may be reduced and their sense of self-worth maintained. While we have little control over direct effects, we can modulate them indirectly through our responses. This explains the huge variation in the subjective experiences of dementia and also how different families of people with cognitive impairment can interpret similar situations differently. Maria Medved highlights this point in her chapter in *Beyond Loss*, when she describes how families of people with neurodegeneration and neurotrauma can help to support or deconstruct that person's identity through the "co-narration" of events in their lives.⁸¹ She compares two interview cases of families where one of the family's members is affected by either dementia or a traumatic brain injury. The interview focused on a particular event: a time where the family member affected by dementia/TBI went to a shopping mall alone, got lost and then returned home several hours later. This event was negotiated as a positive sign of recovery or as a negative symptom of the illness by different members of both families. Medved argues that the way a family narrates these everyday events bears much more significance on the affected person's identity than any cognitive impairments caused by their disease.

4.2 Arguments against an object approach

Many traditional explanations of the persistence of personal identity rely on the persistence of a particular object. In this section, I will revisit three examples of this kind of approach – theories of bodily continuity, psychological continuity and Locke's memory theory – and outline how they relate to the ideas discussed in chapters two and three.

4.2.1 Bodily continuity

⁴ Lindeman et al., *Beyond Loss*, Chapter Six: Everyday Dramas.

The first theory I described in Chapter One is ‘bodily continuity theory’. In this theory persistence of a person’s identity is understood through the persistence of that person’s body. As discussed in Chapter One, a key problem with this theory is that it seems evident that personal identity persists through significant growth and modification of our bodies. It is obvious that changes in the body occur through growth and repair, and through the aging process. Simply identifying the person with the body says nothing about what changes in the body might substantially affect identity. If we are to meaningfully understand identity in bodily terms, it is necessary to specify in which part(s) of the body identity is constituted, and what form these need to have in order for the person to be the person they are. In regard to dementia, it should be noted that memory is not significantly implicated in this model, unless it is understood in strictly physical terms. This is in fact exactly what neuroscientific forms of the archival memory model describe: a purported existence of ‘memory traces’ stored in the brain which are vulnerable to the deletion due to the pathological damage in dementia. There is an obvious parallel here with the Lockean memory theory of personal identity, which I will discuss shortly.

If we apply the bodily continuity theory to the kinds of ethical problems that have been described, all apparent losses or changes in personal identity must be attributed to physical changes in the body. From this position, one might reject the idea that personal identity can be affected by dementia in any significant way, as the body of the person is largely unaffected (the person’s body is at least still recognisably the same). Of course, this again raises the question of which part of the body is most important in determining identity. Consequently, this simple answer reveals nothing about how difficult cases like those described should be resolved. It says nothing, for instance, about how we should decide whether or not Margo’s advance directive should be applied.

Despite these limitations, it must be acknowledged that the apparent changes in identity associated with brain disease provide some evidence that identity is in some way associated with the brain. As first glance, this may point to a simple and bleak solution to the problems. If the personality disturbances are solely caused by dementia pathology and we have no curative treatments, then we have no control over the personality changes and there is nothing

we can do to stop it.⁸² However, given the ways that the effects of dementia are psychologically and environmentally modifiable (as discussed in Chapter Three), it seems evident that this view is at best incomplete. Attributing the identity problems entirely to the pathological changes in the brain disregards any ways that identity can be indirectly affected in dementia. While direct effects undoubtedly play a significant part in the emergence of the identity problems, attending to psychosocial factors involved in dementia either intensify or alleviate the suffering of people with dementia and this cannot be explained solely in terms of brain pathology. In the words of Thomas Kitwood, "it is inept to consider 'the problem' of dementia as lying exclusively within the individual who carries the neurological impairment,"⁸³ and this approach does just that. A theory of identity suitable for people with dementia must be able to account for both the direct effects caused by the pathological process of dementia and the indirect effects caused by changes in the interactive social environment surrounding the person with dementia that are not directly related to their cognitive impairment.

4.2.2 Psychological continuity

Psychological continuity theories of identity come in various forms. The classic dualist account locates identity in the continuity of some notion of mental substance, ontologically distinct from bodily substance. As argued in Chapter One, the radical separation of mind and body seems unsustainable as it runs almost completely contrary to modern cognitive neuroscience. Moreover, as just noted, the effects of dementia evidently reveal an important connection between identity and the brain. This connection would be difficult to explain if our personal identities were wholly dependent upon some non-physical substance of the mind. From this standpoint, we would be required either to suppose the changes to be caused by some non-physical pathologies that affect the person's mind, or attribute them entirely to the indirect effects of dementia that the bodily continuity theory ignores. It seems much more plausible to conclude that psychological processes are in some respect dependent on physical processes, and that a combination of direct and indirect effects is responsible for dementia symptoms. Hence, to explain these symptoms and the ethical problems they generate we require a theory of identity that can incorporate both.

⁸² Some could argue that this may be a positive conclusion in some circumstances e.g. if someone's behaviour changed to become very distasteful, they can chalk it up simply to the dementia and not worry that this is what the person was *really like* under a polite visage.

⁸³ Kitwood, T. M. *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press, 1997.

However, not all psychological continuity theories involve a dualistic ontology. One might hold that mental objects operate through physical processes, and yet still hold that identity is constituted in the persistent set of such mental objects. The key point would be that these identity-constituting objects are only recognisable as such when described in their mental aspect (i.e. as they are to the subject). John Locke's memory theory of identity is an example of this kind of approach.

4.2.3 Locke's memory theory

Locke's memory theory of identity is one of the most prevalent versions of psychological continuity. It holds that the persistence of personal identity relies on the person retaining certain autobiographical memories (a person's ability to "extend their consciousness" back to their past actions), but seeks to bypass the ontological issues related to substance dualism by placing focus on memories as a phenomenological fact of conscience experience, independent of specific substance. The conception of memory traditionally deployed in this theory is archival. Indeed, despite the problems that I will describe shortly, the combination of an archival model of memory with Locke's theory of identity has endured for some time, and at a surface level seems compelling. Dementia is often referred to as a 'memory disorder' and our definitions of common dementias are intertwined with our understanding of memory. In Chapter Three, I noted that many descriptions of memory disorders including dementia use archival language, being described as problems with either encoding, storing or retrieving memories. Accordingly, dementia is popularly imagined as a disease that 'deletes' or destroys stored memories. This commonplace language is essentially archival, imagining dementia as damaging the very neurons where memories are stored. If Locke's memory theory of personal identity is combined with an archival model of memory, it seems obvious that dementia can damage someone's personal identity. In other words, if someone's personal identity depends upon the persistence of archival memories and these memories are destroyed by a pathological process, then it seems reasonable that their personal identity is also destroyed. The widespread acceptance of these theories is perhaps why the ethical problems associated with dementia are so pervasive. However, this view becomes much less credible when we consider the significant parts of a person's identity that are not captured by memory and the flaws inherent in archival model of memory.

Although Locke's theory attempts to bypass the metaphysical problems that accompany dualism, it still presents identity as reliant on the persistence of certain 'psychological' objects, *viz.* 'memories'. Thus, it ultimately suffers from the same problems as the other object theories,

in being unable to account for any aspect of identity that does not inhere in the relevant object. As bodily continuity ignores mental aspects of identity and psychological continuity ignores physical aspects, memory theory fails to capture important aspects of our lives that we have no memory of. As discussed in Chapter One, this would include our early infancy and when we are asleep. It also fails to explain why important aspects of our identities concern intersubjective relationships, including social roles and pre-determined dispositions/traits. Moreover, it dissociates us from any actions that we forget, which is an indefensible position when considering any reasonable account of obligation or accountability. Applied to the ethical problems associated with dementia, Locke's theory limits the scope of the personal identity problems to within an individual's memory deficits. Furthermore, it does not address the second kind of personal identity problem, in which changes in identity are associated with uncharacteristic behaviour. Frontotemporal dementia profoundly affects behaviour and mostly spares memory, and so arguments about memory are irrelevant in explaining how identity is affected in these cases.

The problems just described are in direct response to Locke's claim that identity consists in memories. If we abandon the archival model of memory, as discussed in Chapter Two, then further problems come to light. In the emerging understanding of memory, the purported objects that Locke's theory bases identity on (memories) are not in fact objects (or even 'traces') stored in the mind or the brain. Rather, remembering is a process of re-imagining past events in collaboration with others which is neurologically similar to perception or imagination. By contrast, when we relate this new process model of memory to the experiences of those with dementia, we find a remarkable fit. As described in Chapter Three, the cognitive impairment caused by dementia is transient in nature. A person with dementia might struggle to describe a past event at one time and have no difficulty doing so at another time. People with dementia are much more successful when their 'remembering' is assisted by other people, and when they use mnemonic tools.⁸⁴ If the archival model was correct, and memories were like 'files' kept in the brain, vulnerable to 'deletion' by dementia-type diseases, then the fluctuating ability of people with dementia to remember specific events is difficult to explain. However, if

⁸⁴ This is not specific to people with dementia – all people become more successful at remembering with help of other people and strategies to remember.

we adopt the view that remembering is an intersubjective process, then it is no surprise to find that people can sometimes struggle to remember and that they perform better with assistance.

It seems that we must look elsewhere for a helpful way of exploring these personal identity challenges in dementia. In the next section I will explain how agency theories succeed where object theories fail, in accounting for both direct and indirect effects of dementia.

4.3 Arguments for an agency approach

Where object-based theories conceive a person's identity as existing as the same persisting object (or perhaps set of objects), agency-based theories conceive persons fundamentally as agents and their identities as formed by and expressed in the decisions they make 'as themselves'. A contemporary proponent of an agency-based approach is neo-Kantian philosopher Christine Korsgaard. According to Korsgaard, a person becomes and remains 'who they are' by establishing and maintaining a rational coherence to their actions. I will briefly outline how she arrives at this view here.

Through the course of our lives, we face many situations that require decisions. In making decisions we must select a reason as the basis of our action. Our ability to articulate the reasons underpinning our actions will vary, but in so far they are intentional (i.e. the result of a decision), there will be a reason (or reasons) behind the action. This is evident in several ways. For example, when making a decision we typically go through a process of 'thinking through' the situation, i.e. identifying possible reasons. In every area of human interaction there is an expectation that people should be able to explain their action, i.e. provide reasons for why they do what they do. Again, the extent to which we can do this varies, but the basic expectation is there, and if a person had no ability to do this we would question their ability to act autonomously, i.e. as themselves.

Korsgaard argues that when choosing which reasons we will act upon, we apply a conception of ourselves and the values that we regard as important. This conception is partly based on the values that others have instructed us in and the descriptions that have been applied to us, and in part on the decisions we have made before and the reasons that we have personally resolved to act upon.⁸⁵ On this view, who you are is a result of the interaction of your 'given' (or 'natural') psychological and biological propensities, the community that has raised you, and

⁸⁵ Korsgaard, *The Sources of Normativity*, p 100.

then ultimately what you decide to do in the situations you find yourself in. Korsgaard's account focuses on the deliberative processes internal to the individual. In Chapter One I mentioned other agency-based theories which emphasise other ways our actions are formed. For instance, relational theorists present a person's identity as constituted within their relationships with objects, environments and other people. Similarly, social constructivist theorists conceive identity as determined by a person's self-conception and the conceptions that others hold of that individual. Despite these differences in emphasis, the various approaches all agree in holding that a person is fundamentally an agent, i.e. a being whose existence must be understood through their abilities to act in ways that are distinct to that individual.

When applied to the questions of identity that arise in dementia, an agency-based approach attends to the ways that the person's capacities are impaired, and seeks to understand these in relation to the overarching value structure that gives coherence and continuity to the person's life (rather than focusing discretely on the damage or disruption that has occurred in the body or mind). In other words, these approaches examine how a person's ability to act 'as themselves' is affected, both directly by the various forms of cognitive impairments and also indirectly by the ways that their family and society has responded to those changes.

While other models tend to ignore either direct or indirect effects, agency models can explain both direct and indirect effects of dementia on identity. In particular, having noted that a person's capacity to act is affected by their relationships with others, certain indirect effects of dementia on identity become evident. If dementia undermines a person's ability to maintain relationships with significant people in their life, or prevents them from accessing certain environments they are familiar with, this could damage their identity. Being required to live in an unfamiliar place, no longer surrounded by the objects and environments that constitute one's identity, a person would naturally be unsure of how they should act, and whether the values they regard as important will be accessible. They would feel, as it were, not 'at home', which is to say, not free to 'be themselves'. For example, if maintaining a healthy garden was considered an important activity to a person, such that they took great pride in the status of their garden, being forced to move into a residential care facility where they are unable to care for their own garden would be significant blow to their identity (even if they still possess the capability to tend to a garden). In some cases, modifications to the relationships or environment might be possible that restore a person's ability to enact who they are (or to feel 'at home' in their surroundings). However, if, for example, a person's dementia progresses to the point

where they have lost all ability to recognise family members they have been close to, then on an agency-based account one is forced to conclude that this part of the person is gone.

Another important indirect effect to consider is undue disabling of people with dementia by misinterpreting peculiar actions as signs of dementia, when they are actually rational and reasonable responses to their unique situation. Steven Sabat describes this idea in his chapter in *Beyond Loss*⁸⁶. He describes the importance of appreciating a person's social context in understanding their actions and warns against attributing peculiar behaviours simply to dementia. When we do not have an understanding of a person's social context, actions can be interpreted as abnormal or pathological when in fact it is completely appropriate given the person's true situation. Sabat provides the example of Dr. B, a retired professor with AD whose ability to focus in on one conversation in a busy room is diminished. When put in this situation, he covered his ears and wept. While at first glance this peculiar behaviour could be interpreted as evidence of the progression of this man's dementia, another interpretation emerges when we appreciate his particular situation. If we have prior knowledge of Dr B's direct impairment (difficulty focusing when surrounded by multiple stimuli), then his behaviour becomes much more reasonable. Dr B's intentions and goal forming were coherent (wanting to focus on a particular conversation), he was unable to execute these intentions and so he reacted appropriately to the frustration. His actions were meaning-driven and appropriate given his situation and were reasonable responses to his direct impairment. An accurate understanding of the direct effects caused by a person's dementia avoids unnecessary indirect impairments involving misattribution of peculiar behaviours to dementia.

The distinction between direct and indirect effects can be further developed through the social constructivist approach to identity, which highlights the ways that our agency is socially and interpersonally determined. In dementia, people find their roles still important and yet can lose their roles through direct and indirect means. In the same chapter, Sabat describes the idea of a "personal present" from historic psychologist William Stern. This is essentially the idea that it is possible to bring to our present identity any part of our lives, past or future that we consider relevant. Sabat describes a participant in one of his interview studies, who when introduced by the phrase "Mr. K was a lawyer-", interjected with "I am a lawyer!" Mr. K was not delusional

⁸⁶ Lindemann et al., *Beyond Loss*, Chapter Two: The Person with Dementia as Understood through Stern's Critical Personalism

about no longer practicing as a lawyer, but it was important for him that his accomplishments were acknowledged and recognised as still relevant. Though no longer able to practice law due to his cognitive impairment (a direct effect), the significance of this can be modulated by continuing to treat him with the same deference and respect as you would a practicing lawyer (an indirect effect).

There are several complex indirect effects involving role changes within family structures. A common example is when one person in a couple gets dementia and their partner takes on the role of the primary carer. The role changes involved here can have significant effects on a person's identity. For example, increased carer stress can have detrimental effects on their role as partner or spouse. Similarly, children of people with dementia sometimes describe a loss in their parent's identity due to them no longer acting in ways that fit with that role. Taking a social constructivist approach to identity, it follows that when people close to a person with dementia relate to them differently, the identity of that person is affected.

Another important way in which identity can be socially constructed is through the stigma associated with dementia and the attribution of new negative roles. When a person receives a diagnosis of dementia, people around them often treat them differently, and (often unintentionally) assign them a new role as a 'dementia sufferer'. This new 'role' conceives ('constructs') the person as dependent or incapable, and consequently denies them the opportunity to do things they are in fact able to do. In this way, the social construction of the person effectively disables the person by preconception, over and above whatever actual physical or cognitive impairment they have. Kitwood refers to these kinds of disabling responses as part of the "malignant social psychology" that surrounds dementia.⁸⁷ However, it is not necessarily as malicious as this sounds: often family members of those with dementia are responding as best they can to particularly unusual and stressful situations and are trying to protect their loved ones from harm. To illustrate, imagine a person with dementia accidentally burns herself in the kitchen, when for many years she was a proficient cook. Her family may take this as a sign that she is no longer able to safely cook for herself and so might stop her from doing so. This may seem like a relatively banal example, but consider if this person regarded the activity of cooking for her family as vital to her role as a mother. Being prevented

⁸⁷ Kitwood, *Dementia reconsidered*

from cooking would therefore threaten her identity as a mother. Furthermore, this kind of disabling behaviour is usually not isolated to single functions; people with dementia may be gradually but increasingly viewed as incapable of completing multitudes of tasks, not just cooking, and these small things can often build up. Instead, if people with dementia are regarded as valued members of the family (or social group) with important things to contribute, their agency, and, as a result, their identity would be supported. Perhaps instead of completely stopping this person from cooking, her family members help her in the kitchen, but manage the more dangerous tasks. Instead of disabling people when they struggle to carry out their regular behaviours independently, we can provide some assistance to them to act as ‘themselves’.

So far this discussion of agency-based theories has provided a more detailed picture of how a person’s identity can be affected in dementia, compared to the object-based theories. It has not yet addressed the questions that arise from the problematic cases described in the introduction. More specifically, it does not yet inform us of when a particular choice or action should be regarded as autonomous and when they should not be. This requires closer analysis of what underpins an individual’s commitments to act on certain reasons and not others, and why certain values become more important to that individual than others. In Chapter One, I described ideas from Ronald Dworkin who argued that these significant commitments are based on what he calls our ‘critical interests’, which are formed through conscious deliberation about what makes our lives ‘successful as a whole’. In response to Dworkin, Agnieszka Jaworska has argued that critical interests are formed through a person’s sense of obligation to act in a certain way, and where failing to act in that way is detrimental to their self-esteem.

On Dworkin’s account, if dementia causes a person to lose the cognitive capacities required to reflect on what makes their life successful as a whole, then they can no longer form or enact critical interests. Therefore, the decisions they make are simply guided by experiential interests and should not be regarded as autonomous. On this reasoning, he suggests that in cases similar to Margo’s an advanced directive to withhold treatments should be honoured over any contemporary decisions. For the other cases, if the same line of reasoning is applied, we must regard the actions made by both Mr O’Connor and Mr D as non-autonomous. By contrast, Jaworska argues that a person’s ability to act on their critical interests is a matter of degree, and that though people with dementia struggle to a greater degree than most other people, this does not mean that they do not hold, form or strive to act on them. This means that in managing a case like Margo’s, we may infer from the apparent enjoyment she takes in ‘reading her novels’ and participating in various other activities that she still values her life, despite what

she had expressed in the prior directive. In other words, the fact that she is still engaging in things that are meaningful and important to her, indicates that she is acting in ways that are true to who she is, and that these are reasons for her to receive treatment. If her responses to her circumstances changed as her dementia progresses, then the interpretation of her interests would change accordingly.

From the discussion in Chapter Two, it may be observed that the process model of memory aligns neatly with Jaworska's view, and with agency theories in general, by viewing memory as an active, agentic process, rather than a matter of passive retrieval of a stored object. Similarly, agency-based accounts of identity conceive the formation and expression of a person's identity as a process constituted by decisions and actions. In short, remembering and 'being someone' viz. having an identity, exist through actions, rather than as objects. Incorporating physical environments and intersubjective collaboration in a relational theory or social constructivist theory of identity, echoes the process model's incorporation of media and intersubjective negotiation in the process of remembering. On this view, the deterioration of memory in dementia is a threat to identity, but not because 'parts' of the person are disappearing, but rather because the person is finding it more difficult to maintain the relationships that constitute their identity. As such, strategies used to support a person's memory might also help these people maintain those relationships and thus support their identity. In this chapter, I have argued that a person's identity and how it is affected by dementia can be modulated by our responses to their direct, or primary, impairments. It is possible to support the identity of a person with dementia, by understanding and engaging with what is significant to them, just as we might 'unlock' streams of information from people with memory problems by understanding the things that are meaningful to them and asking the right questions. Succeeding in this may assist these people to carry out meaningful decisions 'as themselves' viz. autonomously, and failing to do this would have detrimental effects on their identity. This idea is illustrated by Sabat through some other interactions with Dr. B, which had been further discussed by Jaworska.⁸⁸ Dr. B refused to take part in the activities at the day care centre he attended several days a week, where he met with Sabat. When asked why he refused, Dr B. described these activities as "filler" and "something that doesn't mean anything". He compares this to engaging with Sabat in the interview study: "If I'm working

⁸⁸ Sabat, Steven R. "Voices of Alzheimer's Disease Sufferers: A Call for Treatment Based on Personhood." *The Journal of Clinical Ethics*, 9(1):35-48, February 1988.

with you, I can-look, I can work in here for 30 times and all that, but in this group, I'm nothing.” Being unable to endorse the activities that are made available to him, Dr B is unable to act as himself, and this literally negates who he is. And we can say that Dr B advocating to take part in Sabat's study is an autonomous choice, because it engages with things that are important to him, in this case, science.

On the view I am advancing, autonomous actions are exhibited in the meaning that a person finds in their activities, e.g. the meaning Margo finds in her 'novel reading' and the meaning Dr B finds in participating in Sabat's study. In most cases of dementia, the person retains this capacity to find meaning. However, as described in Chapter Three, there are cases where this capacity seems to be profoundly altered, *viz.* some cases of bvFTD. The behaviour of people with this kind of dementia seems so much 'out of character' that we seem forced to conclude that their capacity to evaluate their situation has been profoundly impaired. This phenomenon has been explored by Antonio Damasio in his book *Descartes' Error*.⁸⁹ In contrast to Sabat's Mr D, the people Damasio describes appear unable to attach meaning to any outcomes of a decision and so seem to have lost their agency. Damasio offers a modern neurobiological interpretation for the abrupt personality changes in a well-known case, Phineas Gage, and one of his own patients, 'Elliot'. Phineas Gage was an American railroad construction worker who had an accident at work in 1848 where a metal bar went through his skull. Following the accident, Gage appeared remarkably functional in some cognitive domains but had considerable changes in his personality – as his friends put it: “Gage was no longer Gage.” Moreover, Gage seemed no longer able to function well in society, no longer being able to hold down a job, often using profane speech and treating co-workers poorly, making future plans and then abandoning them quickly for others. Damasio compares Gage with Elliot, who after suffering from ventromedial frontal lobe damage had similar problems. While Elliot still scored very highly in IQ and cognitive testing, he was unable to make decisions, especially in social or personal matters. Both of these cases exhibit similar symptomologies to some cases of severe dementia and those with bvFTD. From these patients' presentations, Damasio argues that damage to the ventromedial pre-frontal region of the brain is the cause for this change and that this region is critical for normal decision making through mediation of emotional investment and valuing. Damage to these areas meant that these men were incapable of caring about the

⁸⁹ Damasio, Antonio R. *Descartes' Error: Emotion, Reason, and the Human Brain*. New York: Putnam, 1994.

outcomes of their decisions. Although they possessed the cognitive capabilities to understand the decision (weighing up costs and benefits), they did not attach any emotional significance to the available options and so were unable to make a choice they cared about, making their decisions non-autonomous.

Damasio's analysis may be useful in comparing cases like Mr O'Connor and Mr D. Because Mr O'Connor's change of mind to no longer receive medical treatment can be linked to his loss of his wife, it can be understood as a meaningful decision. By contrast, it seems difficult to find a justifiable and meaningful reason for Mr D's actions, so we could regard these as non-autonomous, concluding that his dementia has progressed to the point where his agency is significantly impeded. According to this line of reasoning, FTD presents a greater threat to a person's identity, likely because it affects the brain areas that are important for decision making and emotional investment, as identified by Damasio. The implication is that while there is much we can do to sustain a person's agency through many forms of cognitive impairment, there are some functions related to our capacity to value without which a person cannot act. In some respects, we may view this as no different from a person's dependence on other 'vital' organs. The important difference is that the body of the person lives on, and certain residues of the self continue, meaning that our obligations to the person *as a person* also remain, despite the inevitable changes to the relationships involved.

4.4 Personhood

As stated in the introduction, it is sometimes thought that a being who was previously considered a person can somehow cease to be 'a person' due to the significant cognitive impairment present in advanced dementia. This notion leads to the conclusion that these beings no longer carry the same moral status as persons and so it would perhaps not be wrong to withhold life-sustaining treatments, or perhaps even administer life-ending treatments to these beings. Before continuing, I will reiterate that these issues are very complex and carry significant weight and so my treatment of them is limited by the scope of this thesis. Nonetheless, let us reconsider the theories of personhood described in the first chapter, in light of the discussions on personal identity.

Firstly, John Noonan's theory of personhood, the human criterion, is rather unhelpful when considering advanced dementia. This is because the genetic make-up of a person with dementia and the humanness of their parents is unchanged throughout the course of disease. As such, this approach would regard personhood as necessarily unaffected. However, as noted in

Chapter One, this view of personhood also seems to extend the same moral status to anencephalic babies, brain-dead patients sustained by life support and perhaps even dead bodies, which are generally not considered as carrying the same moral significance as persons.

Using a cognitive criterion to determine personhood, such as those put forward by Locke or Kant, or contemporary theorists Mary Anne Warren or Peter Singer, brings the personhood of a patient with advanced dementia's into question. This is because these theories determine moral status based on a kind of 'personhood test', and these usually include a list of cognitive functions. Given that most patients with advanced dementia would fail any of these tests due to their significant cognitive impairment, it would follow that these patients have indeed lost the moral consideration of personhood. This conclusion is somewhat problematic though, as many families of patients with advanced dementia continue to regard their loved one as a person and would consider the notion of 'killing them' abhorrent. As such, a cognitive criterion of personhood is perhaps too cut-and-dried.

Charles Taylor's approach looks to "peculiarly human behaviours", like pride, shame and honour, when determining if a being is a person. As such, someone using this approach may conclude that when a patient with advanced dementia no longer behaves in such ways they are no longer a person. However, Taylor's approach also focuses on the potentiality of a being to behave in these ways. For instance, he states that "those who through some accident or misfortune are deprived of the ability to exercise these capacities are still understood as belonging to the species defined by this potentiality."⁹⁰ And so, it is likely that Taylor would conclude that advanced dementia cannot strip someone of their personhood. Perhaps this view, like the cognitive criterion, is too definitive, as it does not account for the inverse cases, where families consider it abhorrent to keep their loved one with advanced dementia alive. It seems a complete account of personhood must allow some degree of nuance for cases of advanced dementia.

A gradient theory is perhaps helpful in this, as it changes the perspective of a personhood test from pass/fail to one of degree. If we consider personhood to be something that develops gradually, then it seems to follow that it is something that can be lost gradually as we lose the functions or behaviours considered essential for it. However, as noted in Chapter One, this does

⁹⁰ Taylor, "Human Agency and Language" pp. 97-114

not provide any clear answers to the practical questions that have been discussed. Carl Elliot's claim that we cannot avoid approaching these issues with a pre-existing moral attitude is perhaps more helpful. This approach allows for a range of views on personhood (which the personhood tests do not), and partly explain how some members of a family might be emphatic that their loved one with advanced dementia is undoubtedly still a person, while others might hold that they are not. Though each person holds their position as 'morally correct' (this is not a 'relativist' position), they cannot be fully articulated in moral discussion, or made universally convincing through moral philosophy.

A social constructivist approach, like the one put forward by Hilde Lindemann, is perhaps useful also, as it holds that personhood is somewhat dependent the construction of a being's personal identity. On the agency-based account of personal identity I arrived at through my previous discussion, a patient with advanced dementia should continue to be regarded as a person if they continue to make meaningful choices and actions and they are treated as a person through natural, everyday actions by those around them. Contrastingly, if a patient has no awareness of their situation nor control of their body it seems that they would be unable to make any meaningful decisions or actions, and so perhaps no longer be regarded as a person. However, this conclusion remains problematic in that judgments about what constitutes a meaningful action are contestable. Some family members might say that simply being in the 'company' of their loved one is a meaningful human act, and that their life retains value accordingly.

In dealing with these issues, there is a difficult tension between promoting and sustaining a shared conception of the worth of human lives, especially in situations of debilitation or impairment, and recognising the limits of medical interventions, and when our efforts to help are in fact not helping. A proper treatment of this conception of 'personhood' requires more attention than I can give it here; what I have sketched are possible ways that different theorists might approach the issue. However, it seems that the approaches which allow some variation due to intersubjective meaning are a more appropriate way to understand personhood in a dementia context.

4.5 Conclusion

In this chapter I have outlined a theoretical shift away from object-based theories of identity towards agency-based theories. I did this by reviewing the theories I introduced in Chapter One and then integrating the information in Chapters Two and Three. I also described the failings

of object theories and how agency theories better explain the experience of those with dementia. Within agency theories, I examined how a person's choices and actions can be informed by the social and physical environments surrounding them and how these too can positively and negatively affect a person's identity. Using an agency approach, I justified the conflicting position outlined in the introduction where some choices people with dementia make are regarded as autonomous and others as not, based on the meaning those choices carry. In the next chapter I will describe the qualitative study I carried out as part of this research project. I will report the results of this study and discuss how they compare with the conclusions drawn in this chapter.

Chapter Five - Interviews

Dementia in its various forms can give rise to difficult ethical and philosophical problems. These problems may be encountered by clinicians making treatment decisions for patients with dementia, or in the day-to-day work of those caring for people with dementia. In the first three chapters of this thesis I discussed theories of identity, the nature of memory, and the current pathological and clinical understanding of dementias. In Chapter Four I presented a broad theoretical account of how identity is affected by dementia, drawing on those previous chapters. I argued that identity needs to be understood in terms of agency, and that agency is socially and environmentally conditioned. On this account, a person expresses and becomes who they are through their interactions with the world of persons and things. Actions (including thoughts) are always undertaken through a body, and hence emergent physical deficits will generally present a threat to identity. However, in many cases such threats may be met by adapting the activities that the person undertakes, and by finding new ways to express or remain connected to the life which the affected person has enjoyed. Society has a critical role in this process, and can either support or hinder a person's efforts to adapt, depending on the options and avenues that are made available to them.

As noted throughout, the position outlined in Chapter Four has been developed using a range of philosophical and empirical sources. These include some studies reporting and interpreting the views of those experienced in caring for people with dementia.⁹¹ Such perspectives are very valuable to ascertain, as they ensure that theoretical work is motivated by genuine problems, and also test the value of theoretical solutions to practical problems. For this reason a qualitative study was incorporated into this dissertation process. Although there are existing qualitative studies focussing on patient perspectives on how identity is affected by dementia, this study is unique in the way that it directly focussed on clinicians' perspectives of how identity is affected by dementia, and whether advance directives should be applied for patients who have dementia. In this chapter I will report on the findings of this study and discuss what they mean in the light of the previous theoretical discussion.

⁹¹ Linemann et al., *Beyond Loss*, Chapter Four: "I'm his wife not his carer!"—Dignity and Couplehood in Dementia; Sabat, S. R. "Surviving Manifestations of Selfhood in Alzheimer's Disease: A Case Study." *Dementia* 1, no. 1 (2002): 25-36.

Although the views of certain experts can be used to ‘test’ theoretical conclusions to a certain extent, they cannot be used as ‘proof’ of a theory’s accuracy or truth. The value in the clinicians’ views is that they are formed with an awareness of the situations in which those problems arise, and their perspectives can therefore convey special insight into ethical problems. However, they cannot be used as self-evident ‘facts’. This is because the phenomenon being described, and the concepts being used to describe that phenomena, require interpretation and some pre-existing theoretical work. This, I suggest, is evident in the difficulty that participants have in expressing their views, and by the variety of views expressed. Thus, the views need to be considered critically. Hence, as I present the views I shall also offer some commentary on how they may be interpreted, and what they mean for the theory discussed in the previous chapter.

5.1 Method

This study used a general inductive approach.⁹² Key topics and questions were developed from a literature review and prior theoretical work. This established the broad objectives of the study, but the understanding and interpretation of these objectives remained open in the analysis of the findings. The objectives were to understand how experienced clinicians working in dementia care understand the effect of dementia on identity, and how they viewed the ethical problems that can arise in dementia, particularly in the application of advanced directives.

Participants were invited to participate via email. The invitation email outlined the project and what would be required in participating. An information sheet was attached which described the purpose of the study in more detail, as well as the topics that were likely to be discussed in the interview. The topics were listed as follows:

- How identity is conceptualized in clinical settings, and how it is perceived to be affected by dementia.
- Whether the loss of ‘autobiographical’ memory brings about a loss of identity, and how identity can be sustained in patients whose memory is deteriorating.
- How ‘advance care plans’ are used in dementia care, and whether apparent changes in identity or personality affect the value in their implementation

⁹² Thomas, D. R. "A General Inductive Approach for Analyzing Qualitative Evaluation Data." *American Journal of Evaluation* 27, no. 2 (2006): 237-46.

- What means or measures are used in assessing whether a patient is able to make particular decisions.
- Any further issues you see as relevant to this area.

These topics formed the basis of the interview questions, however, as the interviews were semi-structured, the order and extent to which each topic was addressed varied according to each participant's responses. Out of respect for the privacy rights of the participants' and those of their patients, no specific, identifiable, patient information was discussed in the interviews, and no identifying participant information is included in any reporting of the study. Participation was entirely voluntary throughout.

Seven participants were recruited for the study using a 'snowball' recruitment method.⁹³ Participants came from a range of healthcare disciplines⁹⁴, but each had at least twelve years of experience working with people with dementia. All those invited to participate agree to do so.

All the interviews were conducted by me, either in person or via video-conferencing. The interviews were recorded on an audio recording device and then transcribed by me. The transcripts were then coded using NVIVO v11. My primary supervisor (SW) and I then undertook independent parallel coding, whereby we each read the interviews closely and created and applied codes according to our respective understandings of the study objectives. The results were then compared and discussed. There was considerable overlap between the two sets of codes that were developed and in how they were applied. Where there was variation, the transcripts were reviewed to check interpretation. Following this, we both independently identified the key themes in the findings, and then worked together drafting a written presentation of the findings. This draft was then emailed to the participants individually, along with copies of their interview transcripts. Participants were specifically notified of instances where their interviews have been quoted, and were invited to comment on or correct our interpretation. No participants offered corrections.

⁹³ Michael Quinn Patton, *Qualitative Research & Evaluation Methods: Integrating Theory and Practice* (Thousand Oaks, CA: SAGE Publications, 2015)

⁹⁴ These included representatives of geriatric psychiatry, gerontology, clinical psychology, occupational therapy, general practice, and palliative care.

I expect that my interview technique improved throughout the process simply through practice and gaining more mastery over the ideas discussed. Furthermore, these interviews were carried out before writing the majority of this thesis. At the time the interviews were conducted, certain ideas were still developing. If I were to conduct a similar interview study after the writing of this thesis, the lines of questioning may have a slightly different process. This is in keeping with the general inductive approach.

5.2 Findings and analysis

The participants' offered a range of perspective on what identity is and how it is affected by dementia. They variously related identity to activities, roles, relationships, and in one case a persisting sense of self. Several emphasised the positive role that carers and social support structures can have in helping people to adapt to the impairments caused by dementia, and so preserve their identity. Others described the challenges dementia could present to carers and families, particularly in responding to the profound dependency of the previously independent person, and to behaviours that were significantly 'out-of-character' for the person. Participants whose clinical work involved situations where advance directives might be applied expressed caution regarding how they should be used in dementia care. While they thought records of prior wishes could be useful for understanding a patient's values and preferences, they stressed the complexity of the decisions that can arise, and how difficult it can be to anticipate the circumstances and options available.

5.2.1 Participants' conceptions of identity and dementia

When asked how they understood the terms 'identity' and 'personhood', participants mentioned a range of factors or concepts. Some used examples of people or patients they had encountered to illustrate their ideas, while others responded directly with a general account. Participants would also often explain their view of identity by describing how it is either threatened or sustained through dementia. The themes identified in the interviews are broadly coherent with the position argued for in Chapter Four, but also raise some further considerations and issues to resolve.

Activities and roles as important to identity

Several participants described an agency-based approach to identity, often identifying activities and roles as important in defining identity. A subset of this group also described ways that identity might be threatened as people become unable to perform such activities or role due to

the progression of dementia. One participant gave an example in which dementia is “taking away” a specific kind of activity (driving) that is seen as “integral” to the patient’s identity:

Because of the dementia, yep, so simple one ah and it's very much in my mind today because of a patient I've recently seen, it's someone who I've had to tell must stop driving because they are not capable of safely driving anymore. But for this man, the fact that "I am a driver" is so integral to his identity, that I've taken- it feels to him as if I've taken away an important part of who he is. He's lost it forever, he's very angry about that and he will grieve about that for quite a while. **Participant 1**

Another participant described the connection between identity and activities in more general terms, and emphasised the importance of agency in everyday activities and pleasurable hobbies within individualised social and physical environments:

P2: As a [particular kind of healthcare profession], identity is a core part of what we think about in our, in our work.

AB: Mmhm.

P2: And I, I, you know, I can't think about identity without thinking about roles. About routines and rituals, the habits that we have and umm, the meaning that we place on certain activities in our life. So, umm, they're probably the, ah - Oh, relationships of course, so. So yeah, as [a particular kind of healthcare profession]⁹⁵ we see us as individuals who have constant interactions with the social and physical environment and, and in, in those, within those interactions there's always going to be an activity of some sort... whether it's your mundane activities of daily living, right through to you know, your work activities, your interests, your umm, the things you do in terms of social relationships. So umm, when those things are removed, identity is at risk. Or if those things have, are compromised, identity is at risk. So, you know, the way in which we do a task, the way. I was talking to my students on Wednesday actually, I had them with me and we were talking about ADLs, activities of daily living and you know, something as simple as noticing as when you have a shower...

Participant 2

This link between identity and activities broadly aligns with the agency-based accounts of identity described in previous chapters (activities being expressions of agency). It follows that in so far as dementia limits or removes the capacity for agency, it will threaten identity. Participant 2’s descriptions reinforce Jaworska’s view of identity, in that it suggests that a person’s agency can be constituted by every day activities that are critical to their sense of self-worth, particularly where they involve social relationships or work.

⁹⁵ Profession withheld here to protect participant’s privacy.

Perhaps with an agency-based approach in mind, some participants noted the importance on focusing on activities the person with dementia are still capable of, rather than focusing on the deficits in their abilities. For example:

But I'm sure there are things she can still do, but for that I ask one of my occupational therapists to go and see her and really do a more detailed assessment, getting to know the- you know, I'm sure she had other things she enjoyed in life that you know we can support her to do those. **Participant 3**

And:

The colouring books are great. So fantastic. I've got a whole lot of people who are discovering them because they often can colour in. My father could paint when he was demented and he could never paint a month of Sundays when he was normal and he was - he got some stuff finished. He used to come back with paintings he was really proud of but- And people might think that's demeaning but in fact, doing things like that, if you can do anything that you can do, that you can engage in, that isn't too stressful, it's lovely to be able to produce things- but a lot of people want to, want to, you know, take them out for meals, do all sorts of- but in fact that's often really, really stressful. **Participant 4**

Indeed, some participants described finding *new activities* to do or *new roles* to fill as being hugely beneficial for people with dementia:

One gentleman, now he's gardening now at the Botanic Gardens, so he's raking leaves, you know, he's right in there during autumn or winter you know, he's out there helping. And he said to me the first time I met him, "you know, I got a diagnosis of dementia and it was like I was placed into a cocoon. Nobody wanted me to do anything in case I hurt myself or injure myself or" umm and he said "I lost myself and I come here and I've found myself again because I'm giving back, I'm doing something, it's returning me to me." **Participant 2**

In this particular example, the idea that the man had "lost" himself when he was denied opportunities to actively contribute to the community reinforces the basic link between agency and identity. More specifically, it fits with Korsgaard's theory that a person forms and sustains their identity by acting on reasons that they can reflectively endorse (i.e. reasons that are in line with their values)⁹⁶. The idea that this person 'found' himself again through an activity that he recognised as meaningful (as "giving back") affirms Jaworska's claim that a person with mild or moderate dementia may still form and act on 'critical interests', and also her characterisation

⁹⁶ Korsgaard, *Sources of Normativity*

of those interests as involving others (or some value beyond the person's immediate experience) and as being related to the person sense of self-esteem. This example echoes Sabat's case of Dr B, who felt similarly impaired by the activities of his day-care facility and found value in participating in engaging in something meaningful, *viz.* Sabat's study.

The activities mentioned by participants as important to identity were not always relating to a patient's occupations or hobbies; some also referred to roles within critical relationships. Participant 3 for example, observed:

So for say, relationships - often that's changed in the roles. Like a husband and wife team, say the husband has dementia, the wife may become the main caregiver and that can sometimes unravel some of the longer term issues within that relationship. At the same time, we really, really value the family input because really when we see someone with dementia, we can't see just that person, we have to see their immediate family.

Participant 3

This comment draws a link between roles and identity in suggesting that knowing the family is a necessary part of knowing the individual. The suggestion that consulting a person's immediate family is needed to have a full account of their identity is in line with a social constructivist approach, which holds that a person's identity is partly constituted by the ways others view them. This quote also highlights that roles within relationships can change as dementia progresses and how this can indirectly threaten a person's identity. Some participants emphasised how challenging such changes in roles within relationships, and corresponding changes in identity, could be for couples and families. Participant 2 put this point as follows:

I think, from the family's perspective, it is a very real thing that they see a loss of the person they once knew. I believe a lot of that is around the roles that people hold. So on one hand, yes, a person living with dementia may become disoriented to person, so they may start recognising a daughter or a spouse as a father or a sister or you know, so there is that degree of confusion. But a lot of it is about, I believe, the fact again that the roles reverse and roles often do reverse as we age. You know, my umm, my Dad's not that old but umm my Mum died 5 years ago and umm, he's not got his you know companion for life and my Mum ran the house, you know so his, so our, my role, you know I cook for my Dad a lot more than I would have once done... **Participant 2**

Participant 4 made similar observations, and quoted a patient who said "often there's an awful lot of glossing over dementia and trying to make it look as if it's you know not as bad as it is.", and then went on to say:

But for the people that have it and the people that look after them, it's, it's so bad, you know, and it's their loss of personhood⁹⁷ that is the hardest thing to deal with I think. You know, it's the loss of, it's the... You've lost a mate, you've lost a person who looked out for you and who had contributed to the relationship and then you've gained a person who is now a dependant and you've gained a person who is often like a child again because they've got such terrible sort of separation anxiety. **Participant 4**

This participant is drawing a clear link between changes in capacities (becoming a “dependant”) and changes in identity. The wife of the patient went on to say that this “glossing over” was “insulting” to her and her husband who has dementia, and she stressed that he was “not the same person he was” (quoted by Participant 4). Building on this point, the participant described how as dementia progresses patients will work hard to convey who they are by talking about things they have done in the past. This idea is similar to Sabat’s description of personal present, with the example of the lawyer, Mr. K.⁹⁸

And most peoples' very long term memory is intact. But as they get worse and worse and worse, more and more of that sort of feeds away and I think it's really sad that they can. But they do want to project who they were rather than who they are now, even if they're demented. They love talking about the things they've done and they'll talk forever. You know they'll tell you the same story 100 times, but that's really good for them. Because they've really got that need to project their identity. And that was the man that talked about dementia. He could say "look, I know I can't do this. I know I'm a burden on my wife, it drives me crazy, but I can't do anything about it." And that was really you know sad and he said "I know that I want to think things through but it just doesn't happen. I know exactly what I want to say I can't say the words, I try to calculate my head, I try to do all the things I could and I just can't do it." But he could express that brilliantly which was just amazing... **Participant 4**

The sense of loss that many people experience with dementia is undeniable. However, as already indicated, some participants described ways that a person with dementia could adapt, or be supported, to sustain a sense of identity despite the impairments. These views are perhaps more evident in the comments made more directly about the link between identity and relationships.

Relational identity

⁹⁷ Note that the use of “personhood” here likely refers to what this thesis describes as personal identity and not personhood. This misuse of terms reinforces the difficulty in discussing these issues as important terms mean different things to different parties.

⁹⁸ Lindemann et al., *Beyond Loss*, Chapter Two: The Person with Dementia as Understood through Stern’s Critical Personalism discussed in Chapter Four of this thesis, p59

The previous section focussed on ways participants linked identity to our ability to perform certain task or fulfil certain roles. Some participants also linked identity directly to the relationships that people have. There is an obvious overlap between these themes, as the concept of a ‘role’ generally implies some kind of relationship, and also a set of normative standards that we will endeavour to meet and which others may hold us to. Indeed, one might say that roles are constitutive of the relationships we have (for example, to relate to someone as a parent one must perform the role of a parent). One participant described understanding a person’s family relationships as a critical part of knowing who they are:

Yeah, um. Yes, identity... I think for me, it's getting to know the person, as a person. And work in psychiatry, we- really as part of our routine assessment is to know about the person's family umm, that's actually probably of the first questions I ask, when I come across a -you know, see a new person- and I'll be asking their family. Their family supports, their relationship, where this person's role is in the family. So that, that sort of covers current family, situations and also the past. And I find it quite useful, for me to get to know this person. Because. I know, no one exists in isolation and for me it's quite a good start to get to know the person, just ask about their family and their relationships Umm. Of course, then I usually ask about the person's occupational history, umm, yeah. Yep. Their interests and their hobbies. Yep.

Participant 3

Another participant described the social and interactive nature of identity, and then suggested that the notion that a person’s identity could be independent of relationships was an artefact of “Western culture”:

Well, I think it's a mistake to claim that there is a single locus [of identity]. So I think it's a... it exists in a dynamic interplay between various aspects of the person, their context and especially their social and cultural context. But in Western culture, because we're quite hyper-individualistic, we have a bias towards thinking that identity, selfhood, personhood, personality, are all inside us. This is not a sufficient explanation but that's our cultural bias I think. Whereas other cultures, especially Confucian and traditional Maori in this country, would see those things as much more suspended or related in where you stand in relation to the land or your family or other people. **Participant 1**

The participant went on to suggest that this exacerbates the threat posed by dementia, because it renders a person’s identity wholly vulnerable to the internal pathological processes, while a relational understanding of identity provides a way that identity can be preserved despite the loss of capacities caused by dementia:

P1: So it's a Western cultural expression of what our response is to dementia if we believe that the heart of being a person is holding my identity in myself. So if that's

our cultural bias, then if I lose my marbles then I've lost everything. But I don't think that's actually true. But I think that drives the "this is not my Mum" [comments]

AB: So because this person can't enact their own identity-

P1: Yeah, as they used to.

AB: -as they used to, then we feel like they - well these people describing their parents in that way - feel that way. But it seems like you think they do hold onto some part of their identity.

P1: Well there's - their identity is capable of being preserved.

AB: Okay, in what ways?

P1: It has to be invested in the social network then because it is true that dementia will eventually erode my capacity to hold onto my identity myself. The previous bits of it - I am still who I am right now but all the history which is clearly an important part of my identity may be inaccessible to me and how I'm acting now might be a different way to how I used to act. So dementia will do that at some point. So, umm, to maintain that part - that connection with my previous self - I'm going to need to have other people do that for me. **Participant 1**

In elaborating on this point the participant provided the following example:

And we will hold for you, your sense of who you are, which wasn't primarily about what you did in your life anyway. It was about the fact that you belonged to this Iwi and this Hapu with this land and this Marae and this role and you still have those things. So I remember the story of someone's Dad who was living on the Marae clearly with dementia but they just couldn't run anything on the Marae without him being there to say the Karakia and just be there. But he was pretty useless at the Karakia now so they have to say them for him, but he still had to be there because he was still that guy. Brilliant! **Participant 1**

The idea that a person's identity is constituted in, and can be sustained through, relationships is in accordance with the several contemporary 'relational theorists', some of whom were mentioned earlier in this thesis.⁹⁹ The suggestion that 'individualistic', i.e. non-relational, conceptions of identity are products of our Western cultural tradition is plausible, given the influence that Descartes, Locke, Hume, and Kant have had on Western philosophical, political and scientific developments. These philosophers build their systems on the foundation of individual thought and experience, and so conceive the being of the person in terms of isolation rather than connection. Alternative systems, founded on more holistic conceptions of being, are available in Aristotle and Spinoza, but their views are less well-known, and less influential.

⁹⁹Discussed in Chapter One of this thesis p25-7

However, despite the positive aspects of these relational ideas, there is still a need to account for the individual as an individual, and to acknowledge the limits to which a person can be sustained through social or cultural supports. This is evident in the remarks made in previous section about the ‘loss of self’ that is experienced with the progression of dementia, even within what appear to be functioning relationships (notice that the case cited involved a married couple who had evidently been very close). It seems that the grief that comes with such loss needs to be negotiated as a person adapts to new roles and activities that remain achievable with dementia.

Identity as grounded in a continuous feeling

One participant highlighted a more individual conception of identity, not conveyed in the concepts of activities, roles or relationships discussed so far. This is the idea that identity is sustained through a basic sense or feeling of self that persist through a life time:

Well the person I was assessing today looked at me... You know, it's that person's birthday, they turned 94. And say to me, "I don't feel any different. Because you know 24 years ago, I was doing fine." and I said "you weren't 94, 24 years ago though, so that's what's different." But it's true that the person in themselves, you know, they could feel the same as when they did when they were 21, but why would that change? Just because their external body has aged, in themselves, they feel no different. And this is something that I think, umm, a person tends to retain. Umm, even when they're quite impaired. There's just kind of a sense of self, which is more than just existing, it's, you know that combination of personality and intelligence, umm, having peculiarities, preferences and, umm, feeling pain from different sorts of things. Umm, feeling umm attracted to or allied to different people, but not being able to perhaps explain that. That doesn't change, it's still there. **Participant 5**

This idea echoes the view put forward by neurologist Antonio Damasio, who argues we are aware of our identity through the operation our continuous conscious monitoring of how we are in the world, and in the feelings of joy, sadness and desire that accompany this.¹⁰⁰ There is also an overlap with the comments of Participant 2 quoted earlier about the importance of each person’s unique patterns of behaviour and mannerisms in constituting their identity.¹⁰¹ One might say that these outward usually, unconscious, behaviour are external expressions of the internal, engrained patterns of feeling that each person develops through their repeated

¹⁰⁰ Damasio, Antonio R. *Self Comes to Mind: Constructing the Conscious Brain*. New York: Pantheon Books, 2010.

¹⁰¹ First quote by Participant 2, p72

interactions with others (and in the sense they are not entirely individual). This idea can also be connected to agency-based accounts of identity, if we understand the continuous feeling as monitoring of our actions, i.e. a sense of how well we are actualising our potential, living in accordance with our values and are able to ‘act as ourselves’.

Memory and identity

Although memory was not directly asked about in the interviews, several participants discussed memory as a concept important to dementia and identity.¹⁰² There was evidence of both archival and process models being employed by participants. Overall, memory was regarded as a somewhat important but far from sufficient criterion for identity.

One participant used archival metaphors when describing memory:

I'm sure that memory is like that and I'm sure the reason your childhood memories are so good is they were formed when your brain was young and your hard drive wasn't full and your memory banks were empty and those memories were well encoded and will you know stay with most people the rest of your life. And then as you get older, you know, your brain is not nearly so good at encoding new memories and ehm, the hard drive's full of rubbish. **Participant 4**

However, the same participant also goes on to use aspects of a process model when describing how people are able to remember more when they are engaged in discussion relevant to them, and through the use of memory media such as “note books and records and photographs”:

They'll often remember nothing, then you can get in there, you can see. When they can't even tell you what they did, you know that they're so far gone that it's really sad because they've almost lost the memory of who they were. But if you talk to them about the old days then you can really sort of cog into how they think and how they thought in those days and then you can sort of see what the changes are to what they are now. So I think people's past is huge and for demented people, I think that people that keep, you know, note books and records and photographs and things that they can look back at is a fantastic thing. Because once those memories are gone, they're gone for good. But actually having them there [in the note books and records and photographs] to go back to, is really good. **Participant 4**

¹⁰² This is a topic which I would invest more time discussing with participants if a similar study were to be repeated.

Another participant emphasised how memories can be shaped by the purpose they are remembered for:

... you know people tend to remember the past through rose coloured glasses, so... She... her... her memories may be... influenced by what she wants to remember.

Participant 6

The case referred to involved someone remembering her husband fondly. This idea links to the process model of memory, and reiterated the view that remembering is often an emotional process and not impartial or archival. In a similar vein, another participant described how engaging with people about topics that were important to them could elucidate many more details:

the detail that she recalled, knowing what she had said to me about how much she couldn't remember, was phenomenal and it really highlighted to me just how much tapping into something that's truly meaningful and engaging ... helps peoples' brain, umm, remember and maintain...[information] **Participant 2**

Several participants argued that memory is an important part of identity. However, their views did not precisely align with a Lockean theory of identity, as none seemed to hold that memory is the sole constituent of identity. For example, one participant described that relationship as follows:

my memory will fail or my ability to express what my memory can tell me will fail at some point, then I won't remember who I am or be able to communicate who I am in a reliable way, so that will change who I am. At least from the vantage point of others.

Participant 1

The final part of this quote, describing how identity is affected “from the vantage point of others” when memory is impaired, actually evokes a social constructivist view of personal identity, rather than a Lockean approach. It also appears that being able to *express* one’s mental life is important for this social construction and if communication is impaired, then the process of construction would also be impaired. It also implies some ‘self-concept’ of personal identity based on memory. However, even in acknowledging this, one participant also made the contrary point, by asserting that aspects of a person’s identity are not necessarily lost simply because that person is unable to remember it, and that there are parts of identity that memory does not encapsulate:

when our memory declines, then we lose our identity, we lose ourselves. But reacting to that, I think and what you've said as well, identity is about so much more than what you remember... I think that some of it is hard wired by genes. Like whether you....

whether you get pleasure out of roller coasters. You don't have to remember even going to Cedar Point as a 6-year-old or whatever. ... You don't have to remember, you don't have to associate it with a pleasurable experience as a child, you don't have to remember that. Either you're somebody who likes it or you're somebody who doesn't and that's based on genes. **Participant 6**

The thought that identity may have an inherent genetic component was also mentioned by other participants:

So we've probably born or formed with a temperament. We're born with the genetic blueprint for a temperament and then life experiences will cause that to be refined or sharpened or dulled or whatever in various ways. ... but our genes are expressed variably in relation to our environment, so even to say it's in your genes, immediately we've got an interplay with what's going on around us. **Participant 1**

Another participant also downplayed the importance of memory, focusing on present experiences for personal identity:

So apart from that very, very end stage, I think people do have some identity because they have an ability to experience pleasure or pain, experience pleasure or distress and to some extent, maybe express it or maybe not. The fact that they don't remember it, is not relevant to the experience of it. **Participant 7**

Overall, the participants did not support the memory theory of identity put forward by Locke and maintained by many contemporary theorists. While participants recognised an important link between memory and identity, and the fact that the loss of memory in dementia can have a profound effect on a person's identity, they also described how Locke's theory is problematic in ways similar to my discussions in Chapters One and Four.

5.2.2 Summary discussion of participants' view on dementia and identity

When discussing the effects dementia has on identity, a range of answers were explored. It seems that as both identity and dementia are individually complex and nuanced topics, the ways they interact are particularly complex and nuanced. Participants recognised that brain pathology can significantly affect personal identity, which I described as the 'direct effects' dementia has. Following an agency model, the threat to identity posed by dementia is a product of the decline in capacities that dementia causes. In others words, a person become less themselves because they are less able to act in the ways that are engrained and familiar expression of who they are. For example, when a person can no longer fulfil a certain role (such as 'partner'), because they are unable to perform the tasks they once did, then their identity is threatened. Given the important links that participants described between identity and

relationships, it is reasonable to infer that of the various forms of dementia, frontotemporal dementia poses the greatest threat to identity. This is because the form of cognitive impairment involved affects the structures that operate as we judge how to interact with others, and so impair our ability to sustain relationships.

The participants also emphasised the importance of what I have described as ‘indirect effects’ of dementia. In particular, they highlighted the ways that other people respond to the person with dementia’s direct impairments (e.g. treating a person differently because they are unable to do the things they used to). This often occurs when a person’s relationship to a person with dementia is changed from partner or parent to caregiver. In accordance with the agency-based accounts, we tend to construct identities (our own and others) around the ways people behave. If a person’s actions change, then naturally, our view of who they are changes too.

Further indirect effects are evident in the language that can be used to describe people with dementia. These are often unintentional and can arise from good motives (e.g. the desire to care for or protect the person with dementia). An example is describing a person with dementia as vulnerable, and then preventing them from working in the kitchen, or in their workshop, because of safety concerns. Whilst necessary in some cases, such protective measure can be overdone, and can cause further disablement over and above what is actually caused by the physical impairments. Similarly, when a person is described as a ‘dementia sufferer’, or similar term, this implies that the person is entirely dependent or helpless, when in fact people with dementia may remain capable of many meaningful activities, if appropriate supports are put in place. This can become circular, as if we misinterpret peoples’ behaviour as evidence for dementia (behavioural symptoms), then we will be inclined to be more protective, and so further deny them opportunities to act.

5.2.3 Personhood

The concept of personhood was mentioned by a number of participants. Some drew a clear distinction between personhood and personal identity, while others spoke of them as overlapping concepts. There was a mixture of views as to whether or not personhood is taken away in advanced dementia, and a variety of explanations as to why this is or is not the case. For example, one participant described personhood as “more fundamental” and less changeable than personal identity, and as something that is shared with other persons but uniquely expressed in identity:

PI: personhood is a bit more fundamental.

AB: Mmhm.

PI: Because no matter what my identity is, I am- what changes in it, that doesn't change umm, my fundamental personhood, I think, which is those things that make me a person... at its most fundamental level - that make me a human. But there is a uniqueness to that too... So it's... Because personality is not... although every person has it, it's not identical because it varies, it expresses itself in our identity so therefore my personhood is unique - those things that make me a person, whilst I share them with every human on the planet, nonetheless they're unique to my particular personality and identity also... They're sort of related too... So that's how I'd see that. If that makes sense. **Participant 1**

Participant 3 also asserted that personhood persists even in severe dementia, regardless of how advanced:

But, this person is still a person! It's just that he or she needs a lot of help. Yeah... For you know, patients are... Similar patients in the past I- even though you can't communicate with the person, you can still stay with the person, being with the person and that's umm. And you can't do that if that's not a person. So the- umm. It's quite important for people with severe dementia... You don't have to communicate, you can be there and provide some comfort or... Umm... have some connection... umm. And that's a person. Because you can't do that with umm, with an object. Connect... Eh... Well some people may... But yeah, for me, it's that connection regardless of how severe the dementia is. **Participant 3**

It is perhaps significant that this participant has mentioned “being with the person” as a way of affirming or acknowledging their personhood. This link between relating and personhood was also discussed by another participant who held a comparatively well-formed view of personhood. Their view was that to be a person one must be able to experience some kind of enjoyment and be able to relate (or at least react) to others. However, in contrast to Participant 3’s comments, this participant suggested that given sufficient time dementia can destroy these capacities:

P6: That unless we have the ability to have relationships with other people, then we are not really in the "human potential."

AB: Mmhm...

P6: So people in vegetative states, people with end-stage dementia and new-born infants are not the same as everybody else... in the... who are able to umm at least have a social smile... or you know to be in some sort of a relationship. And the thing about new-borns is that that's temporary.

AB: And they quickly develop a social smile.

P6: Yeah, right! Yeah, it takes 6 weeks, you know it's one of the very first things... it's like so wired into our brains. Umm, that for survival, it's one of the most important things for an infant, you know! Umm... but yeah, what's the point if you can experience pleasure but not - if you can experience pain but not pleasure, what's the point... of being alive? Of being a human? Of being an alive human being?

...

AB: So can I move on now to asking how you think those things are affected in dementia? So, your ability to form and continue relationships, and the ability to experience pleasure.

P6: Yeah, I think that they're continued certainly through moderate dementia, umm. I think in severe dementia, umm, they can go away completely, or at the best, every once in a while in severe dementia, you know, has a surface of a smile or something where they seem to connect, but it's really hard to even know what that is.

AB: Mmhm.

P6: But yeah, I think by severe dementia it pretty much goes away. **Participant 6**

The thought that personhood could potentially be destroyed by dementia was echoed by another participant who said that at the “very, very, end stage” of dementia there is no discernible of the person’s identity left, and hence nothing of the person:

Is there something going in there that they are unable to communicate so that their sense of self may be preserved in there. So I'm not sure but no, nothing discernible. So at the very, very end, someone who is bed bound and unable to feed themselves and unable to walk and unable to talk, there's nothing that we can tell that there is any identity left. But until you get to that very, very end stage, I think that there's still something.

Participant 7

The disagreement by clinicians on whether or not dementia can destroy personhood reflects my comments regarding the intractability and contentiousness in definitively answering questions about personhood and dementia. As discussed in Chapters One and Four, the definitions of terms like personhood can be subjective and it is possible for one party to regard a being as clearly (still) having personhood, while other parties would be emphatic that they do not. This same distinction can also be evident on a smaller, personal scale when considering the family of a person with advanced dementia where one member may want to abandon life-prolonging treatments while others might want to continue. Situations similar to this, involving decisions about end-of-life care and the role of advanced directives were also explored in the interviews and are detailed in the next section.

5.2.4 Advance directives

The issue of advance directives was introduced to participants by way of the case examples described in the introduction and discussed in Chapter Four (most often Margo and Mr O'Connor). Typically, the participant would be asked to talk about how they would respond if there was an advance directive in place stipulating either a refusal or request for life-extending treatments, should they be medically indicated.

In responding to these cases, several participants wanted more detail about the nature of the advanced directive that was hypothetically in place, and expressed doubts about whether an advance decision could adequately take account of all the possibilities and implications of the decision. One participant expressed this concern as follows:

[T]he core problem with advanced directives [is that] you can say whatever you like but what actually happens is not usually something that you imagined. ... I'm much more in favour of advanced directives that say a few clear things and say why people think that. So that you can work with the 'whys' more than with the details. ... Although I encourage to move towards advanced care plans, and I bring up certain aspects like entry into care or ah, resuscitation regularly, I don't encourage people to write advanced directives outside of those mechanisms because people can never imagine what actually happens. **Participant 1**

If a person does not understand the implications of a clinical treatment and the options available then they cannot consent to that treatment, at least according to most contemporary standards of informed consent.¹⁰³ This extends to advance directives, in that we cannot hold people to their historical wishes when they did not have an accurate appreciation of the situation they would be in. Indeed, the problem of accurately understanding the complexities of any future situation may be as much a problem for the doctor as for the patient. The same participant goes on to say:

... how can we say people have indeed exercised their capacity back in the day, when they weren't talking about the situation? They couldn't imagine it, so they didn't imagine it. **Participant 1**

Some participants focussed on the ambiguity inherent in the notion of 'life extending treatments', referred to by commentators like Dworkin and Jaworska. They argued that the

¹⁰³ See for example Medical Council of New Zealand. Information, Choice of Treatment and Informed Consent. March 2011. <https://www.mcnz.org.nz/assets/News-and-Publications/Statements/Information-choice-of-treatment-and-informed-consent.pdf>.

purported distinction between life-extending and symptom reducing or palliative treatment is often not clear cut, and may involve some very difficult trade-offs. The following remarks from four different participants describe this problem:

You can't do a general scenario, "oh should we do life prolonging measure or we shouldn't, based on his values?" It's like... well are you giving him oral antibiotics that he's taking at home? Or are, is he going to go spend 9 weeks in an ICU, having, you know, painful, expensive, intensive things done that we're really not sure are going to work, for a 1% chance that he will survive 3 months out of the hospital at the end of this? **Participant 6**

There are very few treatments in medicine - contrary to popular belief - that are solely life prolonging or solely symptom reducing. Most medicines do a bit of both, the question is to what extent do they do both? **Participant 1**

Because if you look at it- what life umm, prolonging treatments are there? I mean... We're talking about like CPR or umm... Antibiotics when he's... Have an infection... That, yeah... I guess learning a bit more from him what life prolonging treatment for him means umm. Because it can mean different things. **Participant 3**

You know, someone gets a urinary tract infection, it's uncomfortable and makes them unwell but it probably won't kill them... So it might: they might get an ascending infection and pyelonephritis and die. So when, I think... We have to be clear about the purpose of our treatment at that point. The purpose is to relieve suffering. It probably won't prolong her life. It's possible it might, but probably not. If she gets a really raging pneumonia however, then I'm gonna have to think really hard about whether it's appropriate to treat that because that pneumonia may well end her life, particularly if she's relatively frail. **Participant 7**

The additional problem of patients changing their views between issuing the directive and the directive being applied was also raised by participants. An example from Participant 3 is illustrative:

I've never done one [an advance directive] with my older people because things can change- technology changes, your situation change.... And if you put something down on paper that becomes sort of... official and legal, haha. Umm. Yeah. Because this man, you know, you talked about - he may suddenly meet a new woman in his life and he may choose to live! Rather than not having life sustaining treatment. **Participant 3**

These views from participants expressing scepticism of advance directives are in line with the conclusions drawn in the previous chapter. The participants generally sought to know more about the patient (or case) in question in order to discern whether their decisions were meaningful to them, and said they would look for supporting evidence from family members.

They also emphasised how each decision should be considered on a case by case basis and maintained that a person may be capable of making certain decisions, but incapable of others.

A different set of concerns about advance directives relate to the place of autonomy in determining clinical decisions. One participant spoke about a perceived over-emphasis of autonomy as an ethical principle, and suggested that patient's preferences were not the only important factor in making medical decisions:

Our societies have gone too much to an autonomy focus... There are other ethical principles such as beneficence, non-maleficence and justice, in the principle based ethics. I think that autonomy has come to be like the only value. And so if it's the only value, umm, then the person's medical decisions, would be you know... Well "what would he do if he were not moderately demented?" But I think that's thinking on the wrong track. It's, it's, the, the doctor is a part of that relationship in guiding that and it is not a black and white decision. **Participant 6**

Over-valuing autonomy and under-valuing other ethical principles could perhaps push clinicians towards an aggressive treatment because a patient requests it, even though the clinician believes that the treatment may be more harmful than beneficial. Equally, it could lead to clinicians feeling they must always abide by patient's decisions to refuse treatment, even when there are good reasons to doubt that the decisions are well informed. This may be a problem throughout medicine but it becomes especially important when considering vulnerable patients who have difficulty making decisions or expressing their wishes, such as people with dementia or children with mental impairments. In the case of dementia, a historical set of values and wishes in the form of an advance directive may be used. However, this carries the problems already described: it is difficult to accurately predict what you will want in a situation you have not accurately imagined and your values can change over time. An alternative strategy that is often employed for people with dementia and usually used for children with mental impairments (as they do not have the benefit of an advance directive), is to discuss the decisions with those caring for the person and try to work out what is in the patient's best interests. There are of course problems with this also, for example, doctors and family member may hold different values to the patient. Moreover, the norms associated with established roles can cloud our judgements about what is best. As the same participant explains:

I think the roles, say of children, of protecting their parent is not nearly as strong as protecting a child. So when you get children who are either intellectually disabled or very young and parents and doctors try to work together to make medical decisions - what's in their best interest? And you have a whole confounder in this idea of 'my job

is to fight to my child, my job as a parent, my role as a parent is to fight for my child." And they can.... It might be more profound in the US, but they... a lot of the parents get into an adversarial role, like no matter what the doctor suggests, since their job is to fight, they have to do some... they have to fight for more than what the doctor wants to do and so... there's this... and more is always better... I've also had parents... many a parent who said "I wouldn't do this, I would never choose this for myself, but I have to do it for my child, because I'm their parent and I'm the one fighting for them."

Participant 6

These issues regarding the problems of advance directives and their role in decision making could be explored further, particularly in the light of national and international efforts to promote thinking around end-of-life decisions, and decisions involving patients whose capacity is impaired. Following the United Nations Convention on Persons with Disabilities, several countries including New Zealand are considering a shift towards 'supported decision making' instead of 'substituted decision making'. However, as this participant has pointed out, there are still issues within a system that focuses wholly on autonomy.

5.3 Conclusion

In this chapter I have described the findings of a qualitative study exploring how clinicians experienced in caring for people with dementia view the philosophical and ethical issues discussed in this thesis. Many aspects of the participants' views are broadly supportive of the conclusions drawn in the previous chapter. However, on certain points there is a lack of coherence or agreement in how the participants describe or approach difficult ethical situations raised by dementia concerning identity. Following this chapter, I will conclude the thesis as a whole by summarising my argument and offering areas for further investigation.

Conclusion

In this thesis I have explored the multiple and complex ways that dementia can affect a person's identity. I described several cases in the introduction to this thesis which illustrate some of the ethical dilemmas dementia presupposes, in regard to identity. The main concern of this thesis were the issues surrounding personal identity, though related issues concerning personhood have also been considered. I first approached these issues by outlining various theories of identity in Chapter One. Here, I described an important distinction between 'object theories' that consider identity to persist through an enduring entity, and 'agency theories' which instead regard a person's identity as grounded in their actions (or interactions) and the reasons for those actions. Within these agency theories, I highlighted that some actions and choices are more critical to our identities, and how a person's roles and relationships also have significant effects on these critical choices. The most pervasive object theory is memory theory, based on work by John Locke. According to this theory, a person's autobiographical memories are what constituted a person's enduring identity. In other words, identity is thought to abide in the persistence of memories, which are in turn imagined as psychological entities.

Given the importance of memory in Locke's widely accepted theory of identity, and the fact that memory is impaired in the most common forms of dementia, it was considered necessary to undertake a closer examination of what memory is. This was done in Chapter Two. There I described the recent paradigm shift in 'memory studies' away from an 'archival model', which conceives remembering as a simple, passive process of retrieving stored information, towards a 'process model', which regards remembering as an intersubjective process of renegotiation of the past. Reiterating work by Jens Brockmeier and Ian O'Loughlin, I provided arguments for this newer process model across various fields of memory research, including recent neurobiological evidence which refutes the idea of stored memory traces and places memory among similar mental processes such as perception and imagination.

In Chapter Three I provided some descriptive contextual information about dementia. This included local and global epidemiological data regarding the significant burden of disease that dementia poses to our current and future healthcare systems. I also described a typical clinical course of dementia, emphasising the subjective nature of the disease and the significance of psychosocial factors. Finally, I described the most common dementia sub-types, giving basic information about their pathophysiology, symptomology and treatments. Here, I elucidated a

significant distinction between frontotemporal dementia, which spares memory but significantly affects a person's behaviour, and other dementias which present primarily with memory difficulties.

In Chapter Four I re-examined how identity is affected by dementia, in light of what had been discussed in the previous chapters. I described a key difference between direct and indirect effects and considered how the theories of identity described in Chapter One might explain these. In doing this, I argued that object theories at best only partly explained the etiology of the identity problems in dementia and neglected important elements of a person's experience with dementia. In place of object theories, I argued for the use of an agency approach to personal identity, as these theories fit with the process model of memory, provide a fuller explanation of the identity problems that arise in dementia, and are more useful in guiding our actions in caring for people with dementia. In reviewing the cases outlined in the introduction, I maintained that some choices made by people with dementia can be considered autonomous, while others are not. This was grounded on the link that had been drawn between autonomous agency and a person's capacity to attach meaning to the outcomes of a choice. I also offered brief remarks on personhood, stating that while it seems that advanced dementia can destroy a person *qua* person, as with any terminal illness, it appears that this may happen before the physical death of the person if they are no longer able to engage in any meaningful behaviour. I stressed that the point at which this occurs is difficult to delineate and can be somewhat relativistic.

In Chapter Five I described the findings of a qualitative study exploring the views of seven clinicians experienced in dementia care. I discussed how the views of these participants were broadly supportive of an agency approach, particularly an approach that focuses on a person's roles and relationships. When discussing questions related to advanced care planning, most participants approached the problems from a pragmatic standpoint and were sceptical about the value or applicability advanced directives. Participants who discussed this matter stressed the need to consider these problems on a case-by-case basis.

There is still much left to explore within this topic. I have only given limited attention to the concept of personhood and how it is affected in dementia. A fuller account exploring the kind of actions that are meaningful to a person in advanced dementia could be informative. Similarly, a more thorough investigation into the effects that FTD has on a person's agency would improve an account of these challenging cases. Investigation into how different families

manage the indirect effects that dementia has on identity, and how psychosocial interventions can help manage direct effects, could be very useful to those caring for people with dementia.

It is my hope that the arguments within this thesis convey a coherent (if incomplete) account of the myriad ways a person's identity may be affected by dementia. I also hope that this account encourages cherishing people with dementia for the things that they are still capable of, and regards them as important members of our moral community. I believe this approach cautions against the unnecessary deconstruction of a person's identity through misinterpreting a person with dementia's actions and promotes an optimistic perspective on the degree of control people with dementia and those around them have over their lives.

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