Alzheimer’s: A Shared Disease
Experiences of Couples in an Alzheimer’s Support Group

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Abstract

Alzheimer’s disease, a chronic and progressive neurological disease, is a pressing global health issue affecting an estimated 18 million people worldwide. The clinical hallmarks of this condition are progressive impairment in memory, judgment, decision making, orientation to physical surroundings and language. In Europe these attributes are often seen to be fundamental qualities needed to maintain an image of an independent, rational person. This is indicated by much of the biomedical and social science literature has promoted a view of people with dementia experiencing a steady erosion of self until no person remains. This thesis explores these notions of personhood and self with respect to Alzheimer’s disease. How do couples in which one partner has the diagnosis of Alzheimer’s experience the disease process? How are these concepts experienced and discussed by the affected individual and their partner?

These notions of personhood and self are explored through qualitative research: five weeks of ethnographic fieldwork undertaken in the Alzheimer’s Society support groups, Stockport, UK. All study participants were in the context of a married relationship. The experiences of the individual with Alzheimer’s disease (the ‘cared for’) and their spouse (the ‘carer’) are examined. The research explores whether ‘cared for’ individuals are treated as persons and examines how they experience and express their inner subjective feelings and interactions with their social environment. Study methods include participant observation, in-depth interviews and newspaper research. Individuals with Alzheimer’s are viewed as positioned within a social and political context. An interpretative medical anthropology framework is used to explore the meanings, experiences and effects upon the couples’ concepts of personhood and self within this context.

This thesis argues that positive social interactions are key to the individual’s sense of personhood and maintenance of self. These interactions can be found both within the marriage relationship and in the Alzheimer’s Society itself. The concept of couplehood as an important factor within the discourse surrounding Alzheimer’s, self and personhood is explored. It is shown that the ‘cared for’ individual can be seen to lose independence as an individual yet able to retain it as part of a couple and thus the role of the ‘carer’ as protector of personhood is introduced. This thesis claims that the key to the positive social interactions within the couple and the Alzheimer’s society is the notion of Alzheimer’s disease as a separate disease entity to the affected individual. However, it is shown that the study participants with Alzheimer’s disease do not have such positive experiences within wider society. Their experiences of stigma and denial of personhood and its subsequent effect on their sense of self is explored through the thesis. Alzheimer’s disease is shown to be incorporated into the couples’ lives but not the individual’s sense of self. The thesis illustrates that through viewing the disease as a separate entity to the individual the ‘carers’ and the Alzheimer’s Society can be seen to bestow personhood upon the affected individuals and help them maintain a sense of self.
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1 Introduction

1.1 Background

Alzheimer’s disease, a chronic and progressive neurodegenerative disease, is a form of dementia. The term dementia is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions, including Alzheimer’s disease, vascular dementia, Parkinson’s disease, stroke and many other rarer conditions (Alzheimer’s Society, 2007). Dementia is biomedically defined as a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function. Although many people with dementia can retain their previous personality traits and personal attributes well into the disease process, as their condition progresses they can experience language impairment, disorientation, changes in personality, self-neglect, psychiatric symptoms and altered behaviour. Alzheimer’s disease is the most common form of dementia, accounting for about two thirds of all cases of dementia (Alzheimer’s Society, 2007). Distinguishing Alzheimer’s disease from other causes of dementia is not always straightforward. The clinical hallmarks of Alzheimer’s disease are progressive impairment in memory, judgment, decision making, orientation to physical surroundings, and language. A working diagnosis of Alzheimer’s disease is usually made on the basis of the history of symptoms and neurological examination. However, a definitive diagnosis can only be made after death through the performance of an autopsy. On a cellular level, Alzheimer’s disease is characterized by unusual helical protein filaments in the neurons of the brain: neurofibrillary tangles (Hashmi, 2009). On an anatomical level, there is degeneration of the cortical regions, especially the frontal and temporal lobes, of the brain. Due to this difficulty in diagnosis, the terms Alzheimer’s disease and dementia are therefore often equated and used interchangeably. In this thesis I shall be focussing on people’s experiences of Alzheimer’s disease, not other forms of dementia.

It is estimated that there are currently about 18 million people worldwide with Alzheimer’s disease. Although not solely a disease of old age, the prevalence of the disease increases with increasing age. With an aging population on a global scale, therefore, this figure is expected to nearly double to 37 million affected people by 2025 (World Health Organisation, 2006). Alzheimer’s disease is regarded as the most bewildering and frightening condition facing the aging population in the twenty-first century (Kontos, 2006) and represents a much feared stigmatising label that carries with it the force of a sentence such as social death. Much of the biomedical and social science literature on Alzheimer’s disease promotes the view that individuals with dementia experience a steady erosion of selfhood to the point at which no person remains (Kontos, 2005). It is this notion of personhood and self which this thesis will consider with regard to Alzheimer’s disease.

1.2 A Personal Reflection

It is my personal experience with dementia that has fueled my interest in the topic. My maternal grandmother had vascular dementia and my paternal grandfather was diagnosed with Alzheimer’s disease. They were illnesses I found very hard to deal with. I was more involved in my grandmother’s evolving illness than my grandfather’s. Over the years I felt many mixed emotions: grief, confusion, sorrow, anger at the illness, anger at my grandma for causing distress to my family, not knowing how to be with her anymore. At times I felt my grandma was there, at other times it felt like the woman...
who sat opposite me had nothing to do with my grandma as I had once known her. I felt I had lost my grandma long before she actually died, yet I still felt tremendous grief when she did die. The last time I saw her she was lying in bed, no longer able to walk, talk or eat. I had just returned from a trip to India and had visited the town where she and my grandfather had lived fifty years previously. I told her about the town, the people I had met who had known them, how people still remembered them, how I’d gone to the beach where they had been on Christmas day. I don’t know whether she did really understand what I was saying to her but her smile, to me, seemed like she did. Still to this day I do not know how to reconcile the experience. I do not know whether I think there was anything of my former grandma left by the end of the illness. The way she was with dementia certainly wasn’t the way I wanted to remember her. I wanted to remember her as the ‘supergran’ that my friends had nicknamed her: a strong, independent, caring, selfless, intelligent lady riding a bicycle. Yet I wonder whether she was any less of this lady when she had dementia. I am fascinated with how we view people with dementia, how we view them as people, how we hold on to or abandon their former, pre-dementia, selves.

During my work as a junior doctor I have felt anger at the lack of respect and dignity I perceived people with dementia to receive in hospital. I felt they were denied their personhood and treated very differently to an adult who was considered to have full cognitive abilities. A care assistant from the nursing home in which my grandfather was a resident attended his funeral. My father and uncle spoke about his life, the experiences he had had, the relationships, the jobs, his interests and passions. After the service the care assistant told my father that she wished she had known all about his life when he was alive. She said she could tell he was a ‘true gentleman’ and had a great sense of humour but she really wished she had known more about him. There were obviously some parts of my grandfather’s personality that shone through despite his dementia, some essence of who he was. But how did his illness change him? How did his diagnosis of Alzheimer’s disease change the way he was treated and viewed within society? He was once a respected business man, a husband, a father, a cheerful friend, a church leader. He then became a nursing home resident, his previous roles unknown. I wonder how he felt about his changing roles and if he felt the sense of who he was changed.

Both my grandparents were diagnosed with dementia, Vascular Dementia and Alzheimer’s disease, relatively late in their illness. With my grandmother we, as a family did not know much about dementia, did not know the help that was out there and indeed, the topic did not have as much medical recognition at that time (the early 1990s). With my grandfather we did not realise the severity of his symptoms until my grandmother died; as a couple they had been able to manage the confusion and forgetfulness, my grandma seemed to have hidden the symptoms, but on his own he could not cope. I am interested on the impact of a diagnosis of dementia, both on the individual concerned and their immediate family. I am interested in the experience of dementia from the perspective of the individual labeled with the term; the problems and situations which they perceive. I want to know how they view their lives, who they are and how they view their relationships. This thesis will explore these issues.

1.3 Statement of Interest

In the UK alone there are 700,000 people already living with dementia and with the country’s population ever aging the burden of disease is expected to continue to increase. The problem is vast: an
estimated 60,000 deaths a year in the UK directly attributable to dementia and the financial cost of dementia to the country being put at a value of over 17 billion pounds a year (Alzheimer’s Society, 2007). Alzheimer’s disease is the most common cause of dementia, affecting around 417,000 people in the UK (Alzheimer’s Society, 2007).

Much of the discourse surrounding Alzheimer’s disease has focussed upon the financial burden of dementia upon the state and the emotional, financial and moral burden upon the family. However, I believe it is interesting to look at the role of the person who has, themself, been diagnosed with Alzheimer’s disease; to hear the voice of the person with dementia; to attempt to understand the suffering, or lack thereof, of the person who has been diagnosed. It is this notion of personhood and self which I believe is interesting to consider with regard to dementia. Although this research is not problem based per se, i.e. not aimed at understanding a problem and therefore giving recommendations for its resolution, I do believe that the theoretical interests of this research, having a greater understanding of the issues at play with regard to Alzheimer’s disease could, in turn, add to the debate about how to improve care for people with dementia and their families.

In recent years there has been a small increase in interest regarding the experiences of people who have been diagnosed with dementia. Theoretical models have been proposed that incorporate not only the biological and neurological aspects of illness, but also an explanation of the effect that a person’s social and psychological resources can have on the presentation and the subsequent course of the disease (Kitwood, 1990). However, there has been a lack of research placing the person with Alzheimer’s disease and their experiences into a wider social and cultural context (Bartlett and O’Connor, 2007).

The way in which the body is perceived is inherently cultural and varies hugely, even within a given society. Many Europeans act and experience themselves as autonomous and bounded entities (Cohen, 1998 in Hashmi, 2009). However, this independent construction of self can be perceived as being socially constructed (Markus and Kitayama, 1991), rooted in western philosophical tradition and linked to a Cartesian view in which the goal of existence is to objectify the self: the ontological goal is to separate the individual from the context. It is this notion of an independent self that I wish to focus upon; how it affects the concept of old age, and especially that of the cognitive decline involved in Alzheimer’s disease in the context of the UK.

In some settings the prestige-generating components of old age have been devalued over time (Cohen, 1995). It could be argued that this is the case for the UK. Physically frail elderly people who are unable to contribute to the work or economy of a household may find their status rapidly reduced: what they have to offer may not be seen as particularly worthwhile. As an individual becomes unable to look after themself, unable to maintain an independent existence, their experience and indeed the validity of their self may be questioned. Even during the early stages of Alzheimer’s disease, the person affected may be absolved of subjectivity and agency, their decisions questioned under the remit of lacking capacity. Each uttered memory lapse could be seen to articulate an erosion of what is fundamental to the experience of self in the west: the ability to be independent and account for oneself.

As the World Health Organisation (2006) states, the diagnosis of dementia does not just affect the individual, it has a great impact on those around them, the person’s family and friends. The symptoms of dementia, regardless of their aetiology, are attributional: it commonly requires two or
more bodies for diagnosis, a senile body in which the disease process is located and another who has noticed change in the first (Hashmi, 2009). It is through these care-givers that the symptoms, and disease process, are publicly experienced and made to matter. It would therefore correlate that the timing of diagnosis correlates more closely with levels of family stress than with the extent of disease (Cohen, 1995). It is also the experience of these family members, those who notice changes in their mother or father, husband or wife, that this thesis focusses upon. How did they experience the process, how did diagnosis come about, how did they define that there was a problem and how do they relate to their loved one now?

Diagnosis of dementia and Alzheimer’s disease is reified as biological and objective but I question how this is so when it is usually the carers and society at large that highlight that something is wrong; the individual is displaying inappropriate and unacceptable behaviour; their normality is questioned. Cohen ((1998) in Hashmi, 2009) argues that the biomedicalisation of dementia means that there has been a narrowing of the ambiguous distinction between normal aging and pathological dementia, the common sense knowledge observation that old people forget, some far more than others. Senile plaques and neurofibrillary tangles which are present in the brains of old people with Alzheimer’s disease have become pathognomic of the disease (Hashmi, 2009). However, this cannot be discerned by a doctor when presented with a person with memory or behavioural problems; problems which have been identified by those close to the affected person. It appears to be the cognitive decline, the inability to remember facts, routines and people that is pathologised in western societies. It appears that it may be this that is recognised, that causes distress to family and society and which therefore results in the person with such problems to be highlighted to the medical profession and diagnosed with Alzheimer’s disease. I wonder how these concepts affect people’s experiences of Alzheimer’s disease; how the norms of independence, of being a rational, thinking human and norms and ideals of growing old affect how society thinks about elderly people with memory and behavioural changes and in turn how this influences how the individual thinks about themselves.

In this thesis I will look at the discourse surrounding Alzheimer’s disease in the setting of an Alzheimer’s support group in a small town in the north west of England. I will look at the experience of Alzheimer’s disease by those who have been diagnosed with the label as well as a family member who is close to them. Overarching this research will be an attempt to discover the lived experience of Alzheimer’s disease and how personhood and the self are discussed and experienced within the Alzheimer’s framework. What does Alzheimer’s mean to those labeled with the diagnosis? What is their experience of their symptoms? What do they think their problems actually are: what is at stake for them? What is their story about diagnosis, their relationships with others and their changing role in society? How does society think about these people and how do they perceive society?

I will explore how Alzheimer’s disease affects a diagnosed individual’s family member. I will listen to their story, their experience of problems, diagnosis and life after diagnosis. I want to explore how they view the person now; what has changed, if anything, for them and their relationship with their loved one?

There has been relatively little research on the individual with Alzheimer’s perspective, their own experiences and difficulties (Dewing, 2002). Although there has been a great emphasis in the social science Alzheimer’s literature upon personhood (Kitwood, 1990; Kitwood and Bredin, 1992; Kitwood,
1997) and this lens has afforded the rationale and language for improving care and raising consciousness about the status of people with dementia, the concept remains very much at the individual level, focussing on those with dementia, not how society views these people (Bartlett and O’Connor, 2007). The concept took the notion of ‘demented people’ where dementia was seen as the prominent, pathological entity, to ‘people with dementia’ where, despite the biomedical label, people were afforded respect and their right to personhood. However, this attention to personhood has not viewed the concept as a process; it has not looked at the individual’s effect in shaping the experience but seen it as something that can be bestowed by society to one of its marginalised members. I feel that my research will further explore this notion of both the individual and society shaping a sense of self. My research will look at Alzheimer’s disease as a process and will explore the experiences of both the individual and a family member in this process. I will address the situations, difficulties and experiences that are important to them and that affect their sense of self.

1.4 Objectives

To explore the individual experience of, and wider influences upon, Alzheimer’s disease from the perspectives of the affected individual and their family in Hazel Grove, England, with the emphasis on personhood and self.

To assess the extent to which the inner subjective experiences of those with Alzheimer’s disease can be explored by a qualitative researcher.

1.5 Research Question

How are notions of personhood and self experienced and discussed by people with Alzheimer’s disease and their family?

1.5.1 Subquestions

How is Alzheimer’s disease as a process understood by those labeled with the disease and their family. What does it mean to them?

What is the experience of Alzheimer’s disease as perceived by those with the condition and their family?

How do affected individuals view themselves, their relationships and their roles in society?

How do they feel this has changed through the process of Alzheimer’s disease?

How do family members talk about the effect of the symptoms of Alzheimer’s upon their loved one?

- How has their social interaction with the affected individual changed since the onset of Alzheimer’s disease symptoms?
- How do they view the person now?

How do both the person with Alzheimer’s disease and their family feel society relates to a person with Alzheimer’s disease?
1.6 Overview of Thesis

This thesis explores the concepts of personhood and self with regard to the experience of an individual with Alzheimer’s disease and their family member. Chapter 2 will explore these concepts, the theoretical perspectives used in this thesis. An overview of Alzheimer’s disease as a process in the making will be presented and a review of relevant literature to this study detailed. In Chapter 3 the methodological approaches used in this thesis are discussed and a more detailed context of the study given. Chapters 4, 5, 6 and 7 are the empirical chapters discussing this thesis’ findings: the ambiguity of Alzheimer’s, the importance of the couple, the Alzheimer’s Society: a shared context and society and stigma respectively. A conclusion and discussion of the findings will be presented in Chapter 8.
2 Literature Review

2.1 Theoretical Perspective

This research lends itself to an interpretative medical anthropology framework. I will use a meaning centred approach: how do people attach meaning to dementia, old age, their social functioning and self? What is the meaning for different people and how is this meaning created? Good (1994) explores the idea of the medical system as a cultural system. From this perspective we can see Alzheimer’s disease not as an objective, rational scientific entity, something that is tangible and static, but as a phenomenon created out of cultural meaning. Similarly, Good, in his meaning-centred approach to illness, argues that a disease is not an entity but an explanatory model (Kleinman, 1980), having different meanings for different people. He argues that illness is constituted and only knowable through interpretative activities; people may have a biomedically defined disease but experience their own illness. I argue that dementia is only knowable through its interpretation. I assume that the phenomenon will be interpreted differently by the various people involved in its construction: the individual, their family, the doctor, the scientist, the social scientist, Alzheimer’s advocacy groups, the media, government policy makers etc. Good advocates neither reifying, nor denying, the significance of biology but instead interpreting its meaning in a wider context. My research does not aim to deny the existence of a phenomena of symptoms which we recognise as Alzheimer’s disease. I do not deny that there is a neurological process at play and there are anatomical anomalies that can be identified in the brains of people with dementia. I am, however, arguing that our interpretation of these phenomena, how we react to them, how we label them, how we think people with these symptoms should be managed, are cultural in their essence. The cognitive and behavioural changes which are expressed by individuals are interpreted by the actors with which they are involved and placed in a social, historical and political context. Their meaning is therefore ever dynamic and in flux:

“Cultural interpretations interact with biology or psychophysiology and social relations to produce distinctive forms of illness and illness trajectories” (Good, 1994; 56).

I argue that dementia and Alzheimer’s disease cannot be seen as static biological entities with a given trajectory, instead the meaning and interpretation of the symptoms will depend upon the circumstances in which they are created: in this case that of UK society.

A useful concept in which to understand the influences upon an individual and their family member’s experiences of dementia is the perspective of the Mindful Body (Schepes-Hughes and Lock, 1987). Applying this concept to my own work will allow me to consider the powers at play in shaping how the UK population, at least that of a particular subgroup of the UK population, think about dementia and Alzheimer’s disease, the person and the self. The individual body describes the phenomenological sense of the lived experience of the body-self (Schepes-Hughes and Lock, 1987; 7). I will look at how those labeled with Alzheimer’s disease experience and describe their life; how they view themselves now they are under the label of a disease, that of Alzheimer’s. However, I recognise the limitations in an individual’s ability to express themself and give an insight into their own individual experience. This can only be done through language: the individuals will express themselves in socially appropriate (and constructed) language.
The social body can be seen as the representational uses of the body as a natural symbol with which to think about nature, society and culture (Scheper-Hughes and Lock, 1987; 7). The social body can be seen as the interpersonal relationships in which the affected individual is involved: their family, their friends, the support group etc. Alzheimer’s disease, and the concepts the notion evokes, are discussed between these people. However, it would also be interesting to place these concepts in the wider societal discourse. What are the norms and ideals of growing old? How are the norms of independence and the thinking, rational human discussed and symbolised within society?

The body politic describes the power relationships between the individual and social bodies (Scheper-Hughes and Lock, 1987; p. 23). This concept therefore draws on the structural power relations at play in the discourse regarding Alzheimer’s disease: the structural bodies that influence the individual and social bodies. I see the body politic, in the case of Alzheimer’s disease, including such agencies as the National Health Service (NHS) and biomedicine (the diagnostic criteria and the biomedical discourse in which the condition is explained), the media and advocacy agencies such as The Alzheimer’s Society, Governmental policies (frameworks that look at the problems older people face), economic factors such as pension schemes etc. and issues regarding access to care (the provisions made for people with dementia, help in the community, care homes, hospitals and the funding of this care).

The time constraints of this research would not allow for an in-depth study into the social, structural and political influences on the lived experience of Alzheimer’s disease. However, I have tried to keep in mind that there are powers at play that will shape the individual’s experience and have tried to be attentive to whether these were discussed or alluded to within the Alzheimer’s Society discourse as well as the individual experiences of the disease. I strove to see the individual experience as shaped by social and political factors, not as individuals acting alone in a vacuum.

2.2 Alzheimer’s Disease in Process

2.2.1 Alzheimer’s Disease

Alzheimer’s disease, the most common form of dementia, is a degenerative brain syndrome characterized by a progressive decline in memory, thinking, comprehension, calculation, language, learning capacity and judgment, sufficient to impair personal activities of daily living (World Health Organisation, 2006). Dementia, derived from the Latin words, de=out from, mens=mind, can be seen to equate to loss of impairment of mental powers due to disease. Gaines and Whitehouse (2006) view the development of Alzheimer’s disease as an unfinished, ongoing product in the making, that has evolved from a series of decisive historical moments. These historical moments have contributed to the construction of a disease, that of Alzheimer’s, the character of which is construed as a degenerative biological, clinical entity, one that seems to deny its social construction. Gaines and Whitehouse (2006) argue, however, that Alzheimer’s disease is more a discursive formation rather than a discovered pathologic entity. Instead of viewing Alzheimer’s disease as an objective pathological and clinical entity, they suggest the notion of local biologies (Gaines (1992) in Gaines and Whitehouse, 2006) where biologies are viewed as being constructed differently in different countries and at different times. Alzheimer’s disease and dementia in general, although purportedly found all over the world, have differing meanings and varying presentations in different countries and cultures (Cohen, 1995; McCabe, 2006; Hashmi, 2009; Ikels, 2002; Hinton and Levkoff, 1999). For example, in Bojaca, Columbia, the aged are esteemed
participants in the daily activities of family and community life and respectful allowance is made for the childlike behaviour of the senile (Hashmi, 2009). Hashmi (2009) has argued that by examining how dementia is constructed and treated in other cultures we obtain a valuable insight into why we construe and treat dementia the way we do in the west: why dementia, in the west, is viewed as tangibly pathological, degenerative and neurological.

### 2.2.2 Senility

In order to better understand how Alzheimer’s disease is understood and constructed in north America and Europe, I believe it is essential to explore how it has evolved from a broad concept of senility into a discrete disease entity. Senility has been a much explored topic in both medical and popular literature. Cohen (1998) defines senility as the perception of deleterious behavioural change in someone understood to be old, with attention to both the biology and the institutional milieu in which such change is marked, measured, researched and treated. Senility, an old person showing weakness, especially loss of mental faculties, is inherently cultural. Senility had no grounding in biological research, no demonstratable pathology but was a term used to describe the behaviour of older people. The image of senility was one of mental deterioration signifying the start of the gradual, vegetative process of death, the slow, top down withering away of life (Beard (1874) in Ballenger, 2006). Beard represented the senile in a number of characteristic guises; as miser, tyrant, fool and dirty old man. This stereotypical representation of the senile man remained dominant in medical and popular texts until the 1940s (Ballenger, 2006).

### 2.2.3 Gerontology

The popular and professional literatures on aging which had originally focussed on the notion of senility were reshaped in the mid twentieth century by the creation of gerontology as a field of research and practice contributed to by a diverse array of biomedical and social scientists, policy makers and activists. These groups held a more positive attitude towards aging and a commitment to improving the lives of the elderly. They argued that the elderly were in fact made decrepit and senile primarily because modern society no longer made a place for them (Ballenger, 2006). The problems of aging were seen as an unintended, and unnecessary, effect of modernisation (Simmons (1952) in Ballenger, 2006). Simmons highlighted the cultural construction of senility: whilst it was a virtually universal phenomenon, it was an ascribed status which was culturally contingent. Senility was not an objectively measurable state of physical weakness and mental infirmity but an ascribed status of uselessness and burden, a status that may be attained under various degrees of physical and mental debility in different societies. This account placed senility as a societal problem: modern society created the problems of aging. As a consequence of medical and economic progress far larger proportions of the population lived to old age and mental decline. The model of social production of senility as an account of the pathogenesis of dementia improved the lives of older people (Ballenger, 2006) with a less stigmatised view of growing old throughout the 1960s.

### 2.2.4 Medicalisation

In the 1970s ageism became a key word in the field of gerontology. The term was coined by Butler to describe the “process of systemic stereotyping of and discrimination against people because they are
old, just as racism and sexism accomplish this with skin colour and gender” (Butler, 1975; 43). Butler and other gerontologists argued against the idea that the process of aging involved inevitable physical and mental decline. They rejected the idea of senility because it was not a medical diagnosis but a “wastebasket” (Butler, 1975) term to apply to any elderly person with a problem. This, he believed, led to discrimination and stigmatisation of elderly people and they did not receive the medical attention which he thought they were entitled to. He argued that the ageist refusal to systematically distinguish the various physical and mental disease processes from one another and from the process of aging itself exacerbated the tragedy of mental illness in old age. Butler focussed on making funding for Alzheimer’s disease a priority and played a key role in breaking down the concept of senility. Deconstructing senility involved recasting irreversible progressive dementia in old age as a number of disease entities distinct from aging. Alzheimer’s disease became a collection of symptoms and behaviours that were regarded as a brain disease. Researchers argued that this entity was not a part of aging but a disease whose mechanisms could be uncovered through biomedical research and eventually lead to effective treatments and ideally prevention. It was a disease rather than senility (Katzman and Bick, 2000).

2.2.5 Cultural Construction of Alzheimer’s Disease

Cohen (1998) argues that the biomedicalisation of dementia means that the ambiguous distinction between normal aging and pathological dementia has been narrowed. The boundary between normal aging and a pathological disease entity is clearly in existence but what is this line and how do we define it? When is one merely forgetful and when does one have Alzheimer’s disease? Normal and pathological aging have a tendency to overlap. When our diagnosis of Alzheimer’s disease is not based, at least initially, on a visible, tangible, quantifiable entity (see American Psychiatric Association, 1994) but on recognising a series of symptoms and signs how do we make this distinction? Hashmi (2009) argues that attempts to clearly differentiate between this normal and pathological aging are a social construction to create some kind of order from the disorder of living with a confused elderly person. This boundary, or line, separating the normal from the abnormal behaviour, the normal and the pathological memory loss is clearly described by Gard (1992) in his “fictional synthesis of one of the great human tragedies of our time - Alzheimer’s disease”, one based on his experience of watching an old friend become demented (Gard, 1992; ix). Becoming demented is described, by Gard as a slow process, but one where there is a boundary, albeit difficult to find and define, between normal and pathological:

“They have all passed some invisible line. They can never come back and their families know this and perhaps have witnessed it happening over the years, but they could not prevent, nor could they identify exactly when their loved one crossed the line of no return”
(Gard, 1992; 21).

Where is this line? How and where does one cross over it? How do we define it and is its definition different for different people? For Gard, finding this line was crucial, for it defined the boundary between normal and pathological, between a coherent, stable self and the incoherent, chaotic dependency of dementia. In my own research, I will view Alzheimer’s disease as a process. This thesis will explore how those with Alzheimer’s and their family member view the transition from no diagnosis to diagnosis, how it has affected them and where their boundary lies.
2.3 Personhood Movement in Alzheimer’s Disease

One of the crucial components of this perceived boundary between the normal and the abnormal, normal aging and dementia, is often portrayed as a coherent, stable self versus an incoherent, chaotic dependency. It is this notion of personhood, or self, that will be explored in this thesis. I will explore how people with Alzheimer’s disease view themselves and how others view them.

The concept of personhood, its denial and then its subsequent reification, has been present in much of the literature regarding dementia and Alzheimer’s disease. At the beginning of this personhood discourse, Alzheimer’s disease was seen as a grave situation, a much feared illness, one that allowed no space for a preservation of personhood. People with Alzheimer’s disease were seen to lose things of enormous value in western culture; their individuality; their selfhood. Traditional views of personhood focussed largely upon cognitive abilities such as consciousness, rationality, intentionality, memory, reciprocity and capacity to communicate (Bartlett and O’Connor, 2007). Because dementia is associated with a progressive decline in these cognitive functions, the disease was therefore assumed to strip the individual of their personhood status and lead to a loss of self. The self was thought to be increasingly devoid of content, a process referred to as ‘unbecoming’ a self and ‘drifting towards the threshold of unbeing’ (Kontos, 2005). The literature viewed dementia as a condition of debased personhood and the Alzheimer’s construct was associated with vividly disturbing metaphors and image of Alzheimer’s disease as “the funeral without end”, “the loss of self” and “the death before death” (Herskovits, 1995).

In response to the “loss of self” assumed to accompany the disease, a burgeoning literature representing and debating the nature of subjectivity and personhood in Alzheimer’s appeared. This personhood turn, the movement within and among clinicians, lay and academic spaces aimed to re-discover the person lost within dementia diagnosis and care. Challenging traditional understandings which had linked personhood solely to cognitive functioning, personhood was revisioned as also being socially constructed by and within one’s interpersonal environment. Kitwood (1990; 1992; 1997) stressed the influence of interpersonal relations as an essential aspect for understanding the dementia experience, theorising that at least some of the deterioration seen in persons with dementia was caused not by the disease process itself, but rather how the person was treated. He believed it was this interpersonal environment which resulted in the individual’s subsequent loss of personhood (Kitwood and Bredin, 1992). The claim was made that *malignant social pathology*, the interactions that tend to depersonalise the sufferer of Alzheimer’s disease, was integral to the downward process of dementia (Kitwood, 1990). Kitwood (1990) highlighted examples of these depersonalising social relationships: disempowerment, infantilisation, intimidation, labeling, stigmatisation, invalidation, ignoring, mockery and objectification. The personhood model was built upon a foundation where selfhood was thought to reside simultaneously in the brain and the social context. The personhood literature displaced the biomedical model as the only approach for understanding dementia. Rather than assuming a trajectory of inevitable decline related to neurodegenerative changes, the personhood perspective recognised that performance, behaviour and quality of life are not solely determined by neuropathology but also by interactions with others and by how one is perceived within one’s social context. This social interaction will be a focus in this thesis.
2.4 Personhood and the Self

Before exploring the notions of personhood and self in relation to Alzheimer’s disease, I feel it is important to give an overview of the concepts. In order to understand whether people with dementia are afforded personhood we need to know what personhood entails. To understand how, indeed if, the process of Alzheimer’s disease affects the self, we first need a definition of the self.

2.4.1 Personhood

For anthropologists, the classic source on the concept of personhood is Mauss (1938), *A Category of the Human Mind*. Mauss saw the conception of personhood in terms of individual consciousness rather than the embodiment of social relations (Mauss (1938) in Carrithers et al., 1985). Early development of the person, for anthropology, was concerned not with the experiences of individuals, but with an abstracted and generalised view of the notion of personhood: what it meant as a concept. Mauss saw a person as a category of thought, a fundamental and inescapable component of human cognition (Carrithers et al., 1985). He saw the person as a matter of law and morality, what people should and shouldn’t do, rather than the internal or psychic sense that anyone might have themselves. His interest was not the sense of self but the collective notion or concept that men in different ages have formed of it (Mauss (1938) in Carrithers et al., 1985). It is clear that personhood was conceptualised as distinctively different to that of the self. Personhood was seen as a concept held by society and bestowed upon an individual; it is socially constructed. Mauss’ conceptions of the person as culturally and historically constituted and constantly subject to change provided the foundation for most subsequent anthropological writing on the subject (Barnard and Spencer, 2002).

Kitwood (1990; 1992; 1997) also advocates the concept of personhood as one that is bestowed by society onto an individual:

"
a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements"

(Kitwood (1997) in Bartlett and O’Connor, 2007; 109)

The notion of what it is to be a person, I would argue, is decided by the dominant norms of society. These norms are then considered and applied to people who match these attributes: only some people match the dominant societal notion of what it is to be a person. In the west this notion of personhood has focussed upon cognitive abilities such as consciousness, rationality, intentionality, memory, reciprocity and capacity to communicate (Bartlett and O’Connor, 2007). Clearly, in the case of dementia, there could be debate regarding whether an individual fulfilled these attributes. If our notion of what personhood entailed were to change, i.e. if memory was no longer deemed important but the ability to perform tasks or to display emotion was valued in its place, then we would need to reconsider who, or indeed what, fulfilled the requirement for personhood.

Throughout the course of this thesis I will use Kitwood’s definition of personhood. I will see it as a status that is defined by society and then bestowed upon individuals.
2.4.2 Self

This thesis does not aim to define the self but rather explore how it is experienced by those with Alzheimer’s disease. For the psychological anthropologist, who writes of selves rather than persons, the individual embodied self bears its own character which is distinct from the cultural setting (Barnard and Spencer, 2002). If we consider the self as such an individual notion it can, therefore, be at odds with the society in which it lives or may even be marginalised by it. A person with dementia may see themself as a fully functioning member of society. This may not, however, be the notion that society equates with the person; society may view them as a dependent burden. Whereas Mauss, in his discussion of the person, ignored the relevance of experience to the person, experience and therefore social interactions are valid topics of study with regard to the self (Barnard and Spencer, 2002). What an individual experiences, the social interactions in which they are involved, may influence their self, their subjective experience of being.

The self has been described as a reification of a secreted entity (Whittaker, 1992): a concept of self that is never visible but abstracted and assumed to be there, concealed within the individual. The sense of inaccessibility that characterises the concept is coupled with a sense of the uniqueness of each self. Thus, self can be perceived as a metaphor for what is assumed to exist. However, it is also argued that the self is only possible in society (Whittaker, 1992) for it is only in society that it can become cultivated to the presence of others, a necessary component of its very existence. Taking this view, the self is only experienced in the presence of others, within social interactions. It is an individual subjective experience but needs others in order to exist. We cannot have a sense of who we are without hearing (consciously or unconsciously) what others say about us and how they interact with us, comparing ourselves to the norms of society, thinking about ourselves in the context of these norms and experiences. Personhood was conceptualised as the norms of society bestowed upon a person. A sense of self is, perhaps, an internalisation, a subjective reworking of these societal norms and interactions. Spiro (1993) discusses the idea of self providing a meeting point and framework for the relation between the individual and social world. Societal ideas about what a person should be, the roles and attributes of a person, the ways they are treated by others, are perhaps incorporated by the individual, internalised into their sense of who they are. The cultural context in which a person is situated, the interactions they are subjected to and participate in, therefore make claims upon the person and shapes their sense of self.

The notion of the self as a manager of identities is proposed by Sökefeld (1999). Identities can be considered as building blocks for the construction of an image of self. These blocks are not simply laid as they are supplied but are trimmed and given forms that can be incorporated into an integrated whole (Sökefeld, 1999; 426). Here the concept of agency is introduced. The individual reflects upon these building blocks and determines which aspects of identity, the roles and attributes which society has defined, should be incorporated into their sense of self. In the case of someone with Alzheimer’s disease does the label of Alzheimer’s disease, someone who has memory problems, get incorporated into how they think about themselves? Do they see it as essential to the way they view themselves and how others view them? Do they choose to share their diagnosis with others?

Charmaz (1999) distinguishes between self as a process and self as an object. Self as a process describes the emergent nature of self: a self that unfolds, develops and evolves over time. This follows
the symbolic interactionalist assumption that the self is always in process and never a final static fixed product (Charmaz, 1999). From this perspective, similar to that of (Sökefeld, 1999), individuals can structure and evaluate themselves as they can any other object or person. The self as experienced can be viewed as:

“an organisation of attributes, sentiments, values and characteristics through which people define themselves” (Charmaz, 1999; 367).

The self, as viewed here, has boundaries as well as content: some things are incorporated into the sense of self and others are not. I, like Charmaz, propose seeing this sense of self as a process, not a fixed entity. I see it as something that is managed by the individual (Sökefeld, 1999) through reflexivity and agency. This reflexivity and agency will take place in a context. I therefore see the social interactions in which someone is situated as central to the self as a process. It is within this context, these influences, that an individual will view themselves and reflect upon themselves, their attributes, sentiments and values.

Clearly, as Whittaker (1992) stated, the self is contained within the individual: an outsider cannot know another’s self, only what he or she chooses to share and represent to others. It is this representation which I am interested in. How a person with Alzheimer’s disease represents themselves and how their family defines them; the important roles, attributes, sentiments, values and characteristics they relate to. This thesis will look at how the individual feels they have changed, indeed if they feel they have changed, through the process of Alzheimer’s disease.

2.4.3 The Western Independent Self

Markus and Kitayama (1991) focus on two theories of the self: the independent and the interdependent self. The main focus of difference in the construal of these selves is people’s beliefs about the relationship between the self and others and especially the degree to which they see themselves as separate from or connected to others. These differences are assigned to two cultural frameworks: the western framework being associated with the idea of an independent self and the non-western framework with the interdependent self.

The cultural framework of independence is described as the set of beliefs about the self in North America and Europe. Tied to an ideology of individualism and egocentricism, this self is defined as an independent, bounded entity. Specifically the model states that the self comprises an unique configuration of internal attributes (e.g. traits, emotions, values and rights) and also behaves primarily as a consequence of these attributes (Markus and Kitayama, 1991). An explicit social goal, from this perspective, is to separate one’s self from others and not to allow undue influence from others or connection to them.

It is this western notion of self, that of independence, which appears in much of the literature regarding Alzheimer’s disease. It is the cognitive decline which leads to difficulties in maintaining the activities of daily living which in turn threatens the existence of independence. Alzheimer’s disease often leads to dependency upon others, something, which according to this independent notion of self, goes against its very aim. In the course of this research I will examine how my research participants discuss independence with relation to Alzheimer’s disease, whether independence and its decline to
dependency, being a burden, are important aspects, or fears, of their Alzheimer’s experience and how their social interactions reflect this desire, or lack of, for independence.

### 2.5 Personhood and Self in Alzheimer’s

There is a growing literature emphasising and arguing that there is a maintained sense of personhood in Alzheimer’s disease. Different researchers view the maintenance of personhood and sense of self in varying ways. Li and Orleans (2002), for example, assess the construct of self in Alzheimer’s patients residing in a care facility. They used qualitative research methods, observing patient actions and also interviewing family members and staff, to determine whether a sense of personhood was retained in the individuals diagnosed with the disease. The research emphasised how patients identified meaning in seemingly trivial everyday aspects of residential care and emphasised that a concept of self was sustained despite the effects of the disease. The notion of self and personhood was transformed from one based solely upon cognition, memory, recognition and life-stories to one based in the present moment where meaning is continually created within social interactions.

McLean (2006) assesses the ability of people with Alzheimer’s disease to tell meaningful life stories. She uses a phenomenological approach to explore the narrative meaning of just one lady’s story. McLean challenges the assumption that lack of an apparent capacity to produce a coherent and authentic life story is a sign of a loss or failure of selfhood. She argues, instead, that narratives should be examined as texts that cohere within themselves independent of any external validity of their truth value. She sees people with dementia, despite their considerable loss of coherence, being able to create a story that becomes a form of living:

“*When a person tells her life story, no matter how fictitious the account, her narrative does not reflect the past, but rather becomes the past. An authentic life story is not one that corresponds to an objective indicator of the truth, but rather one that is made the narrators own*” (McLean, 2006; 174).

McCLean believes that through telling stories an inner order is created. Even though there is perceived compromised rationality in the person with dementia she believes that they are still able to create meaning. This meaning, she argues, is fundamental to selfhood. Because of the compromised rationality of persons with dementia, there is considerable scepticism about taking seriously what they say. However, McClean argues that even when what they say does depart from verifiable facts, elders who tell stories may present a coherent picture. It is not the actual historical facts, but their construction of a new story that provides meaning to the narrators and gives us clues to their lived experience: she sees their selfhood being created through social interaction. I will build upon McClean’s arguments and explore whether people with Alzheimer’s disease, through their stories, can produce meaning about the experience of their disease, its effect upon their life.

The use of storytelling in Alzheimer’s disease is also explored by Basting (2003; 2006). Through the use of storytelling and experimental theatre she argues that coherence and personhood are neither essentialised absences of Alzheimer’s victims nor presences of heroic survivors with Alzheimer’s but are possibilities within spaces of storytelling. Performance, Basting argues, is a statement of personhood. Creative storytelling supplies a social role, one with value, that allows for the integration of past and
present and acknowledges the strengths and potential of the present lives of people with Alzheimer’s disease (Basting, 2006; 193). Basting advocated the importance of seeing selfhood as something situated in the present, something created through social interaction. This is not a concept that is normally valued by people who work with individuals with Alzheimer’s disease. There tends to be a focus upon remembering the past and working on reminiscence, rather than valuing their roles and value in the present. This theme of personhood and selfhood in the present, being formed through social interaction, is also reiterated by Basting’s work on autobiographies (2003) and Taylor’s (2008) recount of her experiences with Alzheimer’s disease in the context of her relationship with her mother.

Kontos (2005; 2006) explores the maintenance of selfhood in the present through a radically different way. She focuses on body movements rather than the language of people with dementia. Kontos challenges the presumed loss of selfhood in Alzheimer’s disease by negating the western assumption that status as a full human being is completely dependent upon cognition and memory, both of which become impaired with advancing Alzheimer’s disease. She sees selfhood as being embodied rather than in the realm of the cognitive. Despite the effects of dementing illness, the residents she describes “exhibited selfhood in the face of severe cognitive impairment. It is a notion of selfhood that speaks of a complex interrelationship between the primordial and the social characteristics of the body” (Kontos, 2006; 203). Embodied selfhood, Kontos believes, owes its coherence not only to the foundational unity of the body but also the embodiment of cultural norms and values. As in the definition of selfhood I have decided to use for this thesis, Kontos sees selfhood as a notion that is based upon the interaction of the individual and the society. Her research subjects have embodied notions from their society, Jewishness, friendliness and politeness, for example, and maintain it throughout their dementing illness.

2.5.1 People with Dementia’s own Experiences

There is relatively little research on how individuals themselves grapple with the diagnosis of Alzheimer’s disease and what it means to their sense of being. Cohen-Mansfield et al. (2006), however, examine the self identity of people suffering from dementia. They questioned the elderly person with dementia, their formal and informal caregivers. This research appeared interesting, looking at the attitudes of the different players in the Alzheimer’s story. However, they focussed more upon types of identity, specifically changes in role identity from past to present, rather than the individual’s experience and difficulties. Although they found that the importance of different roles was maintained by the individual with dementia, and there was inconsistency with the the perceived importance of these roles between the individual and the care givers, there was no discussion about the meanings of these differences and how the self identity may be constructed and maintained. Beard and Fox (2008) also interviewed people with early stage Alzheimer’s disease as part of their ethnographic study into the diagnostic processes of dementia. They again focussed upon identity and the memory loss symptoms of Alzheimer’s disease rather than other symptoms.

Pearce et al. (2002) performed research into how people who have been diagnosed with dementia cope with the onset of illness. The study used qualitative methodology to examine the appraisals and coping processes of being diagnosed with early stage Alzheimer’s disease. The men’s accounts suggested that they attempted to manage their sense of self by balancing their wish to maintain their
prior sense of self against their need to reappraise and construct a new sense of self: something that seemed to be an ongoing, circular process. Clare (2003), in a study of individuals diagnosed with early stage Alzheimer’s disease, also identified a range of responses to changes in memory function, from self maintaining in which these people work to maintain existing identities, to self adjusting in which individuals develop a new sense of self by incorporating changes into their new identity. Both these studies gave importance to the perspective of the person with Alzheimer’s disease and explored their agency in shaping their experiences of the disease, something that few qualitative studies have explored. However, they seemed to focus on the individual’s perspective regarding memory loss. I wonder what other issues were perceived to be important to these individuals and how they talked about themselves in relation to the social environment, how their social interactions affected their sense of self and personhood. This will be examined in my own research. Also, although Clare (2003) interviewed the spouse of the affected individual, this seemed to be predominantly in order to triangulate data from the affected individual’s interview: to validate its reliability. In my own research I intend to see how the family member reacts to the diagnosis and their subsequent interaction with their loved one: their notions of changing self and personhood.

Langdon et al. (2007) do acknowledge that the reaction and social interactions of others can have a significant effect on the lived experiences of dementia. In their research they address the fact that few studies have asked people with early stage dementia about their experiences of other people’s reactions to their changed condition and social status and interview 12 men and women with early stage dementia about others’ reactions to them since receiving the diagnosis. The study found that negative reactions were expressed by the individuals regarding the terms dementia and Alzheimer’s disease and although they were happy to share the diagnosis with people close to them they tried to hide it from others, worrying what they would think of them. This study relates the closest to my proposed research. However, I feel my research will add to this knowledge by also addressing the notion of agency: seeing their selfhood as both an individual and a social phenomenon, an ongoing process in constant reflection. I will examine how both the individual, and their family member cope with incorporating the concept of Alzheimer’s disease into the sense of who they are. This dynamic process, much like I described earlier with regard to the self, sees the interplay of both the individual and the context in which they are situated producing a notion of who that person is. Rather than an entity bestowed by society upon an individual, it becomes a dynamic process that both the individual and society shape. Pearce et al. (2002), Clare (2003) and Langdon et al. (2007) have done this to some extent. I feel that my research will further explore this notion of the individual and society shaping an individual’s sense of who they are. My research starts with the premise that Alzheimer’s disease is a process and explores the experiences of both the individual and the family member in this process. I examine the social interactions between the individual and the family member and explore how these have changed and how this has affected notions of personhood and self. As an ethnographic research project I am able to draw on ethnographic observation, seeing what people do, not just what they say they do.
2.6 Working Definitions

2.6.1 Personhood

In the course of this research I shall look at the concept of personhood as attributes which others bestow upon an individual. I will see it as more of an external label than as a concept of individual reflexivity. I will, however, be looking at the individual with Alzheimer’s disease and their family member’s interpretation of whether people bestow this status upon them. I shall use Kitwood’s definition of personhood in my own research:

“a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements” (Kitwood (1997) in Bartlett and O’Connor, 2007; p. 109)

2.6.2 Self

I am using the concept of personhood as an external label. In contrast to this external notion I plan to see the self as a concept that is always in process. I will use the self as a concept representing the subjective experience of being. I see the self as a process that both the individual and the context in which they are situated play a role in shaping. I view the social interactions of the person with Alzheimer’s disease playing an important role in forming this sense of self. Both an individual’s internal subjective experiences and others’ experiences and opinions of that individual will shape how an individual feels about themselves. In the course of this research I will only be able to explore the representation of self that my research participants share with me. I shall work with Charmaz’s view of self in undertaking my research:

“an organisation of attributes, sentiments, values and characteristics through which people define themselves” (Charmaz, 1999; 367)
3 Methodology

This was a qualitative exploratory study utilising fieldwork in the Stockport Branch of the Alzheimer’s Society in the UK as the research method. This section will give a background to the context of the study, that of Alzheimer’s disease in the UK and the Alzheimer’s Society in particular. A description of the methods used and considerations taken will then be detailed.

3.1 Context

Alzheimer’s disease is the most common cause of dementia in the UK, affecting around 417000 people (Alzheimer’s Society, 2007). This number, however, is the prevalence of people who have received a formal diagnosis of Alzheimer’s disease, the actual number is expected to be much higher. To participate in the Alzheimer Society groups an individual has to have received a formal diagnosis. Although symptoms may be recognised by the individual themselves, their family or friends, this diagnosis can only take place by a medical practitioner. The study participants who have been diagnosed with Alzheimer’s disease have therefore all been through the medical system.

3.1.1 Medical System

The National Health Service (NHS) provides the majority of health care in the UK. It was founded in 1948 and has become an integral part of British society, culture and everyday life. NHS services are paid for by taxes and so is free at the point of delivery. A person with memory problems, confusion or other symptoms would first see their general practitioner (GP) as the first point of call. The GP may make the diagnosis themselves or refer the patient on to a specialist such as an old-age psychiatrist, a neurologist, a physician in geriatric medicine or a general psychiatrist.

Diagnosis There is no straightforward test for Alzheimer’s disease or for any other cause of dementia. A diagnosis is usually based upon the clinical picture gained through the history and observation. The diagnosis is one of exclusion: the doctor must rule out conditions such as infections, vitamin deficiency, thyroid problems, brain tumours, depression and the side-effects of drugs which could present similar symptoms. See appendix A for the DSM-IV criteria for diagnosis of Alzheimer’s disease.

Treatment There is currently no cure for Alzheimer’s disease. However, some drug treatments are available that can ameliorate the symptoms or slow down the disease progression in some people. Such drug treatments include the cholinesterase inhibitors, such as donepezil, rivastigmine and galantamine. These drugs are available for the treatment of mild to moderate Alzheimer’s disease. There may be a slowing or even arrest of cognitive decline for about 8-9 months; however the underlying disease process is not halted (Alzheimer’s Society, 2007). Memantine is another possible drug treatment for Alzheimer’s disease. It is a N-methyl-D-aspartate receptor antagonist and is licensed for the treatment of patients with moderately severe to severe Alzheimer’s disease (Alzheimer’s Society, 2007).

Management Much can be done at a practical level to ensure that people with Alzheimer’s live as independently as possible for as long as possible. Many people are able to remain in their own
home with the help of family or professional carers, adaptations to their home, and the use of assisting equipment or technology. Due to the progressive nature of the disease, however, one third of people with dementia are cared for in residential or nursing homes (Alzheimer’s Society, 2007). The amount a person contributes to this care depends on their financial position: the local authority pays the full cost for some people whereas others have to be entirely self-funding.

3.1.2 The Alzheimer’s Society

The Alzheimer’s Society is the UK’s leading care and research charity for people with dementia and those who care for them. It does not specifically cater for the needs of people with Alzheimer’s disease but of all forms of dementia. The society is a membership organisation which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland. There are 25000 members nationally, many of which have personal experience of dementia as carers, professionals or people with dementia themselves. They use various methods to try to improve the lives of people with dementia. The society campaigns and lobbies striving to influence government policies and raise awareness of the challenges faced by people with dementia and the people who care for them. Through their research programme they work to improve knowledge about dementia and its treatment, pursuing the ultimate goal of finding a cure. The Alzheimer’s Society has branches throughout the UK. These branches provide practical services and support for people with dementia and their carers.

3.2 Study Design

This research is a qualitative study using ethnographic methodology. The study is exploratory since it aims to explore the experiences of personhood and selfhood in individuals affected by Alzheimer’s disease and their family, from their own (emic) perspective. The research explores whether it is actually possible to explore the inner subjective experiences of those with Alzheimer’s disease as there appears to be little research into this area.

The fieldwork took place over a five week period. Time restrictions therefore limited the scope of the study. The sensitive and potentially upsetting nature of the research required the development of a trusting relationship between myself and my informants. I felt that given a longer study period more Alzheimer’s Society group members would have felt happy to talk to me outside of the group setting. I also feel that the fieldwork would have benefited from the ability to re-visit some of the study participants in order to clarify some of their responses and meanings as well as to probe further into some of the issues raised in the previous interview.

3.3 Study Population and Sample

The ethnographic research in this thesis was performed in the support groups offered by the Stockport branch of the Alzheimer’s Society. The branch was formed in 2002 and aims to ensure that those with a form of dementia, their carers and family have access to all the information and support they need. Their vision is of a community where carers and those with a form with dementia are recognised, listened to and fully informed. The Stockport area estimates that there are about 3700 people who have dementia. The branch has less than three hundred members. The branch tries to achieve its goals
through four part time Dementia Outreach Support Workers and volunteers who run the office, take phone calls and make visits to people who need support and help coping with the effects of dementia as well as running the formal support groups. Support groups offered included:

**SHARED group** SHARED stands for Support, Help and Access to Resources and Education for Dementia. This project provides fifteen weekly sessions where people with dementia and their carers could be together in a safe, professional environment. It was created with the purpose of emotional support, education, social interaction and the promotion of independence. The group aimed to enable both the ‘cared for’ and the ‘carer’ to meet people who share similar circumstances and to learn more about ways of managing dementia and accessing the supports that were available locally.

There were two SHARED groups a week at different locations. Each session was six hours long and catered for eight couples. I attended five of each of these sessions.

**Walk and Talk Group** The Walk and Talk group was a two hour fortnightly session for people with dementia and their carers. It focused upon a walk around a lake in a country park and then an opportunity for discussion. An outside speaker was usually invited to the session. I attended three of these walk and talk sessions in the fieldwork period.

**Luncheon Group** This is a monthly group for people with dementia and their carers. People meet for lunch and a chat in a church hall. There are no formal activities arranged. I was able to attend one such session during the fieldwork period.

**Drop in Cafe** This is a weekly session at a local independent cafe lasting for around an hour. People with dementia and people who look after someone with dementia are welcome to attend. It is an informal group where people can meet other people with dementia and carers. There is also the chance to make contact with outreach workers. I attended five of these sessions during

3.3.1 Gaining Access

I first contacted the Stockport branch of the Alzheimer’s Society via e-mail, explaining the nature of the proposed research and enquiring whether they would be able to accommodate my study. I had an enthusiastic response but was told that all enquiries for research had to go through the North West UK Area Manager and regional managers before coming to the branch level. I contacted the Area manager who gave the go ahead for the research. I was then put into contact with the regional manager and the research was arranged to take place in the Stockport branch but all contact remained with the regional manager. A joint meeting was planned for myself, the regional and branch manager upon my arrival in the UK. However, this was subsequently cancelled due to the branch manager’s holiday. After a period of difficulty in getting in contact with the regional manager I eventually managed to arrange a meeting between her and myself. I was informed that my research could not start till the following week because nobody knew that I was coming to any of the groups. Although disappointed that my research would have to be shortened I was pleased to have finally made contact. I was informed that I would not be able to interview people with Alzheimer’s disease on their own because I had not been
police checked for the Criminal Record Bureau in the last year. I had been planning on interviewing
the individuals with Alzheimer’s disease on their own as I felt that they may be more likely to express
their true feelings and experiences when not in the presence of a family member or carer. I thought
that not being able to interview them alone may jeopardise my objective of discovering the extent to
which the subjective experiences of individuals with Alzheimer’s disease could be explored. I felt that
their role in an interview may be hindered by others being present. I was irritated that I had not been
told this earlier as now it was too late to embark on getting Criminal Record Bureau clearance for the
study period.

The following week I contacted the branch manager to arrange going to the various groups. There
had been a lack of communication between the regional manager and the branch manager: although
the branch manager knew of me, she did not know anything of the proposed research or start dates.
After a suggestion of a meeting the following week I managed to express the urgency of needing to
start the research soon: I already only had five weeks left. I felt frustrated that I had tried my best
to go through all the correct channels and formalities but the person who I was actually going to deal
with knew nothing about the research. After some pleading on my part a meeting was arranged for
later than day and I was able to start attending the Alzheimer’s Society’s meetings the following days.

At my meeting with the branch manager I learned that I would be the last research student to be
allowed access to the Alzheimer’s Society’s groups. They felt that asking carers and individuals with
Alzheimer’s disease to participate in research was too much of a burden on top of everything else they
had to cope with. Although pleased that I had been allowed access I felt very aware of my privileged
position and that I must strive to not be an added burden for the research participants.

3.3.2 Evolving Research Plan

I had intended to interview an individual with Alzheimer’s disease as well as one of their family member’s
separately. This would no longer be possible due to my access constraints. It soon became clear that
the family member would be the individual’s spouse. All the members of the Alzheimer’s Society’s
groups attended the groups as couples. The SHARED group was specifically designed for couples and
all other groups seemed to have adopted or evolved this set up. I had expected more children of the
affected individual to come to the sessions as well as there to be more single men or women affected by
dementia coming along to the groups on their own. I was speaking to the couples at the groups and it
was clear that my key informants would also be part of couples. It also became clear that I would find
it very difficult speaking to the ‘carer’ spouses on their own as all their time was spent looking after
their husband or wife. They had very little time to themselves and if, on the rare occasion, they did
have some time they had much better things to be doing with it than talking to me. So I decided to
interview couples together. This was logistically more convenient but would also allow me to see the
interaction of couples in their own home, not just in the Alzheimer’s society and would allow me to
probe into and observe their relationship together and how they had incorporated Alzheimer’s disease
into it. My research plan had been limited to the experience of an individual affected with Alzheimer’s
disease and their spouse.
3.4 Methods

I attended the Alzheimer’s Society support groups for ethnographic participant observation purposes and recruited couples for interview from these groups through the convenience sampling technique. Convenience sampling is a method in which for convenience sake the study units that happen to be available at the time of data collection are selected in the sample (Hardon et al., 2001). One couple was identified through snowball sampling\(^1\). This couple were actually from outside the Stockport district but were introduced to me through the Alzheimer’s Society Regional Manager. They were a couple known to her who were keen to share their story with others. Although these sampling techniques were suitable for the study in question they do, however, also provide a possible selection bias. I used members of the Alzheimer’s Society as my research subjects. As already mentioned, this is a society that works to improve the quality of life of people affected with dementia. They are an advocacy group that fights for the rights of people with dementia. People who are members of this society, either individuals with dementia or their spouse, will presumably have similar views or at least have been influenced by them. It is a support group that provides educational and emotional support. My study sample will therefore not be representative of all people with Alzheimer’s disease and their families. They may well be much more well informed about the disease process and ways of coping with it.

Although I attended all the Stockport Alzheimer’s Society Support groups and had the ability to observe and informally chat with many members of the Alzheimer’s Society, my key informants, those that participated in the in-depth interviews were selected upon their willingness and ability to participate in the study. The key informants therefore volunteered to engage in the study. Again this might have created a bias in the results: the individuals with Alzheimer’s and their spouse who participated may well not have been representative of the general population, perhaps being more affected by or aware of their situation.

3.4.1 Participation Observation

The aim of this research was to understand the experience of Alzheimer’s disease from the perspective of those with the disease themselves and their spouse, with particular reference to person and selfhood. If the aim of research is to understand a phenomenon, rather than people’s accounts of it, then observational methods are often sited as the ‘gold standard’ of qualitative methods (Green and Thorogood, 2007). The method provides direct access to what people do, as well as what they say they do. Participant observation was therefore crucial for me to see the experience of Alzheimer’s in action; seeing the interaction between an individual with Alzheimer’s disease and their spouse; seeing how people interact in a support group session; hearing the difficulties that people have experienced; hearing advice that people give to each other.

I attended all the Alzheimer’s Society groups during the five week period of fieldwork. I was a participant observer in the groups. I had been introduced as a research student but I acted as a volunteer within the groups. I chatted informally with the group members, played games with them, helped with the activities, served tea, coffee and dinner, helped tidy up. I observed the interaction

\(^{1}\)In snowball sampling the researcher identifies some individuals who are relevant to the study and then asks them to locate other useful informants (Hardon et al., 2001).
between the ‘carers’ and the ‘cared for’, their interaction as a group and also with staff members. I joined in the group activities for the ‘cared for’ and at other times observed the talk or session for the ‘carers’. I observed interactions, how people with Alzheimer’s were treated by others but also paid attention to the formal and informal topics of conversation discussed.

Due to the participant nature of my observation it was very difficult to make notes whilst in the sessions. I was also very aware that these were sessions that were very valuable to the group members and was very conscious not to make the members feel uncomfortable in my presence. I was aware that some of the ‘cared for’ members were uncomfortable with their diagnosis of Alzheimer’s disease and felt embarrassed that their behaviour could sometimes draw unwanted attention. I did not want to heighten these fears with my own note taking.

3.4.2 In-depth Interviews

I held in-depth interviews with six couples. The couples all consisted of a ‘cared for’ individual with dementia and their ‘carer’ spouse. Five of these couples were couples I met through the Alzheimer’s Society groups. They had expressed interest in my research and after chatting with me agreed to be interviewed. I was introduced to the other couple through the district manager of the Alzheimer’s Society. All interviews took place in the couples’ own home and were arranged at a time convenient to the couple. The interviews lasted for between one and a half and two hours. The interviews were held with the ‘carer’ and ‘the cared for’ at the same time and were of a semi-structured format. I used a topic list to facilitate the conversation but also let the couples take this conversation in their own direction. This format let me set the agenda for the topics covered but the couples’ responses determined the kinds of information produced and the relative importance of each of these topics. The in-depth nature of these interviews allowed the couples enough time to develop their own accounts of the issues important to them (Green and Thorogood, 2007). In many occasions my presence seemed to facilitate conversation between the couples themselves and they started to ask each other questions:

“Mary: I like being in the group. It makes you feel like you’re not doing too bad
Arthur: Yes it does really doesn’t it
Researcher: So you find it useful being with the other people in the group then?
Mary: Hmm yes
Arthur: Does it worry you at all Mary, seeing the others, some of which are much worse than you?
Mary: No it doesn’t. I’m lucky. I’m still coping”

The couples seemed to like the opportunity to tell their story to me but also to discuss the topics together, something they said they rarely did but found useful.

I had been worried that by holding a three way interview between the ‘carer’, the ‘cared for’ and myself then the opinions and thoughts of the ‘cared for’ individual might have been masked by the ‘carer’. I was careful to direct questions specifically to the ‘cared for’ individual rather than just open to the couple. The ‘carers’ were themselves also keen to try and get their spouse to participate more fully in the interview. To start with the ‘cared for’ spouse tended to be the quieter one in the interview
but as I made it clear that I valued their opinion as much as their partners they were also keen to share their story. Holding the interview with the couple together also gave me a valuable opportunity to observe the couple’s interaction together in their own home.

All the interviews were audio-taped and subsequently transcribed verbatim by myself. All the couples gave permission for the use of the recorder after I had assured them that I would be the only one to listen to it and their confidentiality would be maintained. Although we were discussing personal experiences of a sensitive manner all the couples seemed to forget that the audio recorder was there and it did not seem to inhibit the interview process. Having audio recorded the interviews allowed me to go back over the them in my own time, listening carefully to subtle points that I had missed in the interview and gave me the chance to also think about the interaction between the couple, the way they communicated with each other.

3.4.3 Fieldwork Diary

I kept a diary of my thoughts and reflections about events during the period of fieldwork. I felt that reflecting upon my own reactions and perceptions to the people I met, what they did and said, would help aid my analysis of the situation. It helped me to be aware of my own prejudices, the way I have been socialised to think about people with Alzheimer’s disease, both in my personal and professional life. Being conscious of this throughout the research process, from design, through fieldwork to analysis helped me to understand why I might approach a topic in a certain way. I wanted to be aware of the influences that might affect my interpretations.

3.4.4 Newspaper Research

Due to the initial access problems in my fieldwork I decided to undertake a review of newspaper coverage of Alzheimer’s disease in the preceding six months to the fieldwork period. I felt that this would give me some insight into the social awareness and perception of Alzheimer’s disease in the general public. I performed a search on the Lexis-Nexis search engine for British Newspapers reporting about Alzheimer’s disease in the six month period. I coded these for the their portrayal of personhood and self in Alzheimer’s disease. The newspaper coverage also then became a topic of conversation with the couples at the Alzheimer’s society.

3.5 Working with People with Alzheimer’s

Involving people with cognitive impairment in my study obviously posed certain challenges. It is often assumed that people with dementia are not coherent or lucid enough to be able to express a view on aspects of their life (Proctor, 2001). However, at the core of the personhood movement (described in section 2.2.6) is the importance of listening to people with dementia as the first stage in the development of a helpful and empowering social environment (Kitwood and Bredin, 1992). Proctor (2001), in her research with women who had dementia, found that the women sometimes spoke in fragmented ways and sometimes used metaphor in their stories. This therefore involved some interpretation on her part. However, Proctor found listening to the older women with dementia and encouraging a dialogue with the women about their lives and relationships did seem to be both possible and useful, both for the
researcher and the women themselves. Proctor encourages spending more time with the participants prior to interviewing so that a relationship can be built up and the researcher can gain a better understanding of the participant and how best to work with them. I took this advice in my own research and apart from with one couple, I had met the couple on several occasions before I proceeded to an interview. This had allowed me to build up a relationship with the couple, facilitating trust and also communication. I had become aware of some of the difficulties that the ‘cared for’ individual faced in communication and tried to allow for that in my own interviews.

Booth and Booth (1994) discuss their use of in depth interviewing in their research with parents with learning difficulties. The general lessons they discuss apply equally well to research with any vulnerable group of informants, especially those such as individuals with cognitive impairments. The researchers show that in depth interviewing, exploring life histories and experiences, does not only have to be carried out with subjects who are able to articulate and verbalise well and have a good story to tell (Booth and Booth, 1994; 415). The lack of verbal fluency in their informants was not a barrier to the parents telling their story. They suggest that it does, however, have implications for the role of the interviewer and the conduct of the interviews. The researchers advocate the use of techniques other than just talking in order to engage the informant and making sure that there is plenty of time for the informants story to unfold. These are techniques that I engaged in my own research. I took the interview at the pace of the informant, leaving the interview fairly unstructured but with my own topic list of themes that I would like to cover. At times I had to be patient, hearing the same story again and again but gradually the themes evolved over time. Even though at times I did not feel that I was getting relevant information to my research question, when listening to the tapes in retrospect I realised how important some of these repeated stories were, both to the ‘cared for individual’ but also to my research.

3.6 Data Analysis

“The aim of most qualitative analysis is to both reflect the complexity of the phenomena studied and to present the underlying structures that ‘make sense’ of that complexity. The task of the researcher is thus a dual and perhaps contradictory one of simultaneously ‘telling the story’ from the point of view of the research participants, and unpacking that story in some way such that the broader meanings can be elicited” (Green and Thorogood, 2007; 175)

In order to analyse my data I transcribed interviews in full and wrote up my observational data. I used open coding to extract the main themes from the first couple of interviews: a form of thematic content analysis. The codes included in-vivo codes, the emic terms that the participants were themselves using, and more interpretative codes based on my own theoretical framework. I used these codes to code the rest of my data and added to them where necessary. The analysis then moved on to looking for relationships between categories and linking them with known theoretical concepts.
3.6.1 Validity and Reliability

To add credibility to my analysis and increase confidence in its reliability and validity I have, as Green and Thorogood (2007) suggest, addressed the issues of transparency, validity, reliability and reflexivity. At all stages I have attempted to be as transparent as possible, providing a clear account of the procedures and methods used in the data collection. In the process of analysis I have tried to avoid anecdotalism and account for deviant cases that may disconfirm my argument. My interpretation is one of perhaps many possible interpretations of the data but I have tried to improve the validity of the argument through providing a thick description of the context. I have also included quotes from the interview transcripts and informal observations so as to show the reader how my interpretation has been constructed through the raw data. I have tried to be as explicit as possible about the interpretation I have made and meanings inferred from this raw data.

I have taken the information that my informants have given me at face value. I was not looking for a truth about self and personhood in Alzheimer’s disease, but their truth, the truth of my participants. I make no claims that the findings from this research and the argument formulated are applicable to all people with Alzheimer’s disease. My informants were a specific group of people who were affected by Alzheimer’s disease. They were a couple. They were a couple who had had a diagnosis of Alzheimer’s disease. They had accepted this diagnosis and were treating it positively, attending an advocacy group’s meeting. I have also not compared their stories with medical notes of even the Alzheimer’s Society’s records. By building up a relationship with the informants I hope that they were open and honest with me in their feelings and opinions. I wanted to understand their experiences and so believe that the subjectiveness of their stories only adds credibility to this research.

I have used an interpretative framework in this study. Therefore my own, thoughts, beliefs, professional background and personal experiences could affect my interpretation of the study data and indeed its formation. I have had particular experiences of Alzheimer’s disease, both personal and professional, and these helped shape and formulate the research proposal, fieldwork and analysis. I needed to be careful that my research was indeed representing the study participants experiences, not trying to validate my own ideas. For example, I found my personal experience, that of my grandparents’ dementia, to be very difficult to cope with. I was left with the question of who they really were; were they, with dementia, the same grandparent I had previously known? I was unsure of how I viewed them. In my professional life I have been concerned with the lack of respect and dignity I felt people with Alzheimer’s were given in a hospital setting. I therefore had my own view and experience of the research topic prior to carrying out the fieldwork and needed to be careful not to influence the research participants with this view. I also needed to be aware that my subsequent interpretation of the experiences the participants shared with me and the interactions I observed would also be interpreted, and affected, by my lens, my prior experiences and beliefs. Through having repeatedly reflected upon my own role throughout the research process I hope to have decreased these biases.

3.7 Study in Context

As mentioned in Section 3.6.1 these research findings cannot be generalised to the experiences of self and personhood in all people affected by Alzheimer’s disease. All study participants were part of a married couple, all had a formal diagnosis of Alzheimer’s disease at a mild to moderate stage, had
accepted this diagnosis and enrolled in the support of the Alzheimer’s Society. The ‘carer’ was the husband or wife of the ‘cared for’ and all had been married for many years. They had gone to the Alzheimer’s Society support groups together as a couple and had perhaps been socialised together into seeing the disease in a particular way. Although the research participants are special cases, they are not representative of all people with Alzheimer’s disease and their carers, they do, however, provide an interesting case in which to explore the experiences of self and personhood with respect to Alzheimer’s disease.

3.8 Ethical Considerations

My research proposal did not have to go through a formal ethical board but consent was gained from various levels of the Alzheimer’s Society: the North West UK area manager, the regional manager and the local branch manager. They have taken ethical implications into consideration when permitting this research.

3.8.1 Consent

This research probed into private and sensitive issues regarding the experiences of people with dementia and their spouses. Doing research with people with dementia clearly poses some ethical considerations with regard to their ability to consent. My research was person-centred. I was interested in the experience of the person with dementia as well as their family member. Proxy consent, i.e. carers giving or withholding consent for research involving the individual with dementia, is still common in biomedical and gerontological research (Dewing, 2002). However, I believe that it is important to involve the individual with dementia in this decision, to let them be the one who holds or gives consent. Kapp (1998) found that people with dementia are often pleased to be asked to participate in research and to be taken seriously as a capable person again. I also found this in my study. Both the ‘carers’ and the ‘cared for’ were happy to be asked to participate in the study and surprised that their opinions could be of value to me.

The Alzheimer’s Society’s staff explained the nature of my research to the group as a whole. After getting to know the couples in the group I approached people to ask whether they would be interested in participating further in the study. I approached the couple together and wanted to be sure that both the ‘carer’ and the ‘cared for’ were happy to participate. I gave them a small information sheet with my contact details on if they would like to arrange a meeting (see Appendix C). I wanted it to be left up to the couple to decide whether to contact me as I did not want them to feel pressurised into participating further in the study. At the interview I again explained what the interview would involve and asked the permission of both the ‘carer’ and ‘cared for’ individual. This consent was verbal, not written, on the advice of the Alzheimer’s Society. I explained to both the individual with Alzheimer’s disease and their spouse that everything they said to me would be confidential and their anonymity maintained. No-one but myself would listen to the recordings, or read the transcripts, of the interviews. Pseudonyms have been used in this thesis and any identifying information removed. The participants were advised that they could terminate the interview at any point and did not have to answer any questions with which they felt uncomfortable. This did not occur in any of the interviews.
3.8.2 Observation

I felt that adequate consent was gained for the interviews with the couples but was left feeling a little awkward about my role as research student in the Alzheimer’s Society’s group. I had been introduced as a research student and the group participants had been told that I was looking at the experiences of Alzheimer’s disease so would be participating in the group and watching what would happen and would perhaps want to speak to people individually. They had been asked if that was alright but they had been asked as a group not individually. I was sceptical as to whether if someone had had an objection to my presence they would have felt confident enough to voice their concern. This uneasiness was increased when, at the end of a SHARED group, I approached a couple to see if they would be happy to take part in an interview. The ‘carer’ said that he would not like to participate as he was a private man and did not like sharing things with others. I explained that that was fine, it was completely voluntary, and the couple left to make their way home. However, I felt awkward. He wanted to remain private but I had been observing his and his wife’s interactions that day. Although they were not key informants, through their participation in the group, they had automatically become research participants, something that the ‘carer’ at least did not seem to want. The couple did not come to the session the following two weeks. I had not had chance to talk to them further about the research and their desire or not to be participants. I hoped that my very presence in the group had not made them feel uncomfortable and prevent them from participating further in the group. To respect their expression of desired privacy I have not included observations or informal conversations with this couple in the data of this thesis.

3.8.3 My Status

The Alzheimer’s Society had been aware of my background as a medical doctor when granting the permission for the research. Although they were aware that I was researching the experience of Alzheimer’s disease’s and this was qualitative research which was associated with my Master’s degree, it was clear that some of the group leaders had not grasped this concept. At the first group I went to, the Walk and Talk, I had not had chance to speak to the group leader before he introduced me:

“This is Dr. Graham. She’s doing some research on the experiences of people with dementia and their carers. She might want to speak to some of you at some point and I think it’s a really good idea if you do. This research might not benefit you directly but she will be writing a report for the government so even if it does not help you then hopefully it will help others in the future”

I could not have felt more embarrassed. I had not particularly wanted to disclose the fact that I had trained as a doctor because I thought it might affect the way people viewed me and the sort of things that I would be interested. I felt that me and my research had been totally misrepresented. I explained to the group that in fact I was a research student and no longer worked as a doctor. My research would not be used by the government. Although I tried to rectify the situation and in all other groups made sure that I was introduced as a research student I was not quite sure people really knew what I was doing.
I was a research student but I was also acting as a volunteer. I did not have a note book or an audio recorder in the sessions. I was observing and listening, keeping my own mental notes and jotting them down when possible but I was not in an overt research role. People treated me like a volunteer and were genuinely interested to talk to me but during my participant observation I do not feel my role was clear. At the end of the fieldwork period people were still asking me what I was going to be, why I was at their group, was I going to be a social worker? A nurse? Although I feel I tried my best to explain my role and the research I feel that it would have been better to formulate a more descriptive initial introduction with the group leaders.
4 The Ambiguity of Alzheimer’s

“Sometimes you can’t tell who is the carer and who is the one with dementia.” (Dianne, Dementia Outreach Support Officer)

I arrived at the SHARED group in Bredbury excited about finally doing some ethnographic study after my initial access frustrations. I arrived half an hour after the group was due to start in order for the Dementia Outreach Support Officer to explain that I was coming and to check that there were no objections. I entered the resource centre full of anticipation of what it would be like. I had preconceived ideas of a day centre, smelling of urine, people sat in chairs aimlessly staring, not interacting with each other, staff mostly ignoring these people except for the odd patronising comment. My preconceived ideas were wrong. The room was bright and nicely decorated. The first thing I noticed was a large poster on the wall with two elderly people, the man smartly dressed in a suit, the woman wearing a bright red dress and pretty jewelry, looking into each other’s eyes and laughing. Underneath the picture was the caption, “Fighting for a better future” and the Alzheimer’s Society’s logo. Looking at the poster I wondered who the elderly couple were: were they only actors or were they real people affected by Alzheimer’s? If they were really people affected by Alzheimer’s disease which one had it? How could I tell from a photo? In a snap shot moment they both looked happy, positive, laughing together. There was no discernible difference between them, nothing pointing to the fact that one of them had Alzheimer’s disease.

Dianne recognised me and led me into the main room of the centre. In one half of the room sixteen people were sat in large comfy armchairs arranged in a big circle. There were eight men and eight women, virtually all engaged in conversation with the people around them and drinking cups of tea and eating toast. There was a sense of energy in the room, people seemed to be enjoying themselves and enjoying speaking to each other. It certainly wasn’t what I expected from an Alzheimer’s Support Group. The only thing that seemed to distinguish these individuals from any other member of the public was that each person was wearing a name badge. Dianne quickly made me my own name badge to wear and then introduced me to the group: I was a research student working with the Alzheimer’s Society and would be joining their group for a few weeks. I was brought a cup of tea and I found myself a spare chair to sit on in the middle of the group between a smartly dressed lady, who introduced herself to me as Maureen, and a younger gentleman wearing walking trousers and a tee-shirt whose name badge identified him as Gordon. After a quick acknowledgment of my presence and a few hellos directed to me the conversation returned to it’s previous topic of Gordon and Kathleen’s holiday the previous week. Kathleen was very talkative about their trip to the Lake District, the amazing walks they had done and the glorious weather they had had. She was very animated and enthusiastic and everyone around her listened attentively to her stories. I also sat and listened to Kathleen but my attention turned to the other people sat around me. Gordon, who through the conversation I had discovered was Kathleen’s husband, was sat in his chair not joining in the conversation, eyes fixed on a newspaper on his lap that he seemed to be reading. I knew that the group consisted of couples, one with a diagnosis of Alzheimer’s disease and the other their ‘carer’. I found myself wondering whether it was Gordon or Kathleen who had Alzheimer’s. I was unsure but decided it must be Gordon. He seemed quiet and withdrawn from conversation whereas Kathleen seemed to be giving a perfectly coherent
account of their holiday with little anecdotes of things they had done. Her memory seemed absolutely fine and so to me there seemed to be no reason to suspect that it was her who had Alzheimer’s. I started looking at the rest of the group trying to decide who I thought had Alzheimer’s disease and who was the carer. Was it the quieter ones who had Alzheimer’s? They all seemed to be dressed well, were all managing their tea and toast without a problem. A lady called Elsie kept asking the gentleman next to her if he was OK. Was she the carer checking that her husband was managing alright or was she the affected person, a little anxious and not knowing what to do? My dilemma of diagnosing the group into those with dementia and those without was solved by Dianne asking for all the carers to make their way to the other half of the room for a talk. I watched in surprise as Gordon and seven others, some of whom I had incorrectly diagnosed as those with dementia, made their way to the carer’s side of the room.

I was left feeling quite shocked at my apparent need to separate the couples into the ‘carers’ and the ‘cared for’. Why did I feel the need to know? Why did it matter which one had Alzheimer’s and which one didn’t? I wondered what criteria I had used as means of assessing them: their answers to my questions, their ability to hold conversations, the clothes they were wearing? I had been trying to tell who seemed grounded in rationality and who was displaying ‘abnormal’ behaviour. Was this my medical background, my clinical gaze still in tact, trying to medicalise and categorise everyone into neat diagnostic boxes? Clearly some of my diagnoses were inaccurate; I had put people in the wrong category; I was unable to tell who had dementia and who didn’t. So I had learnt a lesson, dementia is not necessarily visible, but I was left with a nagging, quite unsettling question: why had I wanted to know who did and who did not have Alzheimer’s disease? What difference did that knowledge make? Would I have talked to these people differently and judged them differently if I had thought they had Alzheimer’s disease? Would I have taken Kathleen’s tales about her holiday as less true, less valid if I had know that she was the one with dementia?

4.1 Seeking Diagnosis

The ambiguity of Alzheimer’s disease started right at the beginning of my informant’s journeys with Alzheimer’s. Some couples recognised that there was something wrong themselves, for others it was a family member or social worker that suggested that they should perhaps seek medical help. All my informants and participants of the Alzheimer Society’s groups had a formal diagnosis of dementia: this is in fact a pre-requisite of becoming members of Alzheimer Society groups and getting formal help and advice from the Dementia Outreach Support Officers. So for every ‘carer’ and ‘cared for’ person that I spoke to, their initial worries, concerns or problems had been taken from merely that and turned into a medical diagnosis: that of Alzheimer’s disease or some other form of dementia. It was this diagnosis that affected the experience of personhood and the notion of self of the affected individual: in some cases the disease diagnosis protected the individual’s personhood and sense of self, in others it was this
very diagnosis that called these concepts into question.

Before receiving a formal diagnosis all the couples, the ‘cared for’ and the ‘carers’, had recognised that something was different but not all had equated these changes with a diagnosis of Alzheimer’s disease. Nancy, who had been diagnosed with Alzheimer’s disease one year prior to the research period told of how the diagnosis had been a great shock to her. She had been aware of getting more confused and not being able to do the things she had always done with as much ease. She recognised that there was something but she didn’t recognise this something as a problem:

“I guess it had been going on for a while. I noticed with yoga I suppose. Well having done yoga lots of times I knew when the person would tell you what to do I would know, I’d be able to do it. I could stand on my head, I could sit on the floor and grab my toes, you know. And I couldn’t do it anymore and I kept on thinking what’s wrong? But I didn’t think it was anything to do with Alzheimer’s really. And then at my daughter’s house I could never find the fridge. All the cupboards looked the same and I kept putting the things for the fridge in the wrong place. So the next thing there was a piece of paper on the fridge saying which one it was. She noticed that a lot but I didn’t think anything of it really” (Nancy discussing being diagnosed with Alzheimer’s disease).

As Cohen (1998) discussed, Alzheimer’s disease is often attributional, someone else decides that an individual has the problem. It was Nancy’s daughter that recognised these symptoms as a problem, that of Alzheimer’s disease, not Nancy. Her daughter was a Social Worker and has worked with people with dementia. It was the daughter who arranged for the Old Age Psychiatrist to come and see Nancy and provide a formal diagnosis. Nancy and her husband John had not sought diagnosis themselves, they had not perceived the difficulties that Nancy was facing as anything other than “normal old age”:

“Well I had noticed that she was not being on the ball like. But obviously I just thought it was normal at the time like. Well if it hadn’t been for Kim, my daughter, it probably wouldn’t have been diagnosed yet and I would still have been shouting at you for leaving the cupboard door and the fridge door open. But now I understand” (John, discussing his wife Nancy being diagnosed with Alzheimer’s disease).

There was ambiguity about Nancy’s situation: for Nancy and John there wasn’t really a problem, her symptoms were just an inevitable part of growing old but for Nancy’s daughter and then the medical profession, her symptoms were indicative of a disease, that of Alzheimer’s. Despite this ambiguity, it is clear from John’s comment that, after diagnosis, he did come to see Nancy’s situation as a problem, a disease. John no longer shouts at Nancy if she forgets to close cupboard doors: he is now understanding. John has come to see Nancy as someone with a disease, someone who does things that she wouldn’t have used to do, things that can make him angry, but he now sees it as Alzheimer’s causing this action, not Nancy. By now having the diagnosis of Alzheimer’s disease John seems to absolve Nancy of responsibility of her actions.

4.2 When is it Alzheimer’s?

The ambiguity of what constitutes Alzheimer’s disease, what is normal aging, normal forgetfulness, was not only an issue for Nancy and John but for all the couples. For some seeking a diagnosis was
Bill’s symptoms were dismissed as merely old age, despite his wife’s determination that it was more than that. Carol’s symptoms were given various diagnoses but both Carol and Richard felt that their concerns were not taken seriously. Carol was only 58 years old at the time of the research period but had first noticed her symptoms, the feeling that something was wrong, ten years prior to that. She went through a six year battle of being taken seriously before she was correctly diagnosed with early-onset Alzheimer’s disease. It was not only the doctors who were, and continue to be, ambiguous towards the notion of Alzheimer’s disease and Carol, but also friends and family:

“I can walk down the street and we can go to a cafe and I can honestly say that people would not know that Carol has Alzheimer’s. How would they know? And if you do tell them they still don’t know because they don’t know what it means. You get various responses but ‘oh my memory is not too good either’, you know, ‘I forget things’. They think it’s all to do with memory. They don’t take it seriously.” (Richard discussing people’s reaction to his wife, Carol’s, diagnosis of Alzheimer’s disease.

As I discovered in the first SHARE group, Alzheimer’s can be invisible: you can not necessarily tell that someone has Alzheimer’s disease just by looking at them. There is not one clinical sign or one diagnostic test that can be done to identify someone who has Alzheimer’s disease. In some respects this seemed to be a positive thing for Carol and Richard: people could not tell there was a problem, they could carry on like normal. But the problem for them was that they couldn’t; they were very much aware that something was not right; Carol could no longer work but she was also struggling to look after herself at home on her own; she would forget to lock doors, to switch off the gas stove. Richard had to take leave from his own job in order to ensure that Carol was safe. There was ambiguity from the doctor’s perspectives as to what was wrong with Carol. There was ambiguity from friends and family regarding whether Carol’s memory problems were significant or just something that everyone experiences. For Richard and Carol, however, as was the case with Gard (1992), there was a clear boundary between normal and abnormal, between not having Alzheimer’s disease and having it. For them, getting an explanation, a reason, for her problems was vital and they seem to need others to see
the seriousness of the situation and validate her symptoms. For Carol and Richard having a diagnosis
took away the ambiguity and provided an explanation: that their problems were due to a disease.

There is difficulty distinguishing between those who have dementia and those who do not, when
symptoms seem to become so significant that they are seen as a disease and when they are not significant
enough to warrant such a diagnosis. The more serious the symptoms got, the more the couples seemed
to need a diagnosis:

“But I knew what Alzheimer’s was when it started you know, I knew what it was and what
would happen and everything. We hadn’t actually seen the doctor where we used to live
about it. I mean my husband has a few problems and so we were seeing the doctor and I
think the doctor realised what was happening but like me, I mean it wasn’t a problem then.
It was just occasionally that it showed itself.” (Betty commenting on her husband, James’,
journey to diagnosis).

“It’s been a problem for years but I’ve never really felt the need to talk about it before. But
I think now it’s time that other people knew what it is. Maybe we could do with some help
after all.” (May, talking openly at the Alzheimer’s Cafe about why her and her husband
Bert had finally gone to the doctors about his problems).

The couples see Alzheimer’s disease as a process. It begins mildly and doesn’t cause the couple too
many problems: others cannot recognise these symptoms. They seemed to feel the need for a diagnosis
when they felt the symptoms were obvious to others. When the affected individual goes to the doctors
and starts the pathway to getting a formal diagnosis of dementia their symptoms become realised: their
forgetfulness becomes a disease, their confusion becomes a disease, their inability to perform certain
tasks becomes a disease. The ambiguity of their symptoms, whether it is expected behaviour or not,
becomes clarified. Having a diagnosis of dementia becomes a concrete reality in their eyes rather than
a subjective feeling of something being not quite right.

4.3 Alzheimer’s as a Disease

After seeking and receiving a diagnosis of Alzheimer’s disease, the symptoms, the situations and
problems which arose as a result of them, become framed in a disease discourse. Alzheimer’s was seen
not as an inevitable situation that arises with old age but as a disease in its own right which happens
to mostly occur in old age:

“I think when we were kids like and we would see these old people and everybody would
regard them as a bit batty sort of thing, that they were old and I don’t think people knew
much about it then. It wasn’t thought about as Alzheimer’s. Yes, I think this is an illness
in old age. Mostly they are old people getting it, mostly. I think it is an illness that you
are likely to get as you get older but it’s not necessarily that it will happen. I mean you
get forgetful as an old person, I mean I can go into a room and when I get there I have
forgotten what I have gone for. But I mean that is old age but this is entirely different, this
is a disease. And I think it should be made clear to people that it is.” (Betty, a carer for
her husband with Alzheimer’s disease)
Alzheimer’s disease being seen as something occurring in old age was particularly painful for Carol who had early onset Alzheimer’s disease. Carol had difficulty in obtaining a diagnosis and then, once having a diagnosis, receiving the support she needed to help her with that diagnosis. She felt she was “the wrong age” to have dementia: all the services were for older people, it was framed as an older person’s problem. For Carol and Richard, her disease, Alzheimer’s disease, was not associated with old age:

“Hmm we’ve talked about this for a while haven’t we, that when people say dementia you always used to say why do they call it dementia because dementia sounds like an old person’s disease. Dementia means that you are running towards the end of your life and you are forgetting things” (Richard, discussing his wife Carol’s thoughts on dementia).

In Carol and Richard’s opinion Alzheimer’s disease was much more then old people forgetting things but many informants thought that there was still a strong public perception that Alzheimer’s was “crazy old people losing their minds” and people with Alzheimer’s had to face that public opinion, the negating of their symptoms and troubles as a disease, daily:

“Nancy: But there is an old lady down the road that I go to and she said, ‘well Nancy, I can’t remember things I want to get from the kitchen either’. She won’t accept that I have Alzheimer’s. She thinks this Alzheimer’s thing is awful

John: She thinks it is natural for you to lose your memory as you get older. She’s eighty something. But I think there are a heck of a lot of people walking around with it and they don’t know they’ve got it.”

For those with Alzheimer’s disease and their partners, Alzheimer’s is viewed as a disease, a physical disease causing the brain to die. The disease concept sees Alzheimer’s as something that is external to the affected individual, something that attacks them, that attacks the attributes that make them a person and contribute to their self. However, the disease is seen as something which the person affected by it has no control over. The disease is given agency: it does something to the affected individual, it changes them and makes them do things they wouldn’t otherwise do. As will be seen in Chapters 5 and 6 the disease is seen as separate to the affected individual. The ‘cared for’ individuals are people with Alzheimer’s disease: they have the disease but are not the disease. The disease as an entity separate to the individual is given attributes of power and personhood; it makes the person who is affected by it do things; the disease has behaviour which is attributed to it; it is the disease that needs to be controlled, not the person. The disease is blamed for the loss of independence, the altered behaviour, not recognising people, not being able to communicate or remember. The person with Alzheimer’s disease escapes responsibility for their symptoms through this notion. By giving the disease agency, the affected individual and their spouse can attribute behaviour which challenges notions of personhood and self to the disease and instead maintain a constant view of self and rationalise other people’s depersonalising behaviour.

There is a strong sense that the public should be educated about Alzheimer’s as a disease: that a clearer understanding of Alzheimer’s as a disease would lead to a better, more accurate understanding of the effects of Alzheimer’s and therefore conduct towards individuals with the disease:
“This is something about the brain dying and it affects every function of that person. If people understood this and the tag was like for motor neurone disease where the brain is actually dying and the effects of this happening are over a long period of time, the people would sit up and take more notice of that fact and have more understanding about it.”

(Richard, a ‘carer’ discussing his understanding of Alzheimer’s)

The invisibility of Alzheimer’s was also highlighted as a problem preventing the public thinking about Alzheimer’s as a disease. Physical deformities can be easily identified and symbolised. A physical disability or someone clearly struggling physically is equated with seriousness and needing help. Many informants commented on the lack of understanding that people had about their situation, that there was no visual abnormality, no physical symptom or aetiology that people could focus upon:

“But a lot of people won’t know will they? If you have a walking stick it’s saying, look I can’t walk very well. But if you have dementia they don’t know do they? You can’t expect them to know.” (Mary, a lady with Alzheimer’s disease)

In a visual culture a walking stick is a symbol for disability, someone needing help. With dementia there is no such visual symbol. According to one health professional, if the disabling impact of Alzheimer’s disease could be seen in physical terms then the affected individual would have “no arms and no legs”. The abnormalities in Alzheimer’s disease are invisible, a process in the brain which not even those closest to the individual can visualise and understand. In Alzheimer’s disease there is altered behaviour, confusion, not knowing how to do things. According to my informants people do not know how to react to this behaviour, preferring to ignore it and therefore them, but there was also a feeling that people blamed them for this behaviour, placing blame with the individual:

“I think Alzheimer’s needs a kinder image really, something that makes them realise that they can’t help what is happening, that they have no control over what they do. That it doesn’t necessarily mean that they are mad. It isn’t a mental illness in that way, it is more like a dying off in a way, the nerve endings are dying off. Dementia implies that it is hereditary or something in his genes. Whereas this is an illness just like anything else, I mean TB, anything like that. It was an illness and this is an illness and I think it would be better if the term expressed it as an illness rather than as something that is wrong sort of thing.” (Betty, a ‘carer’ for her husband with Alzheimer’s disease)

The notion of blame is pertinent here: by those affected with, or looking after someone with Alzheimer’s, the condition is seen as a disease over which the individual has no control. It is not the affected individual who is shouting, who is wandering, who is becoming violent and doesn’t know who their husband or wife is occasionally: that is the disease, not them. The disease becomes equated with something physical, a condition caused by an external agent such as the tuberculin mycobacterium. The individual is therefore absolved of responsibility for having Alzheimer’s and also the effects it causes. As will be seen in Chapter 5 the concept of Alzheimer’s as a disease becomes central to the maintenance of personhood and self for those with Alzheimer’s.
5 The Importance of the Couple

“As long as we’re still together, that’s the main thing” (Mary, discussing her relationship with her ‘carer’ husband Arthur)

At my first session at the Bredbury SHARED group I was introduced to everybody, “This is Arthur and Mary, this is Elsie and Reg and here’s Margaret and Stan”. At first I did not think much of it but the more time I spent in the sessions and talking to the participants the more I realised how centred around couples it was. The couples arrived together in taxis, sat next to each other in the arm chairs having their tea and toast before the activities started, one couple, Elsie and Reg always sitting hand in hand. They sat together at lunch time and during activities the couples would participate together, talking to each other and helping each other. There was a large social aspect to the group but it mostly centred around the couples together as a unit. The participants in this study were therefore not individuals alone but individuals within the context of a relationship. To be a participant in the Alzheimer Society’s SHARED group an individual with Alzheimer’s disease had to be accompanied by their spouse: the group was for the ‘cared for’ (the individual with Alzheimer’s) and the ‘carer’ (in this case the husband or wife who supports the individual with Alzheimer’s disease). In all other groups the vast majority of participants came as a ‘carer’ and ‘cared for’ married couple. My informants were all, therefore, part of a married relationship, many of them having been married for over fifty years. I came to realise how central this relationship was to my research question: the notion of personhood and self with regard to dementia.

5.1 Impact of Diagnosis

Despite the couple’s prior awareness that there was something wrong, receiving a formal diagnosis of Alzheimer’s disease was initially faced with a feeling of shock and tragedy. Most couples had some awareness, or at least connotations, of what Alzheimer’s disease was and meant. The initial feelings that were evoked by these connotations were that life as they knew it was over, life as who they were was over. Alzheimer’s disease, to them, meant dementia. This in turn meant old people slowly dying, slowly losing who they were, becoming more and more dependent, not being able to look after themselves, being a burden. Receiving a formal diagnosis was therefore a very upsetting period for the couples:

“When I found out that I was diagnosed with it I just wanted to kill everybody. I did. Oh I slammed doors and cried, ‘why me?’ The usual thing, you know” (Nancy discussing her initial reaction to being diagnosed with Alzheimer’s disease)

“Betty: Well it made me feel very upset at the time. It just confirmed my worst fears I’ll say that

James: I was going to say the exact same thing, it confirmed our worst fears about the whole thing. That’s exactly it.”

A diagnosis of Alzheimer’s disease was initially conceived as confirming their worst fears, the worst thing that could possibly have happened to the couple. The diagnosis seemed to be perceived as more
frightening than, for example, a diagnosis they knew more about, a diagnosis such as cancer. They
did not know how quickly and to what extent this diagnosis would impact upon them, how much it
would change who they were and how they could continue to live their life. They had known that
something was wrong but having a formal diagnosis put these symptoms, these difficulties, in a new
state of uncertainty and ambiguity:

“Raymond: It was a shock getting the diagnosis, I mean what does that mean?
Pauline: Yeah but you knew that you had something Ray
Raymond: Hey it was me who knew there was something wrong with me
Pauline: Yeah you knew long before you went to the doctors that there was something wrong
with you because you’ve written it down somewhere. ‘What is the matter with me?’ You
were saying basically that all your co-ordination had gone”

There was little understanding about how dementia would impact upon their lives, how dementia
would affect them, how they could incorporate this disease into their lives and who they were. The
initial shock was followed by a period of struggling to accept the diagnosis, where many of the couples
coped by “cocooning” themselves from the rest of the world. The couples seemed to need time by
themselves to adjust to the diagnosis, decide how they were going to deal with it and incorporate it
into their lives: what it meant for them. After this initial cocooning process the couples seemed to
emerge with a more positive outlook and a determination to keep their lives as normal as possible:

“It isn’t the end of everything. There is a lot in-between and you just have to accept the
changes and adapt to them. It’s a very sad situation. It’s very sad for the person, I mean
I wouldn’t like it, and it is also very sad for the person involved caring for them. Life has
changed really. It’s not the life you expected at this age perhaps. But there we are, we’re
still together. We’re still enjoying ourselves aren’t we love?” (Betty, discussing how she
and her husband James learnt to cope with his diagnosis of Alzheimer’s disease)

The couples came to realise that receiving a diagnosis of Alzheimer’s disease did not equate to the
severe, doom and gloom, scenarios that had been portrayed in the media. There were different stages
of Alzheimer’s: Alzheimer’s disease does not affect each individual in the same way and at the same
speed. There seemed to be a general consensus that the couple would treat life positively, to make the
most of the skills and abilities they had and to work together as a couple at maintaining their previous
life together as far as possible.

5.2 Maintenance of the Couple as a Unit

The SHARED group frequently split the participants into two groups for the morning activities: one
group consisting of ‘carers’ and the other the ‘cared for’. Prior to a talk for the ‘carers’ regarding social
and council services they could be entitled to, Marilyn brought her dilemma to the group. Marilyn was
principle carer for her husband, Frank. Frank had relatively severe dementia with respect to the other
members of the SHARED group. He had difficulty walking, having to be helped out of a chair and
supported whilst he shuffled around. He was able to talk but would not do so spontaneously, instead
he would mumble some words if spoken to directly. He would rarely join in any group activities but
would instead sit alone with his eyes closed. Many of the group participants would comment on Frank:
“It’s a shame isn’t it? He’s bad. It must be awful for Marilyn”; “He can’t do anything. It’s sad. He
must be really hard work. He’s not eating that well is he? He couldn’t do the baking, he just sat
there with his eyes closed”. Marilyn was very attentive to Frank and was constantly trying, pleading,
to get him to join in. She would ask him questions in the quiz and try and get him to sing. She would
talk lovingly about her husband but it was clear that the lack of interaction she received from him
upset her. However, in this group session Marilyn shared with the other ‘carers’ that a social worker
had advised her that she should take Frank to a day centre where he could be looked after after a couple
of days a week to give herself a bit of a break from her full time role as carer. Marilyn didn’t know
what to do. She had been shocked by the suggestion of the social worker. She felt that although she
was exhausted from looking after Frank twenty four hours a day, they were, never the less, coping.
She said she felt guilty at even the thought of putting Frank into day care: she should be the one
caring for him, she was his wife. She worried that he would be unsettled at day care; Frank wants to
know where she has been after only five minutes of being away from him; in day care would he think
that she had abandoned him? Marilyn also spoke of a great sense of responsibility for her husband.
She discussed the stories regarding abuse of older people in nursing homes and day centres that are
broadcast on the news and in the newspapers. She felt Frank was vulnerable and she should always
be there to protect him. There was a general consensus from the rest of the group that although all
Marilyn’s concerns were important, she should put herself first, to think about the impact her caring
was having on her life and her happiness. The group thought that Marilyn could be a better carer,
give more stimulation and help to Frank if she had some time to herself, if only to get housework etc.
done in peace. Marilyn was still unsure but agreed to go and look at some day centres with Frank and
test them together before she considered leaving him there alone. For the others in the group it had
been very clear what Marilyn should do: she should look after herself and her sanity first and foremost
and accept help with Frank. However, when Marilyn turned the question to them, suggesting that
Edward and Dora could also benefit from putting their spouses in day care, the situation was all of
a sudden not so clear and Marilyn’s suggestion was met with some blunt responses: “Oh, my Bert is
not at that stage yet!” They could see the benefits of day care for someone else’s spouse, but not their
own.

Being married and maintaining that independent married unit seemed central to many of my
informants. Many carers expressed the desire to remain coping themselves rather than seeking external
help. As seen in Marilyn’s case, great importance seemed to be placed on the wife looking after the
husband, or vice versa. Feelings of guilt seemed to be evoked if they could not be there all the time
for them or if they got angry with their partner. They did not want to leave their husband or wife
with other people to look after them. The carers expressed a sense of feeling it is their duty to look
after their husband or wife, something they have promised to do. However, the feelings evoked were
clearly more than keeping a promise to be with their husband or wife “for better, for worse” but also
something that they wanted to do: they love their partner and want the best for them.

I was struck, and a little humbled, by the overwhelming sense of partnership within these couples’
relationships. They had all been married for many years and previously faced, and overcome, problems
together. Alzheimer’s disease was seen as just yet another problem to overcome, or at least adapt to. They faced it very much together, as a partnership. I was struck by how much normality in their relationship the couples endeavoured to maintain: going out for trips, dinner, trying to do jobs together. The couples also talked about the importance of laughter: laughing at the things which went wrong, the things they couldn’t do and the situations that arose because of that. Humour still seemed very much a part of the couple’s relationship and approach to life:

“James: I mean Betty has always been good, she’s always been there
Betty: A long suffering wife huh?
James: Very long suffering wife!
Betty: I’ve told him if he doesn’t live till our 60th anniversary I’ll kill him. I want my telegram from the Queen!
James: I mean Betty has always been very good, you’ve looked after me haven’t you love?
Betty: I’ve tried my best
James: You have, you’ve done brilliantly. I can’t be easy to look after
Betty: (laughing) You said that, I didn’t! I always agree with him you know
James: I’ve always been a bit of an educated awkward customer, I used to run my own things and used to be in charge and if ever anyone told me what to do I’d...
Betty: I’m getting my own back now you see!”

The couples seemed to adapt to their new situation and new capabilities. Household roles sometimes had to be reversed, couples often started spending much more time together, they worked together and shared things together. They adapted as a couple rather than as individuals:

“Arthur: We manage very well together really. And we look after each other don’t we love?
Mary: I don’t know where I would be without him
Arthur: Well you marry for better or worse don’t you? Well she looks after me. She’s my carer too. There are lots of things I can’t do and there are lots of things that she can’t do.
We help each other. It must be worse for people who are on their own.
Mary: Yes, what happens to people on their own?”

There was give and take in the relationships, working as a team, both bringing their own skills and attributes to the couple. A few couples discussed the concept of which one of them was the ‘carer’ and which one the ‘cared for’? They both felt that they brought different skills to the relationship and looked after each other. In Arthur and Mary’s case, Arthur was the “memory”, remembering what needed to be done and how to do it, but Mary was the “hands”, the one who could carry out these actions. Although Mary had Alzheimer’s disease, she was much more physically able than her husband, Arthur.

The individual with Alzheimer’s disease could no longer manage on their own, could no longer cope independently. They were dependent upon their husband and wife but in that partnership could maintain an independent existence. The maintenance of the couple as an independent unit seemed to
take importance over the independence of the individual with dementia. They lost their independence within the marriage partnership, having to ask for help, not being allowed out on their own, told what they should do and when they should do it, but as a result only had to ask their spouse for help, not others, and therefore maintained a public sense of coping. As one member of the SHARED group, Doreen, said, “You wouldn’t know that anyone in this group had Alzheimer’s. They look fine. They look like there is nothing wrong with them but it’s only because they are so well cared for”.

5.3 ‘Cared for’ Sense of Self

“It changes you I suppose but you are still you” (Nancy discussing the impact of Alzheimer’s disease upon her life)

During interviews and as part of general conversation in the Alzheimer Society’s groups, those with Alzheimer’s talked about the effect of having the disease, upon their lives. “Frustrating”, was the most commonly used term to describe the disease’s impact; they were frustrated at not being able to do the things that they used to do or not being able to do those things with so much ease; they were frustrated at not being able to rely on themselves; they were frustrated at not being trusted any longer; frustrated that they could not communicate their ideas and thoughts effectively. The study participants with Alzheimer’s disease seemed to have a clear sense of their self, the “attributes, sentiments, values and characteristics” through which they defined themselves (Charmaz, 1999; 109). However, they sometimes felt that this wasn’t adequately portrayed to others: that their self was misrepresented. Having a diagnosis of Alzheimer’s disease and the symptoms, struggles and situations that arose due to the Alzheimer’s disease process did not seem to affect how these individuals thought about themselves but there seemed to be sadness and a sense of loss at the actions and skills they could no longer perform. Some of these lost skills seemed almost incidental, but others clearly had been central to the individual’s idea of who they were. There also seemed, in some cases, to be a feeling of embarrassment and frustration at the way other people viewed them and interpreted their actions.

Bill had always been a keen gardener, it was a hobby but also something that he prided himself on. He didn’t just garden for his own enjoyment but to help other people: he grew fruit, vegetables and flowers to give away to friends and neighbours and also helped them with their gardens. For Bill gardening was synonymous with being sociable, caring and generous. The loss of being able to keep up his gardening with the progression of his Alzheimer’s disease, the loss of being able to help other people but instead needing help himself, was very upsetting to Bill:

“It breaks my heart that I can’t do things I’d like to. My garden, my greenhouse. I used to like to keep everything. Oh I love my garden! I used to have two allotments, I’ve always had a greenhouse. I loved my garden. Everything that could be grown, I grew it, you know. But not now. I try but I just can’t do it. As long as I stay as I am now I don’t mind, you know. As long as I’m never no trouble to anyone. I don’t want to be no trouble” (Bill discussing the effect of Alzheimer’s disease on his gardening).

Bill refuses to let his wife, Marjorie, employ someone to help him with his garden. Bill wants to hang on to his skills and interests: he has always tended to his garden so he still will. He seems to get a lot
of satisfaction by still being useful, trying his best to keep doing the tasks and jobs he has always done, trying his best to help his wife. He wants to do things, he wants to help, and feels down and frustrated when he tries to do these things and finds that he is no longer able to do so. It still upsets Bill that he can’t do his gardening and that he can’t help around the house as much as he used to but the most important thing for him now seems to be to maintain his independence to some extent, he does not want to be a trouble or a burden to anyone else. He may no longer be able to help people through his abilities but he still cares about other people and wants to help them by not being a burden to them. As long as he can wash and dress himself, feed himself, help his wife a little with chores and chat to people he can reconcile himself with the fact that he is not a “trouble”. For Bill’s sense of self he needs to feel that he has a purpose and can help others.

It was the loss of skills which hampered independence that were most harshly grieved by the participants with Alzheimer’s disease. Many informants spoke of the devastation of having their driving licenses taken off them:

“I didn’t think they would take my car away. That came as a big shock. It’s like taking your legs away really” (Nancy discussing the things she has been unable to do since being diagnosed with Alzheimer’s disease)

“Oh losing the car was a blow. Every time I walk past the garage, oh I feel for that car. That’s been one of the hardest things, losing that car” (Bill, on how Alzheimer’s disease has affected him)

“I can’t believe they’ve taken my car off me. I mean what am I meant to do now? How am I meant to go bowling? How am I meant to do anything? I can’t believe it” (George, discussing his experience of being diagnosed with dementia at the Walk and Talk group)

Driving can be seen as a symbol of independence, youth and mobility and for all my informants no longer being able to drive seemed to signify more than the loss of driving skills. For Nancy, no longer being able (or allowed) to drive was like having her “legs taken away”. By not being able to drive she had to rely on others, she had to ask her husband if she needed to go somewhere in the car, she was no longer in control of when and where she wanted to go; to her losing her driving license meant losing independence and freedom. It was this that was important and impacted upon how she felt about herself. Nancy did not like being treated like someone who was unable to look after herself. Despite the fact that she knew she could get confused and muddled, that she could quite easily get lost and not know where to return, Nancy felt angry at not being allowed out on her own but instead having to take her husband or daughter-in-law with her:

“I can’t go out by myself. Well there are shops just round the corner and I can go there. A post box! That’s nice being allowed out there! I don’t like not being able to go out on my own. I think it takes half your life away. Or maybe more. Because you’re not, well you’re just disabled”.

Nancy feels disabled by her loss of independence. She feels capable of looking after herself, she feels like the Nancy she has always been and does not like being treated like a child and reacts against it with defiance: she fights for her independence. There seemed to be incongruity between how Nancy felt
about herself and the representation that others made about her. The thing she found most frustrating with Alzheimer’s disease was not being able to communicate and express herself effectively.

“Nancy: It’s like when I am talking to John I can’t get it out of my mouth! I know it’s up there but I can’t get it out

John: Can’t find the right words

Nancy: And that’s the most frustrating about this whole Alzheimer’s thing for me. We were in Sainsbury’s (laughs)

John: Oh it’s like twenty questions trying to find out what it is. We’ve got to get some of those er er er er

Nancy: (laughs) and then he says I don’t know what you’re talking about!

John: Bananas? No. Grapes? No

Nancy: And then I shout. It really frustrates me. I do know what I want to say, I really do. I mean I’m talking to you. Lucid do they call it? You feel that you are talking to someone and telling them something without them saying, ‘I don’t know what you are talking about’.”

Nancy feels there are discrepancies between how she thinks and experiences things and how she portrays herself to others. She knows what she wants to say and she knows what she thinks. Nancy directly attributes this inability to communicate her thoughts, her inability to write or tell the time, to symptoms of Alzheimer’s disease. She does not incorporate these loss of skills into who she is. Nor does she incorporate a loss of independence into her sense of self: she rationalises her loss of skills and abilities to part of a disease process, not who she is. Her selfhood is constant whilst the disease causes an altered portrayal of this selfhood to others.

James also seemed to experience a constant selfhood, unaffected by the Alzheimer disease process but was aware that this may differ from other people’s perception of him. James seemed to repeatedly assert his sense of self: the attributes, sentiments and characteristics that he felt were pertinent to him. I met James at an Alzheimer’s Society Lunch Group for the ‘carer’ and ‘cared for’. James was very chatty and interested in why I was at the group, what my research entailed. Over lunch he spoke in depth about his own education and subsequent career in the Army and later in teaching. He told the same stories over and over again, almost to the exact word. A week later I was invited to James and his wife Betty’s home in order to talk further about their experiences of Alzheimer’s disease. Once again I heard the same stories, the same achievements, trials and successes. James was educated, he felt that he had been successful in his life and was clearly proud of his achievements. During the interview we talked in James and Betty’s living room, the couple sat next to each other in armchairs, myself perched on a couch next to them. The room was full of ornaments and photographs. There were photographs of James’ children and grandchildren, all in their graduation gowns. Success and achievement were clearly things that James valued. At the lunch group I had not fully identified the importance of James’ repeated stories but when talking to him once more in his own home I realised how central this portrayed image of an educated, important and respected man was to him. The repeated statements seemed to not only be for my own benefit but also for James himself and for his wife Betty, a constant assertion of who he was:
“I feel awful about this because I was very much the organization man. I ran a pretty big department really. OK I was deputy head of my department but my head of department left me entirely to it. I did the lot and it was a lot of responsibility and I was quite happy doing it. I am very well qualified, I mean I have a Master of Philosophy degree and various other odds and ends and I mean those don’t come easily. I have lots of letters after my name. Educated idiot I suppose I am and I think, what the heck have I come to? (sighs) I don’t know. I get cross with myself when I feel like this, I do. I get cross don’t I love?”

James is educated. He has been successful in his career. He is used to being in control and people looking up to him for advice. However, he now sees himself as an “educated idiot”, an educated man not behaving in an educated manner. James still feels that he is intelligent and capable of being organised and in control. He is upset about what he has “come to”, not being able to do things himself, needing help, and in his eyes, “making a fool” of himself. James has a clear idea of who he thinks he is and what he values in himself but is worried about what others will think of him, that their view of him will not match his own:

“James: What happened that day? What did I get into a state about?
Betty: I don’t know lovey, you got in a state at the checkout. You do get into a state at the checkout when I am there. You’re always asking these awkward question (laughing) at the top of your voice and I always think the checkout people must think we are mad!
James: I shouldn’t be doing that
Betty: Oh no, it’s funny dear, it’s not your fault
James: I shouldn’t be doing this”

The nature of other people’s perception of him is very important to James. The fact that they might see him and think he is “mad” is devastating. As soon as I met him at the Lunch group, James started telling me about his educational background and about his career. He was interested in me but also very interested in portraying an image of himself, an image portraying him to be intelligent and successful. He is aware he has a disease, that of Alzheimer’s, he is aware that his behaviour, getting confused, speaking inappropriately, could lead people to think that he is “mad” but he does not feel this to be true himself: the disease that he has “no control over” makes him do these things, makes him behave in a particular manner, one that he does not feel is representative of his true self.

All participants with Alzheimer’s had a constant view of their self despite the affects of Alzheimer’s disease. The disease effects were seen as external to themselves, something that affected their abilities but not their core sense of who they are:

“I am never thinking in my head, oh I have this disease. I would never say that” (Carol, talking about her own experience of having Alzheimer’s disease).

Carol has a clear sense of purpose and self worth. She experiences depersonalising behaviour from friends, family and strangers. To Carol, treating someone like a person is treating them with respect and dignity, including them in conversations and decision making, making an effort to communicate and understand them. Carol does not feel that she is always treated this way. She does not always
feel that she is bestowed with the status of a person. She feels ignored and unvalued. Carol attributes this behaviour to other people’s lack of knowledge regarding Alzheimer’s disease: she feels that she is treated as being Alzheimer’s disease rather than a person with it. Society viewing people with Alzheimer’s disease as being Alzheimer’s disease causes much frustration for all the couples and is what they believe to be the route of the public not bestowing personhood on those with the disease. Carol, in contrast to the way she is sometimes treated, views herself as a person worthy of dignity and respect, a person who happens to have Alzheimer’s disease, not as someone who is Alzheimer’s disease. Carol still sees herself as worthy of being bestowed the status of personhood and does not incorporate this depersonalising behaviour into her sense of self. She does not see the effects of Alzheimer’s disease as part of her core sentiments, values and attributes, as part of her self:

“They think you don’t have a brain you see. But I do have a brain and I want to understand too” (Carol talking about people’s reaction to her Alzheimer’s disease).

This concept of “having a brain”, of being a capable acting human being with feelings and understandings seems to be of great importance to all the study participants with Alzheimer’s disease. It is this that they seem to attach to the notion of personhood. They feel that others think they do not have a brain, are no longer capable of interacting, holding a conversation, being independent, making decisions and being valuable to others. They feel that others deny them the notion of personhood but do not feel this to be true themselves and do not think about themselves in this way.

Independence seemed to be the most important component of self for those with Alzheimer’s disease. They were not prepared to have their independence taken away from them: they still felt very capable of making decisions and looking after themselves, albeit with help from their spouse. They could accept help from their husband or wife but not from an external agent; maintaining independence individually had not been possible but this help from their spouse was subtle; they had always acted as a team and still were. However, accepting external help was too much of an insult upon their independence. Accepting help would impinge upon their ability to maintain a constant experience of self. Being independent and self-reliant, making their own decisions, was clearly important to how my informants thought about themselves:

“I don’t want people to come and help. I think I don’t want the interference. I want to make my own mind up and do it my own way and not have some other person saying you have to do x, y and z. No, I want to make my own mind up. I mean for a long time I was pretty much in charge” (James discussing his refusal to have carers come and help him get dressed in the morning)

“Well I can do what I want. No one will tell me where I have to go. It’s up to me” (Raymond explaining why he has refused to go to an Alzheimer’s day care centre)

Having Alzheimer’s disease was not incorporated into the sense of self of the study participants with Alzheimer’s disease. The skills and activities they were no longer able to do were experienced as a loss but not as a change in who they were, their self. Their self was constant despite Alzheimer’s affecting their abilities and the way they were perceived by others.
5.4 ‘Carer’s’ Loss of Self

“People don’t understand from the perspective of the carer. It’s never one person’s life, it’s two people” (Richard discussing the impact of his wife Carol’s Alzheimer’s disease).

It was not only the ‘cared for’ individual, the individual with the diagnosis of Alzheimer’s disease, who was affected by the disease process. The ‘carer’, the husband or wife of the affected individual, also had to incorporate Alzheimer’s into their life: it had a profound effect upon how they lived their lives and what they thought about themselves. Alzheimer’s had changed their roles within their relationship and also their roles as individuals. They had stopped being a person in their own right with their own interests and attributes but had instead become a carer: they felt their sole role was now to look after their husband or wife, to preserve their quality of life as much as possible. Being a carer had been incorporated into their sense of self.

Becoming a full time carer was not a job that any of the ‘carers’ particularly wanted, nor one that they felt particularly good at. Although this was felt by all the carers it had it’s biggest impact upon the male carers. Things were different for the female carers but not so different. The women who had become carers had always had caring roles within the family or work. Marjorie had been a nurse, Pauline and Betty had been the organisers at home, looking after the children and caring for elderly relatives:

“Well things have changed, obviously they do. But I always did do quite a bit because we had four kids so I was always very busy with the home. James was very busy with his job. But I suppose I am responsible for everything now. The jobs he did I have to do now. The finances, all that kind of thing. But we've always been a bit of give and take. There have never been rigid roles” (Betty discussing the impact of her husband James’ dementia).

There were practical implications of a carer’s spouse having Alzheimer’s disease: roles had to be reversed, tasks that the individual with Alzheimer’s used to do had to be taken over by the carer. Cooking, for example, came as a daunting task to some of the male carers at the SHARED group: Jeremy had enrolled in a cookery class having previously left all cooking to his wife. John looked forward to the lunch at the SHARED group stating that it was the “only good meal” he got all week. He spoke at length with the Dementia Outreach Support Officer about tips for cooking, having previously never taken any interest in it. However, it was not just taking on extra household acts that was difficult for the carers but actually taking on the role of carer and incorporating that into their sense of self.

Perhaps the role of carer was felt most harshly by Richard. Richard was in his late fifties and had been caring for his wife, Carol, for almost ten years. I interviewed Richard and Carol in their own home, a beautiful converted barn which Carol had helped plan with the architects and had been in charge of the interior design. When I arrived at their home both Richard and Carol were in the garden, Richard weeding, Carol knelt next to him watching what he was doing. They looked like any other middle aged couple doing gardening together, unusually in the garden, not at work, on a week day. However, they weren’t really doing gardening together, Richard was doing gardening whilst trying his best to keep Carol occupied, constantly aware of where she was, what she was doing, trying his best to prevent her from wondering off out of the garden. Whilst talking to Richard and Carol it became
clear that externally they had managed a facade of coping, of everything being OK, of managing to keep doing things together and enjoying things together and they had, they had achieved it, but it had come at a price. Richard had given up many things, his job, his financial security, his friends and hobbies in order to look after Carol and strive to give her a positive experience of Alzheimer’s disease:

“And that’s what I spend our money on - looking after Carol. You don’t pay very much attention to yourself because you can’t. You see I kind of forgot who I was and well it’s hard to explain” (Richard discussing the impact of his wife, Carol’s, Alzheimer’s disease upon himself)

Richard, in his own mind, had become less important than Carol. She was the one with the disease, she was the one that was suffering, she was the one that needed looking after and protecting. But in this attempt to help Carol, to help her think positively about herself, to encourage her stimulation and preservation of skills and abilities, to protect her from the stigmatising views of others, Richard had forgotten about himself, forgotten about his importance:

“Because inside everything had gone wrong, not just with the relationship and the marriage and our friends, our social life but all my, you know, all the things I had used in the past. My intellect, my mental abilities, they were all diminishing. All I was doing now was the cooking and cleaning. That wasn’t who I used to be! You know I used to be a business man and I looked after four hundred staff, I had a budget of thirty million pounds and a turnover of three hundred million. So you know there was a massive turn around in what I was doing. To be doing what I’m now doing, well it made me lose my own self esteem, but more importantly, well I felt a bit of a failure looking after Carol.”

Richard had gone from being a very successful business man to a full time carer, a man in charge of a budget of millions and a staff of four hundred people to a man in charge of looking after just one person, his wife. Although a purpose was still present in Richard’s life that purpose had changed. He had gone from feeling successful to feeling like a failure, from being proud of himself and his achievements to feeling worthless: the things he prided himself upon no longer being present in his life. Richard felt “ugly” because he was no longer proud of who he was, he didn’t even know who he was anymore. He had stopped using his intellect, something he had previously prided himself upon. He was no longer in control but instead constantly struggling to maintain his and Carol’s relationship, to remain positive about the effect of Alzheimer’s disease:

“See what you don’t realise as a carer and and basically as someone who has the disease is that actually being together all the time is not healthy. But, never the less, as a carer you don’t have a lot of options most of the time so what you do is do these things because, A you care about the person, and B you tend to forget about yourself. You never put yourself first and so what happens is that you suddenly find that you’re in this black whole of intellect, mental and physical decay and you can’t really change that very quickly.”

Richard and carol still claimed to be happy, to love each other, but things in their relationship had clearly changed. Both of them had taken on the burden of Alzheimer’s disease. Richard was determined
to make life as positive as possible for Carol but for this he had to sacrifice some of his own independence and interests.

When faced with a husband or wife with Alzheimer’s disease, caring for their spouse became the most important thing for the ‘carer’. They went from being a friend, a successful professional, a bowler, a cyclist to almost exclusively a carer. They began to think about and define themselves as a carer. They spoke of not having time to do the things they used to enjoy, nor the energy or inclination. When they were not physically caring for their spouse they were thinking about them, worrying about them. They maintained life as an independent couple unit, managing to look after themself and enjoy life but the carer took on this pressure and in maintaining the self and personhood of the ‘cared for’ individual, lost a bit of their self in the process.

5.5 The Triad of the Relationship

How did the couples maintain their solidarity as a couple? How did the ‘cared for’ individual incorporate Alzheimer’s disease into their lives whilst still maintaining a constant sense of self. How did the ‘carer’ take on a role as carer but still maintain much respect for and get enjoyment out of their relationship with their husband or wife? I argue that this was maintained through seeing Alzheimer’s disease as a disease entity that was separate to the person that had the diagnosis. They had Alzheimer’s but Alzheimer’s did not have them: there was more to the person than Alzheimer’s disease. Behaviour and actions that challenged the individual with Alzheimer’s sense of self were blamed on the disease. Things which challenged the carer’s notion of who their husband or wife was, their behaviour, memory and attitudes, were blamed on the disease, not on the person. Agency was attributed to the disease: the disease caused the individual it affected to behave in certain ways. Alzheimer’s disease as a disease entity became a scapegoat for maintaining the self and personhood of the individual diagnosed with the condition. Any behaviour or attributes which could be perceived negatively could be blamed upon the disease, not the individual.

In section 4.3 I showed how the couples had come to see the affected individual’s symptoms as a disease, something for which they had no control over. Alzheimer’s disease was seen as an external agent such as a bacteria or parasite that had effects upon the affected individual. These effects, however, were not the person’s fault: it was not them who did not recognise their partner but the disease. The disease controlled them at times but it was still the same person who was under the control of the disease, the same husband or wife that the ‘carer’ had been married to for so many years. The carers seemed to rationalise the effects of Alzheimer’s by seeing it as separate to their husband or wife: their spouse was a constant being but the effects of Alzheimer’s disease caused them to behave in ways in which they would not, without the disease, otherwise do. By seeing negative symptoms in their husband or wife as the disease, not them, they could continue to find continuity within their relationship.

It was in the first SHARED group that I was faced with the concept of behaviour being the disease, not the individual. Before a talk for the carers which would detail tips and services to help them in their caring roles, one of the carers, Donald, asked the group whether they had noticed their partners deteriorate in the hot weather in the previous week. Many of the carers had: there had been increased confusion, wandering, aggression. Donald talked of how upset he had been at his wife’s aggression
towards him when he would not let her “go and find her mum who has been dead forty years”. Donald felt guilty at himself for getting angry with her in return. Many of the other carers sympathised with Donald and said that they often feel guilty at getting angry too, at not being understanding towards their partner. The speaker for that week’s talk, a professional carer, but who had herself also been a carer for a parent with dementia, said that carers could not expect themselves to be saints, to not get angry, but that they should remember “it is the disease acting up, not the person [they] cared for”. The carers were being taught to detach themselves from the situation and their subjective feelings and to instead rationalise it; they could get angry with the disease but not with their partner; it was not their fault.

When talking to the study participants in their own homes it was clear that the ‘carers’ had come to see dementia as an intruder into their relationship: no longer was it just them and their husband or wife in the relationship but Alzheimer’s disease was also prominently there. Importantly though, the ‘carers’ did not see Alzheimer’s disease as being synonymous with their partner, but as a separate entity to be managed. The individual diagnosed with dementia could still be seen as the husband or wife that they had been married to for years and who they loved and respected by using Alzheimer’s disease as a scapegoat, something which controlled them, the reason for behaviour which might otherwise make them angry or see their loved one in a new light, a scapegoat for behaviour which might jeopardise the image that they hold of their spouse:

“It’s hard when Carol’s mum is here. Because Carol thinks she is not here, that she is dead. So it’s very difficult for Carol to understand. But that’s the disease as well by the way that makes her do that. So it is very difficult for Carol to understand when she sees her mum and she looks at her and says well you’re not here so I don’t need to speak to you” (Richard discussing the difficulties in Carol’s relationships with others)

Richard sees Carol as being controlled by the disease, Alzheimer’s. It is not Carol that is willingly not recognising her mum and making the situation awkward: it is the disease. Carol not recognising her own mother and being rude to her does not fit in with Richard’s image of his wife. In order to preserve his image of Carol, his respect and feelings towards her, Richard blames this behaviour on the disease and absolves Carol of all responsibility for her actions.

Other carers also seemed to use the notion of Alzheimer’s as a disease, as a separate entity to their husband or wife, to encourage kinder behaviour towards them by others. Betty had coped with her husband James’ altered behaviour through seeing it as being caused solely by the disease, not by him. Betty saw James as being in no way responsible for his altered behaviour and wanted others to also see that James was not to blame, nor responsible for his actions:

“Well it was very slow to begin with and then er I thought I ought to say something to the kiddies because once or twice I thought he’d perhaps been a bit funny with them. It wasn’t his fault of course but he had appeared to be funny with them”

“We don’t go into a lot of new social situations. We don’t go into situations where people don’t know us. And if we are going somewhere new I tend to let them know about the Alzheimer’s before hand”
By telling people that James has Alzheimer’s disease Betty hopes that this will provide an understanding environment for James to be in. By seeing his altered behaviour as something caused by a disease Betty hopes that people will not start seeing James as someone different, someone who doesn’t need to be treated with respect and dignity: by trying to get others to see Alzheimer’s disease as separate to James Betty is trying to protect James’ personhood.

### 5.6 Carer as Protector of Personhood

“People think that you are crazy. They treat you differently, don’t respect you. They think you don’t have anything worth saying, perhaps I don’t” (Mary, a lady with Alzheimer’s disease discussing others’ reaction to her)

The ‘carers’ had started seeing Alzheimer’s disease as separate to their partner; the disease was a scapegoat for their altered behaviour and attitudes. However, the ‘carers’ were very aware that others, friends, family, and the public, might not see their husband or wife in the same manner. The ‘carers’ tried to look after their partners without being overbearing, without trying to impede too much on their independence. The ‘carers’ were well aware that their husband or wife could no longer look after themselves like they had once done: Alzheimer’s had hindered their ability to maintain an independent existence. The ‘carers’, however, did their best to preserve the personhood of their ‘cared for’ partner by trying to maintain an external appearance of an independent, coping person. It was this independent, coping individual, being viewed as a rational independent adult capable of decision making, that the carers thought was fundamental to their partners being bestowed personhood by others. It was, however, a fine balance between maintaining an experience of bestowed personhood by others and preserving the affected individual’s sense of self, how they felt about themselves. ‘Carers’ often wanted to protect their partners from the stigmatising attitudes of others. They wanted to do things for them and prevent them from doing certain things, such as going shopping on their own. The carers wanted to prevent situations arising that could embarrass the individual with Alzheimer’s and cause people not to treat them as persons: not to bestowed personhood upon them. The ‘carers’ wanted to protect their partners but not “wrap them up in cotton wool” from the outside world, nor hinder their ability to think positively about themselves.

It seemed important to the ‘carers’ to try and maintain their partner’s independence as far as possible, to try and let them do things themselves:

“But the fact that he doesn’t want help, that he can be stubborn, is good because it means he hasn’t lost his ability to be sort of I don’t want this or that. He still has that independence. I think that’s a very important thing. I think you have to try and stay as independent for as long as you can. I think it’s just important to give them the feeling that they are in charge. I mean this I’m in charge business is very important to James because that is what he was. That’s his life sort of thing. Without that his life has gone, really. It’s difficult because he needs more help and obviously I am here to help him but you don’t want to over help. You want to let them do what they can.” (Betty discussing James’ desire to not except help from external agencies)
This was a pattern I saw repeated in many of the couples. The ‘carers’ tried to leave their partners
the space to do things on their own but were always there, almost like a back-up, a support system,
if things went wrong, if the ‘cared for’ individual needed help. It was something I noticed at the first
Walk and Talk meeting. After the walk the couples were all sat in little groups having snacks before
the talk began. Tom and his wife Audrey were sat next to me, Tom talking to the couple next to him
and Audrey intensely concentrating on the satsuma in her hands. She had been holding it for a few
minutes, turning it round and round in her hands. Tom had asked whether she needed any help in
opening it up ready to eat to which Audrey had been quite adamant that she didn’t. Tom returned to
his conversation but kept on looking at Audrey every now and then, checking that she was OK, that
she was managing with the fruit. After a few more minutes without any progress in peeling Audrey’s
satsuma, Tom took his own satsuma from the table in front of him, dug his thumb into the skin and
started peeling the fruit bit by bit. Audrey watched as Tom did so and then started to peel her own
fruit. Tom had clearly found it hard not to take Audrey’s fruit off her and peel it for her. She was
clearly struggling, clearly needed help but did not want to accept it: she wanted to peel her own fruit,
not have to have to have help from her husband. Tom had subtly helped Audrey, had shown her
what to do without explicitly making it clear to everyone around them that Audrey was unable to
peel a satsuma on her own. Audrey had received help but had not lost face, Tom had managed not to
embarrass her in the situation and not impinge on other people’s notion of her personhood.

Many other ‘carers’ also found it hard not to over help their partner. Doreen found it difficult to
know what to do when her husband, Jack, who had Alzheimer’s disease needed the toilet when out in
a public place. She told me that she was too scared to let him go into the men’s toilets any longer after
one time he had been in there for fifteen minutes. She had been hovering nervously outside, waiting
for him to come out, worrying what had happened to him but also too nervous to go into the men’s
toilets herself. She had waited, seeing men go in and come out again but with no sign of her husband
Jack. Eventually he came out, unaware that he had been a long time. Doreen was very concerned to
maintain her husband’s dignity: “He’s a very private man. I mean he was chief constable of the police.
He’s always been respected. He would hate me to go to the toilet with him. He’d be so embarrassed”.
Doreen and Jack had found a compromise which would stop Doreen worrying so much but would also
allow Jack not to feel that his dignity had been compromised, that he is still able to be independent.
Jack now goes into a disabled toilet cubicle without locking the door and Doreen stays outside. Doreen
wanted to preserve Jack’s personhood, as an independent man being able to go to the toilet on his
own, but wanted to do this in a safe manner, one in which she knew she could be on hand to help if
Jack needed it.

Betty had had a similar problem keeping up her and James’ swimming sessions. She had wanted
to keep it going for as long as possible, thinking it gave them both exercise and a chance to get out of
the house and do something together. However, Betty has decided not to take James swimming any
longer as he would not be capable of getting dressed on his own in the male changing room. Betty
does not want to make an issue out of it. She felt that James would not want to come into the Ladies
changing room to get changed. However, she also worried that people would not know why he was
there and would ask lots of ‘awkward’ questions. This, she feels, would make both her and James feel
embarrassed and awkward. Rather than put James’ personhood at stake, making him get changed in
the ladies changing room, people viewing him as incapable of doing so alone, the couple would rather sacrifice their former hobby and not go swimming at all. Betty is concerned about how other people will view and subsequently treat James and so would rather stay in situations in which they feel safe, in which people know James and that he has Alzheimer’s disease: so the disease can remain a scapegoat for his behaviour and inabilities.

Many of the couples thought that people, the general public, did not know how to respond to individuals with Alzheimer’s disease. This, the couples believed, caused people to behave as if the individual with Alzheimer’s disease was not there: personhood was not bestowed upon them. The public did not know how to speak to people with Alzheimer’s disease, decided they were incapable of communicating and social interaction and so instead ignored them. This was something that Richard and Carol were very aware of and reacted against:

“I think people don’t actually know how to respond to Alzheimer’s. That is the real crux of the matter and they do it, and I do it, even like just now for instance. People will talk over Carol, they don’t understand that the words Carol uses take a while to sink in. So there is a complete lack of understanding about how to be with someone with Alzheimer’s, including some of our closest relatives actually. We’ve been to a lot of places where people actually just talk over her and I just say, by the way, Carol is here, she’ll give you the answer to that. So it’s difficult. When Carol was first being diagnosed we saw this consultant and he sat across the table and never looked at Carol once. I stopped him, I mean I was just a business man in my own right and I said, ‘I’m sorry but it is not me who has got this disease, it’s Carol’. I actually said that to him and he looked a bit blankly at me and I said, ‘No, talk to Carol about this because she is going to have to face the problems she has got, not just me’ but he didn’t seem to really take it on board. He just ignored her. Carol reacts against it, very poignantly sometimes actually. She said, ‘If you don’t want to talk to me then that’s fine. But don’t come again’. But that’s the problem with this whole thing, it’s wrapped in this bubble of treating people with dementia as old people who don’t understand, they have memory problems and you don’t need to treat them like ordinary people or as human beings or with dignity’” (Richard discussing his and Carol’s experiences of people not including Carol in situations).

Richard protects Carol from others’ insensitive behaviour. He feels that people do not always treat her as someone worthy of personhood and he tries to protect her from experiencing such behaviour, experiencing others not treating her like a person. Instead of trying to avoid such situations, as other ‘carers’ did, Richard tackles such behaviour assertively, pointing out that their behaviour is not appropriate nor justified: Richard publicly defends Carol’s personhood and instills confidence into Carol’s own view of herself.

“Richard: You’re a human being aren’t you love and you always say this
Carol: Yes
Richard: You have feelings and you have understanding and
Carol: Oh yes I know, I have all my marbles
Richard: You do have and all your marbles are there but what they think is that with dementia all your marbles aren't there

Carol: Ah but they are. They are

Richard: And the perception is that you don't understand

Carol: They're still there"

There seemed to be a running theme within the Alzheimer’s Society groups that ‘carers’ saw their own partner as less severely affected by Alzheimer’s disease than other group members. They seemed to be able to preserve their own spouse’s personhood but did not always seem to be able to do the same for others. They can see the quality of life and personality shining through in their own partner but can not always see this for others affected by dementia:

“But obviously there are some people that I have met at the Alzheimer’s luncheon who don’t know what they are doing and are so far gone that they have to be helped with their food and everything. That’s not much of a life. But a lot of people have got it and they’re not too bad, they can enjoy life” (Betty, a carer, discussing other members of the Alzheimer’s group)

The ‘carers’ and indeed many of the ‘cared for’ identified different stages of dementia and seemed to bestow different levels of personhood to these different stages. Most of the couples I spoke to counted themselves “lucky” that they were not as badly affected by Alzheimer’s disease as others, felt they were capable of most things, albeit with a little more help than they used to need. It seemed to be independence and the ability to interact meaningfully with others that the couples seemed to value. All interview participants were able to feed themselves and look after themselves with prompting. They were all able to hold conversations with other people, even if not so lucidly as in the past. It was this that was important to them, that they thought defined them as persons and which they feared would deteriorate. The couples did not associate themselves with people who they saw as having “severe” dementia. It was clear that Arthur and Mary saw Mary as different to all the other people with dementia in the Alzheimer’s Society group:

“Arthur: (talking about chatting with people at the Alzheimer’s group) It would be helpful to hear other people’s stories. To hear how they are getting on together, problems that they have come across and got over. I don’t know how Mary feels about this. Er, in the groups some of them are a bit past it aren’t they? They can’t remember anything can they?

Researcher: Hmm. So you would like to be able to do more talking, more confiding at the Alzheimer’s group Arthur. How do you feel about this Janet? Would you like the opportunity to talk to others about your experiences?

Mary: Not really no

Arthur: Well Mary I don’t think would be able to talk to hardly anyone there who is being cared for in an intelligent way I don’t think”

Arthur sees Mary as being able to communicate intelligently, to hold an in-depth conversation with people, to communicate her thoughts and feelings: in Arthur’s view her personhood is intact. He
protects her from being grouped together with all the other people with Alzheimer’s disease but singles her out, for Mary’s and my benefit, as different. Arthur sees the others as people with dementia but sees his wife as Mary with all the qualities he has known her to have during their life together. Mary, from Arthur’s perspective, comes with her own context, a history that is shared between the couple. When Arthur sees the other people with Alzheimer’s disease in the SHARED group he does not view them with this shared context, the maintained social interactions; they, to him, are purely people with Alzheimer’s disease and therefore are viewed with the connotations that this disease implies; that they are not capable of holding an intelligent conversation; that they are not true persons. Mary was indeed capable of having an “intelligent” conversation but so were many of the other members of the SHARED group that Arthur had dismissed as being incapable of doing so. He had maintained and protected the personhood of his wife but not, at least initially, that of the others in the group. He can see that dementia can take away the personhood of others but not his own wife. The context of a relationship, in this case a marriage relationship, and the social interaction that that entails, seems to be key to the maintenance of personhood as experienced by the individual with Alzheimer’s disease. The ‘carer’ spouse treats their partner as someone who is bestowed personhood, as someone capable of acting and experiencing. They also act as protector of this personhood, highlighting to others that they deserve it or shielding them from people who do not bestow it upon them. I argue that this protection of personhood subsequently nurtures the selfhood of their partner, emphasising their retained skills and abilities, protecting them from stigmatising behaviour.
6 The Alzheimer’s Society: A Shared Context

“The thing is you can just relax here. No-one is looking at you funny. Everyone understands, everybody has been through it too” (A carer, Elsie, discussing her impression of the SHARED group)

The Alzheimer’s Society events, especially the fifteen week SHARED group, had become a haven for the couples. It was somewhere they could come, relax, feel safe and form new social relationships. Elsie and her husband Reginald had been going to the SHARED group for five weeks when I met them. Elsie said that attending the group had literally transformed their life. Elsie had been so uptight about Reginald’s diagnosis of Alzheimer’s disease, feeling ashamed to go out in public because she worried what people would think of them: what if Reginald wet himself in public; what if he made a mess whilst eating dinner; what if he talked inappropriately to people; what if he wandered off and got lost? It was not only Reginald’s symptoms and behaviour that Elsie was uptight about but also her reaction to it. She felt embarrassed but she also felt angry towards Reginald too: it was his fault they couldn’t go out anymore; his fault that their hobbies had disappeared and his fault that she now had to do everything; Reginald had abandoned her. Through coming to the SHARED group Elsie and Reg met people in a similar situation. Their friends had tried to be understanding but according to Elsie they didn’t really understand, how could they? Elsie felt that when she talked to people at the Alzheimer’s Society they understood, they had been through the same or worse. She no longer worried about how Reginald would behave, if he would wet himself or get confused: she knew that others would understand, she would not have to explain and apologise. Elsie felt accepted at the Alzheimer’s Society. All the couples’ situations were transparent: everybody knew that one of them had Alzheimer’s disease and their behaviour could be attributable to this disease. The Alzheimer’s Society also recognised Alzheimer’s disease as a disease, as a separate entity to the affected individual and it was perhaps here that the couples got socialised into this viewpoint, into seeing the maintenance of self and personhood despite the disease. The couples weren’t judged and weren’t blamed but felt they were in an open place where they could express themselves freely.

6.1 Couples in the Alzheimer’s Society

The Alzheimer’s Society SHARED group was designed for couples, one ‘carer’ and one ‘cared for’. Everything was geared up around couples and the group gave the couples a space to be together, to interact together in a safe space. It was a public space in which the couple could relax and be themselves, to be afforded personhood through being treated with dignity and respect and to maintain and nurture their selfhood, their inner feelings and experiences. The couples were meeting new people, something that most of them tried to avoid in their everyday life. They were meeting other couples, other couples in a similar situation to themselves. The couple were able to interact socially outside their couple unit. The friendship groups that formed in the SHARED group seemed to not be between individuals but between couples. The couples were a unit in themselves and interacted with others together as this unit. At lunch time the group participants were served dinner at their tables. There were tables that seated four people, nobody had set places, they were not told where to sit each week but each week the couples would sit on the same table, with the same couple. The couples formed
friendship groups and although everybody spoke to each other some couples seemed to have stronger inclinations to certain couples than others. However, I found it strange that this friendship formation did not seem to be occurring as individuals, only as couples. The ‘cared for’ did not seem to make special friendships with other ‘cared for’ individuals, nor did the ‘carers’ seem to make friendships on their own, it always included their partner. The couples seemed to stick together as a unit, making friends and doing activities together as this unit.

I was struck by the solidarity of the couple as a unit and also the love and the enjoyment that seemed to remain in that couple. Each afternoon at the SHARED group there was some sort of entertainment or session for the ‘carers’ and ‘cared for’, the couples together. One afternoon it was a gentleman singing and playing the keyboard. The group started off quite quiet, sitting in a circle in their respective couple units. Alfie, the musician, however, tried to involve the whole group. He sang songs from the past, the 1940s and 50s, and reminisced about those times, going to Blackpool on the tram, the dancing halls and the fairgrounds. Soon everyone got involved, singing along to the music, tapping their feet and clapping their hands. I looked around at the group and everyone was smiling, everyone seemed to be enjoying it. The couples were enjoying it together, asking each other if they remembered dancing together at the Ritz. Towards the end of the session Alfie played a Waltz on the keyboard. A few of the couples, some of them normally shy and reserved, got up and danced together. Marilyn had been dancing with another ‘carer’, Doreen, but went and asked her husband Frank whether he would dance. Frank had been sat next to Marilyn, his eyes closed in his normal manner but he had been singing along to the music. Marilyn, with Doreen’s help, helped Frank get up out of the chair. He looked quite unsteady on his feet, not quite standing up straight but him and Marilyn shuffled a few paces in towards the middle of the circle. They held each other, embracing and swayed to the music for a few minutes. Dianne, the Dementia Outreach Support Officer, was clearly a little worried about the situation, Frank was not at all steady on his feet and could quite easily fall, but she let them continue until the music had finished and then helped Marilyn get Frank back to his seat. Other couples remained dancing but Marilyn and Frank sat, Marilyn holding onto Frank’s hand in her lap. The experience could be perceived as an escapism for the couple. Marilyn found it difficult caring for Frank. She didn’t feel appreciated and felt that she got little interaction from her husband. She got angry with him for not opening his eyes and not making more effort to walk and try to do things. She struggled to find anything to do together: even watching television turned into as issue as Frank’s concentration was poor and he would start telling Marilyn to turn it off, it was boring. This was a rare experience where Marilyn and Frank had been together as a couple and had both enjoyed themselves. Marilyn had had to support Frank but he had stood himself and held Marilyn himself. The Alzheimer’s Society had given them the space and the relaxation to stop the caring and cared for roles and instead be together as a couple.

6.2 Providing a Sense of Normality

The SHARED group seemed to provide a much wanted and needed sense of normality for the couples. It was a space in which they could forget about their worries and problems and the attitudes of others. It let them forget about the impact of Alzheimer’s disease as, within that group, everyone had Alzheimer’s disease or lived with someone who did; everyone was affected by the disease; within
this context the couples were normal, not abnormal. They felt normal in this situation because they were in a supportive environment where people with dementia were bestowed full personhood: they were treated like persons with full dignity and respect, all encouraged to interact as equal group members. The SHARED group was therefore a place for the couples to be together in order to enact this normality.

As part of the fifteen week SHARED course a summer trip was organised for one of the week’s sessions. The group decided to go to Portland Basin, an industrial history museum. The couples had talked about it for weeks with much excitement. Many of the couples expressed their thanks to the Alzheimer’s Society for organising the trip as it is not something they felt able to do on their own. The whole day was an enactment of normality. The couples were safe in the knowledge that there were helpers on hand if things got too difficult. There were wheelchairs if people got too tired walking, people to watch the ‘cared for’ spouse if the ‘carer’ needed to leave them. However, this watching was subtle. Being in a large group on a trip together there was no ‘carer’, ‘cared for’ divide: everybody was together, out in public, having a nice time. For that day especially, having Alzheimer’s did not matter, being a carer for someone with Alzheimer’s disease did not matter. The couples were merely that, couples; couples that had gone for a day trip together. The couples, some alone, some with other couples, wandered around the museum, animated about the things they saw: “Oh my mum had an agar like that”, “Do you remember buying your soap like this”. The set out of the museum was as a regular street at the turn of the century: a living room, grocery store, church, doctors, washing room. It brought back many memories to all the couples.

At lunch time we all ate together in the museum restaurant. A large table had been prepared ready for us and everyone sat down. Going out for dinner was something that many of the couples were normally too nervous about doing or saw it as too much of an effort. They were worried about making a mess with the food, not eating politely, the person with Alzheimer’s being rude or behaving inappropriately. Today, however, they were in a large group, a group that all understood the difficulties that could present themselves. The couples were out in public but were surrounded by a safe context and source of interaction, the Alzheimer’s Society group. The table was laid with crockery, cutlery and glasses. Some of the couples joked that they would have wine with their lunch as it was a special occasion. We had already pre-ordered our food so the waitresses soon came out with the first course. A small argument then broke out between Dianne, the Dementia Outreach Support Officer, and the manager of the resource centre who had also come on the trip. Dianne had taken the orders for lunch from the group participants the previous week but had not made a copy of this order. The resource manager thought that this was “ridiculous”. Nobody would remember what they had ordered and then there would be a huge fuss and mess up for the kitchen. The main course, however, proceeded successfully: everybody had a dish they were happy with even if it wasn’t the dish that they had ordered. The couples commented on how delicious and special the food was. They ate their food and chatted happily to the people next to them. Margaret, a ‘carer’ I was sat next to said it was the first time for a long time that she had been out for dinner and felt relaxed. She was actually enjoying herself rather than worrying about everything. She didn’t feel that everyone would be looking at her and Stanley, her husband: “It’s lovely, well, to just feel normal. I don’t think I’ve felt normal for a long time”.

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When it came to dessert, the waitresses came out with the different desserts: fruit crumble and custard, gateau or fruit salad. This time most couples seemed to think that they had ordered the crumble and the waitresses soon ran out. People refused the gateau, that wasn’t what they had ordered. The waitresses went back into the kitchen but there was no more crumble. Having followed the order that Denise had rang through to them earlier in the week they had provided the correct number of dishes but this was no longer what was wanted by the group. I was surprised when they then offered more desserts for the couples to choose from and eventually all the group had a dessert that they were happy with. I was left wondering why the restaurant had been so accommodating to the group. Was it because they knew we were from the Alzheimer’s Society? Was it only to be expected that nobody would remember what they had ordered but there was no point making a fuss about it? If Dianne had not disclosed our Alzheimer’s Society status would we have been met with the same kindness, the same understanding? I was left thinking of Betty’s words,

“We don’t go into a lot of new situations. We don’t tend to go into situations where people don’t know us. If we are going somewhere new I tend to let them know before hand” (Betty, a carer, talking in an interview about her and her husband James’ approach to social situations).

Betty wanted to warn people about her husband’s dementia before he was put in a social situation with them. This, she thought, made them perceive and interact with James in a kinder manner. Instead of treating him like he didn’t understand, wasn’t capable of interacting with them and shouldn’t have been out in public, Betty hoped they would see that James was not in control of his actions. Through the knowledge of his diagnosis they could rationalise his behaviour and attribute it to the disease, not James himself. The disease once again becomes a scapegoat. Symptoms are attributed to the disease, the individual is absolved from blame for the situation and therefore afforded full status of a person. They are a person with a disease not someone who is behaving oddly and doesn’t need to be treated like they “have a brain”, like they are full persons. I felt that this may be what had happened in the restaurant situation. We were the group from the Alzheimer’s Society, the staff had known this before we came to the restaurant. The mix up with orders may well have been attributed to the fact that some members of the group had Alzheimer’s disease and therefore were liable to forget and subsequently likely to forget their order. The restaurant staff did not, however, object to this situation. They did not highlight the fact that people must have changed their mind about the order and claimed a dessert which they had not ordered. Instead of highlighting this and making a situation which could easily embarrass the group members, the restaurant themselves took responsibility for the situation, took the gateaux back to the kitchen and offered new desserts to those left without the dessert they wanted. Through the restaurant’s discretion the dignity of the group members remained intact: the mix up of the orders was the restaurant’s fault not their own. By the restaurant attributing the situation to the disease, the symptoms of Alzheimer’s disease, the group members had been treated with kindness and afforded full personhood.

Everybody had enjoyed the meal, and from the couples’ point of view it had gone without mishap. They had felt like “normal” people going out for lunch with friends. They had been able to forget their everyday worries, their burden of Alzheimer’s disease and instead enjoy themselves. One gentleman had brought his camera along and had taken pictures of the different couples, some by themselves and
some with other couples. The next week he brought printed copies of these photographs and gave the group members their relevant photographs, a souvenir of the day out, a picture of them smiling, happy together, eating lunch at a restaurant. Everybody seemed pleased with their souvenir.

On the way home from Portland basin I was in a taxi with two couples and Dianne, the Dementia Outreach Support Officer. Arthur and Mary were in the front of the taxi. I was in the back, facing backwards, sat next to Dianne and Margaret. Stanley was in front of us sat in his wheelchair, strapped in to the floor of the taxi. Margaret thanked Dianne for such a wonderful day, stressing how her and Stanley would never have been able to do the trip on their own. Whilst Dianne was talking to the taxi driver Margaret mouthed to Stanley, “say thank you”. Dianne turned her concentration back to us and Stanley did indeed say thank you to Dianne. It reminded me of being little, my parents whispering to me to say thank you to whoever’s house I had just been playing at, a gentle reminder of my manners. Stanley had said thank you for such a lovely day. Dianne had not seen the prompt from Margaret: as far as she was aware the thanks came from Stanley alone. This was yet another performance of normality. Margaret had not embarrassed Stanley publicly, had not openly told him what to say to Dianne, but instead had done so privately and subtly. I had observed the prompt but it had been intended to be private. Margaret had prompted Stan but had not acted for him. A performance of independence had been enacted: Margaret had helped Stanley act independently, as if the thanks were his own idea. Through Margaret’s discretion Stanley had appeared to be independently thankful, to have maintained his social manners and politeness. The couple had performed a sense of normality. The same thing had happened on the trip that day: the Alzheimer’s Society had given the couples the space and opportunity to perform normality: they had gone on a trip, wandered around a museum together, talked together, laughed together, eaten lunch in a restaurant together. This had all been performed within a safe context, as part of the Alzheimer’s Society. The Society organisers were there to help if anything went wrong. The couples were out in public together but were reassuringly protected by the Alzheimer’s Society and the group members. All the couples, even if they were treated differently or unkindly by the general public were “normal” within the Alzheimer’s Society group. They were all supported and accepted, their behaviour understood not questioned. They were able to have meaningful interactions as a couple and amongst the couples. They were treated like persons, with dignity and respect, not blamed for their actions and behaviours. People were interested in them as people: in these interactions the disease did not matter. The Alzheimer’s Society group was therefore a safe place for the couples to be together and enjoy each other.

6.3 Maintaining Personhood

The Alzheimer’s Society group was a place where the personhood of the individual with Alzheimer’s was fought for and respected. The group tried hard to treat the group members as couples, not individuals with Alzheimer’s disease and their carers. This caused great problems in dividing the SHARED group for the morning session: a session for the ‘carers’ and the ‘cared for’. It was this terminology, the individual with Alzheimer’s disease being the ‘cared for’ and the spouse that looked after them as the ‘carer’ that was used in the Alzheimer’s Society’s literature advertising these groups. It was clear, however, that this literature was intended for the ‘carers’, not the ‘cared for’. Within the group itself, when the ‘cared for’ and the ‘carer’ were both present there was great uncertainty
over what to call the group members with dementia. The group did not seem to want to label the individuals as people with Alzheimer’s. I had witnessed different strategies of splitting up the group. Sometimes one of the helpers would ask the carers to make their way to the other side of the room or into a different room. It was then up to the ‘carer’ spouses to tell their ‘cared for’ husband or wife where they were going. Then “everyone who is left” would be asked to go somewhere else. There was not an agreed term to use when talking to the ‘cared for’ directly. The Alzheimer’s society did not want to treat them like ‘cared for’ people, did not want to single them out as different but as people able to act independently and have a sense of achievement on their own: they wanted them to feel that their personhood was maintained. Dianne, the Dementia Outreach Support Officer talked about how difficult it was to know what to call the ‘cared for’ as a group:

“It’s hard to know what to call them really. How to separate them out. We can’t say patients because well, they’re not in hospital, they’re not ill. We can’t say those with dementia, I mean some of them might not even know. Service users? It makes it sound as if they are all drug addicts!”

One morning the ‘cared for’ were going to do baking whilst the ‘carers’ had a relaxation session. One of the staff members came and put a plastic apron on all the ‘cared for’ individuals with dementia. She then asked all those with aprons on to make their way to the kitchen as they were going to do some baking. She had managed to single them out, split them into a group without highlighting that they were different, without highlighting the fact that they were the ones with dementia and needed occupying whilst their husband or wife had some much needed time away from them. They had made them feel like people, not the “demented ones”. Some of the group members were astute to the fact that they were the ‘cared for’ and that they did things together whilst the ‘carers’ did something different but it didn’t seem to be an issue for those in the group: they were happy to do whatever activity had been planned for that day.

I went with those in the aprons to the kitchen to join in with the baking. I walked with Jack who seemed a little agitated. He kept asking where his wife was: “I wonder where she has got to. Perhaps she had gone to the toilet. She’ll be along in a little while I’m sure. I hope she is not worried”. Another lady was also agitated about the whereabouts of her husband. The staff member assured them that their partners were just in the other room but that they knew where they were and were happy that they would be doing baking. Despite further repeated questioning she remained calm and reassuring towards them. Soon they had forgotten their angst about their partners and were enjoying baking. Today they were making scones. The ingredients had all been weighed out and put ready prior to the start of the session. On the central workspace there were four bowls with flour in and around the large bowls five little bowls containing sugar, butter, egg, milk and dried fruit. After having washed their hands the group was asked to split up into pairs and take a bowl each. They were then taken, step by step, through the process. The pairs did it all themselves, putting the ingredients in the bowl, mixing it with their fingers, getting it to the right consistency, separating the mixture, patting it into little scone size portions and putting them onto the baking trays. They were told exactly what to do, shown or given help if they were struggling but in the main part had done it themselves. The group felt that they had made the scones themselves and felt proud of themselves. Bill particularly enjoyed the baking session:
“It reminds me of baking with the grandkids. Oh I did enjoy that. I’ve always helped Marjorie with the cooking. I like to help. I enjoy it, it makes me feel like I’ve done something useful.”

After lunch the scones were brought out and showed off to the group. Everybody had one to eat after lunch and then also one each to take home. The ‘cared for’ individuals had made something. They had all been treated as people capable of doing things themselves. They had been encouraged to participate, had been helped to some extent but had each, collectively made something to be proud of, something to share with others. They had been treated with respect and dignity, as people who were not different and needed caring for, but as people capable of having fun together and achieving something together. They had been attributed the status of personhood.

6.4 Nurturing Selfhood

The Alzheimer’s Society was not only a space for the couple, allowing them to be together and enjoy each other, to meet other couples in an understanding environment but was also a space for the ‘cared for’ and the ‘carers’ as individuals. The emphasis of most Alzheimer’s Society groups was very much the couple as a unit. The SHARED group, however, also took time to look after the interests of the individuals within that couple unit: they recognised that the ‘carers’ and ‘cared for’ had different needs. The importance of the ‘carers’ state of mind and health was repeatedly emphasised within the groups. Although they were a couple, the ‘cared for’ individual depended upon the ‘carer’: without them the affected individual would struggle or perhaps not be able to look after themselves at all. It was the ‘carers’ that maintained a sense of normality for their spouses. A professional carer who came to talk to the carers went as far as calling them the “unsung heroes” saving the government billions of pounds. The Alzheimer’s Society recognised the burden which the carers had undertaken, the invisibility of the role to others and the overwhelming nature of the twenty four hours a day job. The fact that a ‘carer’ was affected by the Alzheimer’s disease process, that they would be trying to keep everything going for their spouse, taking on physical and emotional pressures and suffering a sense of loss of their own self in the process, was recognised and expressed by the Alzheimer’s Society.

When the ‘carers’ and the ‘cared for’ were split up in the SHARED group’s morning session the ‘carers’ had a space to themselves, both physically and emotionally. The ‘cared for’ were normally taken into another room, out of sight of the ‘carers’. It was a time in which the ‘carers’ knew that their husband or wife was safe and happy: they did not have to worry about them. The separation also meant that the ‘carers’ could talk about the problems that they were experiencing, the anger, guilt and depression that they felt, without the fear of upsetting their spouse. One morning the ‘cared for’ were taken off to pot some plants and the ‘carers’ all gathered in one part of the room. All of a sudden Ethel began to cry. She felt overwhelmed and just couldn’t cope any more. She had been shocked at how angry she had got with her husband, Donald, that morning. She described how she could normally control her emotions and not blame Donald but that that morning it just got too much for her. She gets so frustrated that he can’t do things any longer and that everything, even the smallest of things, turns into a big hassle. Just getting ready to come to the SHARED group that morning had turned into a big argument, an argument that Donald would now probably remember nothing of. He hadn’t wanted to come to the group, then he was unable to get dressed by himself, then he got...
undressed and got back into bed, Ethel dressed him again, he was asking question after question and then would repeat them again five minutes later. She felt terrible that she had got angry with him:

“I feel so guilty when I get angry. It’s not his fault. It’s not him. He doesn’t mean to. But sometimes I just feel so sorry for myself. I shouldn’t but I do”

Some of the other ‘carers’ started comforting Ethel, reassuring her that they often felt the same way, that it was only natural to get angry every once in a while. Marilyn shared many of Ethel’s frustrations and disclosed that she often felt sorry for herself too. Why did it have to happen to them and why is she the one who has to do everything? She found it hardest that she never got any thanks for it, not from her husband Frank, but also not from anyone else. No-one, apart from the Alzheimer’s Society and other carers, ever said what a marvelous job she was doing and how proud she should be of herself. All she ever got was a feeling that she should and could do better. If she left Frank for a moment he would be asking where she had been: “I’ve been cooking the dinner, or doing the washing up, doing the ironing, the gardening. I’ve certainly never been having any fun I can tell you!” Marilyn felt that it was her role to look after her husband, she didn’t want anyone else doing it and in the most part she felt satisfied that she had maintained a good quality of life for the pair of them but like Ethel, she too got overwhelmed and occasionally angry:

“It’s not that I don’t want to do it and it’s not like I really resent him for it, I mean he is my husband and that’s what life is about. Give and take. It’s just that it would be nice, just once, to have a thank you”

Dianne, the Dementia Outreach Support Officer, talked about the importance of the carers not feeling guilty, that it was only human for them to get angry and frustrated, that anyone in their situation would. She also reiterated Ethel’s point, however, that it was not their spouses’ fault that they behaved in the way they did: it was the disease’s fault, not theirs. She was advocating the rationalisation of the ‘carers’ feelings towards their partners, to blame the disease not their partner, to see the disease as the cause of their problems, not their partner. Whilst making the ‘carers’ feel better about themselves, to see their own behaviour as understandable and perhaps even healthy, Dianne was also protecting the personhood of the spouses with Alzheimer’s disease. She was absolving both the ‘carer’ and the ‘cared for’ from blame in the situation.

The ‘carers’ talked about the support of the group and how glad they were to have participated in it. They were all “in it together” and knew that they could talk together and that others would understand. Ethel had felt safe enough, when Donald had left for the other room, to confide in the other carers. She knew that she would not be judged but that others would understand her predicament:

“It’s good to see that other people go through the same thing. It always seems as if everyone is coping and are so caring and kind to their partners. I always thought it was just me who felt like a failure. It’s good to know that others do too, that it’s not just me”

The group was a place where the carers could be honest, where they knew people would understand, or at least try to. It was a space where they were socialised into their role as carer, sharing experiences and learning new tactics. This was perhaps most important for the male carers who felt more uncomfortable with their role and didn’t feel it was the sort of thing they could talk about with their friends. They
could get help and support from other carers and the professional staff but more importantly it was a place where they could just be themselves, with or without their partner. They had space to be with their partners in a safe and understanding context but they also had space to discuss how they were as individuals, how they were coping themselves, not just as a couple. It was a space where they could discuss their difficulties without having to be at crisis point. It wasn’t long to be without their partner, to be relieved of the responsibility of caring, but all the carers felt that it was an important time in the week where they felt that they mattered as people. It was this that the carers wanted and needed, that they wished they had more of within the Alzheimer’s Society. The practical help was useful but the emotional time and space was invaluable.

It was not just the ‘carers’ who found the Alzheimer’s Society, especially the SHARED group, to be a valuable experience for maintaining positivity and a sense of self, but also the ‘cared for’. Mary, when talking about the SHARED group during an interview with me, commented:

“I feel more like me there. I like it. I’m happier. I don’t have to worry what I will say, that I might say the wrong thing and then what people will think of me”

Mary felt more like herself at the Alzheimer’s Society. She felt accepted there and also valued. Time was given to the ‘cared for’ as individuals, they were given the opportunity to do things themselves: crafts, baking, singing, music and quizzes. The staff chose activities which the ‘cared for’ could do or at least could participate in. They were included in everything and their input valued. The activities could be done with help and instruction and they would have a tangible object, something to show for it, a sense of achievement at the end of the session. The quizzes would be of a reminiscent style, stimulating memories and asking questions which both the ‘carers’ and the ‘cared for’ could answer. The activities therefore promoted a sense of achievement, purpose and value in the ‘cared for’ individuals. Although most of the ‘cared for’ individuals did not seem to talk to each other about how having dementia was for them, did not share their experiences together, the fact that there were individuals in similar, or worse situations that themselves, seemed to be helpful:

“It makes you feel lucky really. It doesn’t make me feel scared seeing people that are worse than me, just lucky. I’m glad I can do what I can do. You have to be thankful really” (Nancy discussing her experience of being with the other ‘cared for’ individuals at the SHARED group)

The Alzheimer’s Society groups were also somewhere where the ‘cared for’ individuals could come and socialise. Many of their social activities had dwindled, as had some of their friends. The groups were therefore somewhere where the couple could come to together, participate in activities which made them feel good about themselves and socialise with people who would not judge them but accept them. Being with new people and talking to new people was important to both the ‘carers’ and the ‘cared for’. The couples could do things together, be together, rather than just exist together. They were able to form new friendships and support networks and regain some confidence in themselves and their importance, both individually and as a couple. The Alzheimer’s Society provided positive social interactions for the couples. These interactions did not deny personhood to the individual with Alzheimer’s disease but instead nurtured how they and their spouse felt about themselves: the ‘carers’ and the ‘cared for’ sense of self.
7 Society and Stigma

“People don’t understand it. They don’t know what Alzheimer’s is like and what it’s like for us. They just think we’re mad” (Betty, a carer, discussing public opinion regarding Alzheimer’s disease)

The couples had managed to maintain an experience of personhood and a positive sense of self within their own relationship and in interactions within the Alzheimer’s Society. The Alzheimer’s Society made the couples feel normal and valued, a place where they could interact socially and feel accepted. It provided the ‘carers’ and ‘cared for’ with a feeling that they were seen to be persons by their social environment. I argue that this maintained experience of personhood and self was achieved through seeing Alzheimer’s disease as something separate to the affected individual. The couples, however, did not feel so accepted within wider society. The ‘cared for’ individuals felt like they were treated differently to the past, that people thought them to be crazy. Their social relationships dwindled and they felt that people avoided them, out of fear and ignorance. They felt they were not treated as the persons they once were and in some cases not as persons at all: at times they felt that they were denied personhood. Those with Alzheimer’s disease thought that people did not recognise their symptoms, their loss of skills and abilities, as a disease but as part of them. They did not feel treated as people beyond the label of dementia and all the connotations that that label held. The couples, with the help of the Alzheimer’s Society had incorporated Alzheimer’s disease as a disease entity into their lives, but not incorporated it into their sense of self. The couples did not feel that there was the kind understanding, the absolution of blame, the recognition that there is a person beyond dementia within the wider society. They felt Alzheimer’s disease was portrayed as dementia, a devastating condition which destroyed the person and all purpose of life.

7.1 Social Relationships

All of the couples sought refuge in their relationship with each other and also with others in the Alzheimer’s Society. They wanted to cloak themselves in a safety of understanding and acceptance, where the individual with Alzheimer’s disease was not judged and blamed for their behaviour but instead supported, treated with dignity, respect and kindness: they wanted their personhood to remain intact. Many of the couples had experienced reduced social circles since the affected individual had first started experiencing symptoms of dementia. These reduced social circles had sometimes been actively sought by the couple, they had tried to hide themselves away from the outside world, but sometimes it was an unwanted phenomena and the couples felt hurt and abandoned by their former friends.

Many couples found that their circles of friends just seemed to diminish spontaneously:

“But I have to say our circle of friends has diminished quite rapidly over a period of time and I think it is two things. One is a lack of understanding but also they have to get on with their lives because I mean we’re quite young, they’re still busy and want to get out” (Richard, a carer discussing his and his wife’s Carol experiences of friends since her diagnosis)
Richard thought that part of the reason his and Carol’s friendships with others had diminished was that they did not understand what Richard and Carol were going through. They thought that people did not understand the symptoms of dementia, the affect it had on the ‘carer’ and the ‘cared for’. They didn’t see the behavior, lack of recognition, empathy or understanding as symptoms of dementia but as changes in Carol and they blamed her for those changes. Carol had changed and so had Richard. Richard was no longer the fun, enthusiastic, intelligent man he was: he was now a carer with nothing to talk about but caring. He was tired and did not have time for his former hobbies, nor his former friends. He did not feel he had the time or energy to put effort into maintaining friendships with others but their former friends did not put this effort in either. Richard thought that people were “scared” of seeing them, seeing the effect of Alzheimer’s on their lives, not knowing how to react to and be with Carol, what they should say, what they shouldn’t, what they could actually do with her: they did not know whether Carol should be bestowed personhood. Richard and Carol believed that the public did not have enough awareness about Alzheimer’s disease. They were scared of it because they didn’t understand it and therefore would try to avoid contact with people with dementia at all cost.

This public lack of awareness regarding Alzheimer’s disease was also expressed by other couples. Pauline, a ‘carer’ for her husband, Raymond, was surprised about how few of Raymond’s friends had kept in contact with him:

“Well I think men especially, if they have not come across dementia then they don’t want to come across it. Well Jim has kept in touch, but none of the choir. At first when they knew they were like, oh we’ll come and see you, we’ll come and see you. But they just haven’t been” (Pauline discussing loss of friendships)

“Out of sight, out of mind” was how Pauline thought people reacted to dementia. She didn’t think that Raymond’s friends were intentionally, consciously trying to avoid him but that they found it hard dealing with someone with dementia. As with Richard and Carol, their friends did not know what to do when faced with Raymond’s diagnosis: they did not know what it meant or how it would affect him. They did not know how Raymond would behave and why he does behave how he does, why he can sometimes be rude and angry:

“Pauline: You find that a lot of your friends disappear. It’s very strange  
Researcher: And why do you think that is?  
Raymond: They don’t know  
Pauline: They don’t know how to handle it”

Friends don’t know how to adapt to their friend having a diagnosis of Alzheimer’s disease, what that means for the affected person and subsequently what it means for their relationship with them. However, it is also the affected individual who does not know how to adapt to their diagnosis with relation to social interactions. They are worried that they might embarrass themselves, that the equality of their relationship will shift, that they will be seen as someone not capable of being an equal friend but instead come to be someone that is pitied, someone that needs to be cared for, someone who does not have personhood. Raymond used to be in a choir. He had a bass voice and sang nationally. However, with the development of his symptoms of dementia, before his wife, Pauline, had recognised
that there might be a problem, Raymond no longer wanted to go to choir. He had taken to not
going to choir as often, stating that he did not want to go, that he did not enjoy it anymore, not
wanting to perform in concerts and gradually going to choir less and less over a twelve month period.
Raymond was trying to avoid social situations which made him feel inadequate and embarrassed.
He was struggling to read the music, to remember the words, to come in at the right point in the
music. He had not told anyone of the difficulties he was experiencing at this time and instead tried
to avoid situations in which the problems might present themselves. He avoided situations in which
people might identify these symptoms as problems, recognise that something was wrong. This feeling
of inadequacy had remained during Raymond’s journey with dementia and had perhaps hindered his
chances of maintaining friendships:

“Pauline: Quite a few friends used to come up and see him but well, you’re not very
interested in seeing any of them are you?
Raymond: No
Pauline: Because he feels he can’t communicate, yet they are ever so good
Raymond: Well most of them don’t come any more do they?
Pauline: Well no because you didn’t make them feel very welcome a time or two did you?
It’s very difficult
Raymond: Yeah I find it hard. It’s very hard for me to sit and talk. It’s very erm I can’t
do it. A lot of those things I can’t do. It’s embarrassing. I don’t know”

Raymond finds it embarrassing not being able to communicate effectively with his former friends. He
feels embarrassed at not being able to express himself, to not be able to laugh and joke with them as
he used to. He would rather avoid situations where he will be in a social setting so as not to feel that
he is unable to follow the conversation and participate appropriately. He has avoided keeping in touch
with old friends and from making new ones. He feels safe in his own company where he will not be
judged, patronised or told what to do. He does not like the shift in equality with his friends, that his
friends would come and see him, pity him, rather than doing things together as equals. He fears that
they will see his inabilities, his poor communication as changes in him, threats to him as a person, not
effects of the disease process.

The feeling of inadequacy is something that also worried Bill. He no longer has many “real” friends,
preferring to rely on family for support rather than friends and neighbours. Bill no longer feels as
confident as he did in social situations:

“Marjorie: He has said to me that he worries. He’s frightened that he will say something
silly. But I say oh you won’t, don’t worry about it. But I think that holds him back a little
bit
Bill: Well yes I don’t want to be no trouble for them. Don’t want to be a trouble”

Bill is worried that people will interpret his behaviour and conversation as abnormal. His family all
know that he has Alzheimer’s disease and so attribute anything that he says that could be considered
as “silly” as being caused by the Alzheimer’s disease. Bill does not feel vulnerable in his close social
circles but when these are extended, such as at his granddaughter’s forthcoming wedding, he feels worried and panicked about how he will appear to others and how they will judge him, what they will think about him and his behaviour. His close family do not attribute it to him, it is the disease, but strangers will not understand enough about Bill to do this.

All the couples seemed to want to shield themselves from harmful or stigmatising situations. They only wanted to put themselves in situations and friendships in which they felt that Alzheimer’s disease was understood and therefore they, as individuals and as a couple, were also understood. This understanding seemed to include recognising that there was more to the affected individual that Alzheimer’s disease, that they were still very capable of holding lucid conversations and join in activities but that they might need a little more time or help to do so. The couples did not want to be in situations where the ‘cared for’ individual was treated as if they had Alzheimer’s disease, as if they and Alzheimer’s disease were the same thing, as if they were no longer persons. They wanted others to understand that they did indeed have a disease, this disease sometimes made them behave in ways that they would not ordinarily do so, it caused them to have trouble recognising people and following conversations, it did not, however, mean that they were not the same person and should just be ignored. The couples therefore chose their friendships and support networks carefully, forming new friendships at the Alzheimer’s Society and other groups, whilst letting go of old friendships which no longer made them feel positively about themselves:

“And the friends we do have are the friends who tend to understand more, tend to want to help in a way that is positive. So what we have done is we have chosen to be with the people we want to and to the degree that actually if someone is not happy with us then I am quite happy to say, OK we’ll move on” (Richard, a carer discussing his and his wife Carol’s experiences with friends since her diagnosis)

7.2 Media Representation

A lot of the couples felt that the media representation did nothing to increase the general public’s awareness of Alzheimer’s disease. They felt that the media portrayed a “doom and gloom” scenario of Alzheimer’s disease, they portrayed a life over, a person lost, as soon as a diagnosis was received. The couples felt that the public should be made aware that there were different stages of dementia: just because they had Alzheimer’s disease did not mean that they needed to live in a nursing home and were no longer capable of enjoying life. Most of the couples did not want to watch programmes on the television or read newspaper articles about dementia. They felt they did not want to see their disease misrepresented and nor did they want to see what might lay in store for them in the future:

“Personally I don’t watch these programmes about Alzheimer’s. It’s just something I don’t do. I can’t really explain myself. It’s something I have to cope with and I don’t really want to see how anyone else is coping with it. I don’t want to see how it’s going to get worse. You want a bit of relief when you watch telly. I want escapism” (John, a carer, discussing his opinion of the media representation of Alzheimer’s disease)

The only positive aspect of media representation that the couples commented upon was a television programme highlighting the novelist, Terry Pratchett’s, experience of Alzheimer’s disease:
We watched Terry Pratchett on TV. We watched that and I thought that it was brilliant. It was very good. Can you remember that Raymond? Terry Pratchett? He was saying how he felt having dementia. You were very impressed with it when you saw it. His challenge was to fasten his tie. He was determined that before the end of the show he would fasten his tie. And he did! He was still positive. Obviously he was shaken but he remained positive. It was good to see someone being positive rather than it being so awful all the time, people having a rough time and having given up” (Pauline, a carer, discussing the lack of positive images regarding Alzheimer’s disease in the media)

It was the positivity of this programme that Pauline and Raymond found useful. Terry Pratchett was still able to express himself, to describe the difficulties he faced on a daily basis and other people’s reaction to him. Pauline liked seeing a famous author advocating a life after Alzheimer’s: he was still a capable person, setting himself challenges and enjoying life. She thought that the programme portrayed a positive image of Alzheimer’s disease which she hoped would educate the public and dilute false myths regarding the disease. The programme was, unusually, from the perspective of the individual diagnosed with Alzheimer’s disease rather than from the perspective of the carer. It finally gave the affected individual and therefore people with dementia as a group a voice. Pauline thought that Terry Pratchett had shown that people with dementia should be valued and treated with dignity and respect, that he was worthy of personhood and had maintained a sense of self. This was something which she believed most media articles did not do.

In my own newspaper search covering the main national English newspapers I found that most articles were indeed portraying an image of dementia where life was over, no longer worth living, a burden on society and carers in particular.

“It’s a very cruel disease that robs the sufferer of many things we take for granted. It’s very hard for carers to watch someone they love deteriorate from a vibrant, active person with a sharp mind into something quite changed” (Beatty, 2009; in The Mirror 17.4.09)

“My gran and my aunt both had Alzheimer’s. So many people have to watch their loved ones lose themselves in this fog of uncertainty” (Bolouri, 2009; in The Sun 20.3.09)

Here the newspaper articles deny people with Alzheimer’s disease any sense of personhood. The affected individual goes from being a someone, someone loved by another, to a something, something devoid of all human qualities, something indistinguishable from all other somethings. The article implies that people with dementia no longer have any defining features, nothing that makes them who they used to be: they are denied all personhood and portrayed as losing their selfhood. The person with dementia is no longer perceived as a worthwhile human being. It is the carer that matters in this situation, it is them that the public should think about and try to help and give support to, not the person with dementia themself.

One such carer featured in the newspaper articles was John Suchet, a news reader and television presenter. He had disclosed that his wife had been diagnosed with Alzheimer’s disease and gave interviews about their experience of this, how their relationship and their life had changed in the process of Alzheimer’s disease. The interview was with only John Suchet, it did not include the thoughts and feelings of John’s wife, Bonnie. The disease and the changes are expressed from John’s
point of view only. The situation is described as bleak:

“As dementia wraps its empty, sad arms around society, Suchet movingly has described the poignancy of watching his warm, lively partner reduced to a passive, acquiescent shell - an empty but otherwise healthy body who will require 24 hour care, possibly for decades to come” (Reid, 2009; in The Times 19.2.09)

John’s wife is no longer portrayed as his wife, but as an empty shell, a human body devoid of all human qualities. She has been denied personhood and is losing her self, at least others are denying her a self, denying her any human abilities, emotions or enjoyment. Bonnie is portrayed as no longer existing, no longer someone worth talking to or even talking about: she has become someone (or something) else.

“I am losing the woman I love and have lived with for nearly 30 years” (Milliard, 2009; in The Times 22.2.09)

“Worst of all is the sense of loss. I have lost the Bonnie I knew and loved. Yet she is physically still there. We do not talk or behave or laugh as we used to” (Suchet, 2009; in The Sun 18.2.09)

Bonnie is lost to John. He is grieving their relationship, their love, joy and laughter with each other. He no longer perceives the Bonnie that he loved as existing: to him all sense of who she was has gone. She is now someone different, someone he is no longer capable of loving:

“She’s gone. It is as if she has died’. And he admitted that he would rather she had contracted cancer, for then they could talk and cry and fight it together. And presumably because, although he left this unsaid, she would die more swiftly, with their love undiminished” (Reid, 2009; in The Times 19.2.09)

In losing Bonnie, John, like many of the carers in my study’s couples, has lost some of himself:

“I’m now a man called John, not a lover or husband any more” (Suchet, 2009; in The Sun 18.2.09)

He no longer perceives himself as the same person but unlike my ‘carer’ informants John Suchet no longer perceives his wife as a constant self, does not seem to be fighting for the maintenance of Bonnie’s personhood. John Suchet, or at least the newspaper articles reporting their interviews with him, deny Bonnie, an individual with Alzheimer’s disease, any sense of personhood. Alzheimer’s disease is cruel, it is merciless, but in this case it seems to be portrayed as synonymous with the affected individual, it is not seen as a separate entity, something which can be blamed. Bonnie has been destroyed by Alzheimer’s disease, she no longer exists. There is no longer a person alongside the disease.

Only two newspaper articles counteracted this denial of personhood in dementia. One of the articles was in the ‘agony aunt’ section of The Independent. It was a reply to a letter from a lady who’s mother had just been diagnosed with dementia:

“Dementia is a horrible disease but it doesn’t mean that the person who is suffering with it should lose their quality of life or that they should stop being the person they always were. You need to remember that she is still your mother and a woman that deserves your love and respect” (Barry, 2009; in The Independent 13.4.09)
The agony aunt advocates that personhood does not need to be denied to a person affected by dementia, nor does that person lose all sense of self. An image of a lady requiring help, support and nurturing from others, is conjured up by this comment. It is in the daughter’s power to maintain the person and selfhood of her mother as far as possible: with support a person with dementia is not automatically “lost” to the disease. As Kitwood (1990; 1992; 1997) described, the social environment is crucial to the maintenance of personhood.

A comment replying to an article describing Alzheimer’s as a disease robbing the sufferer of all sense of being also portrayed a maintained personhood as a possibility:

“The presence of dementia does not remove an essential humanity: the greatest threats to our dignity with such illnesses lie from misrepresentations of others, insensitivities of the case system, and the stereotyping of the illness. We need to fight reductionalist views of what it is to be human, and realise a fuller conception of ourselves to include relationships, emotions and complex attributes such as wisdom.” (O’Neil, 2009; in The Guardian 13.5.09)

This sentiment mirrors the attitudes and the feelings expressed by many of the couples I interviewed and indeed other members of the Alzheimer’s Society. People with Alzheimer’s disease are still people, people who deserve dignity and respect and to be treated as human beings capable of participating in life: they should be granted personhood. The stereotypes of dementia, the ones portrayed in the media of “empty shells of people”, cause the public to treat individuals in such a manner, as people incapable of understanding or by ignoring their presence all together: their personhood is denied. The ‘carers’ in the couples had themselves tried to fight against the reductionalist views of what it is to be human. They had fought to maintain their partners’ personhood. They had protected them from situations which could jeopardise this personhood being bestowed upon them and had endeavoured to maintain positivity within their relationship in an attempt to instill a positive sense of self in their partner. For the ‘carers’ their ‘cared for’ spouses were more than individuals with dementia, they were individuals who they had been married to for years, who they knew and loved, and who, within their relationship, within their social interactions, could maintain a sense of their former self.

7.3 Invisibility of Dementia

The lack of awareness among the couples’ friends was attributed to a lack of awareness regarding dementia in the general public: the invisibility of Alzheimer’s disease to society. This invisibility identified itself on several levels: the invisibility of the disease itself in the people that have it and therefore the subsequent invisibility of the disease to others, the invisibility of people with dementia within society and the invisibility of the disease in terms of services, public awareness and funding.

As discussed in Section 4, Alzheimer’s disease does not have an obvious physical manifestation: it is not always immediately clear that someone has Alzheimer’s disease. It is this invisibility of the disease to others that the couples found hard. There is no physical abnormality to alert the public to the reason for the ‘cared for’ individual’s behaviour:

“I mean he looks normal doesn’t he? No-one would know that there was anything wrong with him” (Betty discussing her husband James’ diagnosis of Alzheimer’s disease)
The fact that people don’t know that James has a disease, that they don’t always know that there is something wrong with him, is difficult for Betty. People treat him differently, with scepticism and sometimes annoyance because of his behaviour but they don’t know the reason behind this behaviour. Betty, and many other carers and individuals with dementia, wanted people to understand what having Alzheimer’s disease was like for them. If they told people that they had Alzheimer’s disease they wanted people to know what it meant. They wanted to be treated with kindness and understanding, not people ignoring the situation, laughing it away as not serious, or behaving like the affected individual was not there, that they were no longer a person. This behaviour was all put down to a lack of awareness:

“The fact is that the stigma has been taken out of cancer because if you tell people that you have testicular cancer well they understand. We don’t tell people that we’ve got... In fact, it’s stupid really, but I tried telling people that Carol had had a stroke because she was so young and people just didn’t understand and in certain situations it was so obvious that something was wrong. So if you say she has had a stroke people know what a stroke is, they can understand it and understand its effects. Then they just say, ‘ah, is that all’. They’re OK if they understand. Because if you have a stroke or something all the effects are there in your face straight away. But this is something which might take ten years, twelve years, gradually getting worse and worse but nobody can see it. There is nothing physical. But in that time it is no less prevalent in its effects on the people who have got it” (Richard discussing the impact of his wife, Carol’s, diagnosis of Alzheimer’s disease and the lack of understanding that that diagnosis has faced)

Richard would rather tell people that Carol has had a stroke than disclose her real diagnosis of Alzheimer’s disease. People can see that there is something wrong with Carol, that she does not behave and respond in the way that they would expect. She looks like any other lady in her late fifties, there is no physical symbol that there is anything wrong with her. However, people, when with her, are aware that there is something wrong: she will not necessarily recognise them, she no longer seems to know how to shake hands with them or kiss them in greeting, she cannot always articulate herself. People know that there is something wrong with Carol but do not know what. According to Richard, even if he tells them that Carol has Alzheimer’s disease, they still don’t know, they don’t really understand what Alzheimer’s is. If he tells them that she has had a stroke there is more understanding, people know what to expect. Although there are not always physical manifestations to indicate that someone has had a stroke, the diagnosis is more visible to society. People can visualise what happens in a stroke, that the blood supply to the brain has been affected and therefore the way the brain works is also affected: the symptoms of a stroke can be understood and rationalised.

This invisibility of Alzheimer’s disease, the lack of awareness of its meanings and effects were attributed to larger structural issues. A lack of individual awareness regarding Alzheimer’s disease was due to a lack of awareness in society generally:

“There is not enough awareness out there. There are not enough services, not enough support or anything out there. The support mechanisms out there in terms of doctors are all flawed and more importantly if you go into the charitable world I think there are about five hundred websites for cancer but only three or four major ones for dementia as such” (Richard, a carer, discussing the lack of attention he perceives Alzheimer’s to get)
"The Alzheimer’s Society is very very good. But of course they need more funding. And nobody seems to think about them. I know the children are very important but also the Alzheimer’s and the older people are important. They shouldn’t really be ignored should they?" (Marjorie, another carer, discussing the funding problems of the Alzheimer’s Society)

It was perceived that there was inadequate attention given to Alzheimer’s disease as a problem. Many thought that this inattention was due to Alzheimer’s disease predominantly being a disease of older people. “Who cares about old people” was a sentiment that many of the couples shared. It wasn’t a disease affecting many young or middle aged people, it wasn’t a disease that ruthlessly robbed children of their lives. It was perceived as a cruel disease, certainly in the media, but what could anyone do about it? There is no cure. Alzheimer’s disease was perceived as invisible in its aetiology. Still today ambivalence remains regarding what causes Alzheimer’s disease, there is no one causal agent, nor is there a tangible outcome such as with a tumour in cancer. Many of the informants thought that it was this ambivalence which was responsible for the invisibility and lack of awareness regarding Alzheimer’s disease. They thought that it was not seen as a physical disease but as a mental illness:

“Mary: I think dementia is associated with mental
Arthur: Well it is, the mind, yes. And no-one understands that. Take depression!
Mary: There is a better understanding of cancer, people know what that is. I don’t want to tell people what I’ve got. They won’t understand what it is”

People could not see the cause of Alzheimer’s disease, they could not understand and rationalise its symptoms. The couples did not feel that it was recognised as a real disease. They believed that the disease was cloaked in misunderstanding and stigma. It was this that led to its invisibility in society: people did not know how to react to those affected, preferred to not interact with them or believed them to be incapable of interaction. The disease got little public attention as compared to other diseases, less funding and service allocation in relations to its disease burden. This in turn, the couples believed, led to even more misunderstanding and stigma and the denial of people with dementia as people with feelings.

7.4 Stigma

Many of the couples spoke about the stigma of Alzheimer’s disease in particular and dementia in general. According to the literature, stigma can be defined as an undesirable or discrediting attribute reducing an individual’s status in the eyes of society (Link and Phelan, 2001; Weiss and Jadhav, 2001; Brown et al., 2003). Stigma is said to exist when “elements of labeling, stereotyping, separation, status loss and discrimination occur in a power situation that allows them” (Link and Phelan, 2001; 377).

The individuals with Alzheimer’s disease felt this stigma. It changed the way they viewed themselves and how they thought others perceived them. They felt that there was a negative view and indeed fear of Alzheimer’s disease in society and that this caused some people to treat them differently than if they did not have the disease. They felt labelled and subsequently stereotyped according to this label. The couples did not like the word dementia and thought that it was this concept that brought the negative connotations to people with Alzheimer’s disease:
“There is a stigma attached to it: the word dementia and the word Alzheimer’s. You tend to want to shield yourself from it. At least we did. And I am not wrong because we know a lot of people in the same boat” (Richard, a carer, discussing his reaction to his wife, Carol’s, diagnosis of Alzheimer’s disease)

Richard and Carol did not want to tell people that Carol had been diagnosed with Alzheimer’s disease. They were afraid of disclosure, they wanted to shield themselves from the world in their couple cocoon because they were afraid of the reaction they would be greeted with. They feared stigmatising behaviour from others. At this point in their journey with Alzheimer’s disease they had not actually had any difficult reactions to Carol’s diagnosis or behaviour, they had not been victims of enacted stigma but they felt stigma and perceived it to be present. This perceived stigma perhaps arose from their own stereotypes and prejudices regarding what Alzheimer’s meant. They presumed that others would have similar attitudes.

A lot of the perceived stigma felt by the couples seemed to arise from the notion that Alzheimer’s disease was a mental illness:

“I think that the majority of people think that dementia is a mental illness which is degrading isn’t it? It’s stigmatising having a mental illness. People think that you are crazy. They treat you differently, don’t respect you. They think you don’t have anything worth saying. Perhaps I don’t” (Mary, a lady with Alzheimer’s disease discussing her feelings of being diagnosed with Alzheimer’s disease)

It was this idea of having a mental illness that the participants found most upsetting. This again linked back to the invisibility of dementia, people didn’t understand what caused it or how it manifested itself. There was a general consensus that Alzheimer’s disease was associated with the mind. The couples felt that it wasn’t seen as a physical disease of the brain, a neurological disease, but as one affecting the mind, an invisible mental illness:

“Betty: I don’t like the term dementia because as soon as you say dementia people think of loony
James: Yes madness, madness, they think that you are mad!
Betty: And I think it would be much kinder if they could think of another word
James: Demented is a term, even in English, demented, they’re mad!” (James, a gentleman with Alzheimer’s disease, and his wife, Betty, discussing the public’s opinion of dementia)

The stigma of Alzheimer’s disease, at least the perceived stigma, is associated with mental illness: madness, crazy people, people not situated in reality. This stigma was not only felt by those with the condition but was also acknowledged by the regional manager of the Alzheimer’s disease. The stigma was believed to present a large problem in increasing the publicity of Alzheimer’s disease, the knowledge and understanding of the disease in society and engaging people who may have the disease in public health measures, diagnosis and treatment. The regional manager thought that Alzheimer’s

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2Enacted stigma is the presence of overt discrimination. Perceived stigma (also known as felt or self stigma), in contrast, is not based on overt behaviour but on past images of the disease and stereotypical thinking (Jacoby, 1993).
disease, despite its ever increasing prevalence in society, was still something that people were afraid to admit they were affected by:

“It is a psychiatric condition I guess but it’s not like other mental illnesses, I mean things like depression or stuff, or psychosis. It’s different. But still people think that you are crazy and you lose lots of your friends and your old life. People don’t like to admit that they have something like that”

For the couples Alzheimer’s disease was something that was real and serious, affecting their life daily. They did not, however, feel “mad” or “crazy”. They felt like the same person, capable of the same things, just requiring more help. Most of the couples felt that they had a physical disease and it was this that caused their problems, not them. Mental illness, to the couples, implied blame and some sort of responsibility for their symptoms. A mental illness, the couples thought, was part of you. For most of them, Alzheimer’s disease was something quite different, it was a disease of the brain, something they had no control over, something that could happen to anyone.

One of the consequences of the stigma of Alzheimer’s disease, the stigma of having a mental illness of the mind, was individuals with Alzheimer’s disease being denied their personhood. The individuals with Alzheimer’s disease expressed that they were treated as irrational beings no longer capable of participating in social situations, making decisions for themselves or having worthwhile things to say. Although this negating behaviour was not performed by everyone the individuals met it was felt to exist, in some respect, across the board, from hospital consultants to strangers in the street. Many of the couples spoke of people behaving like the affected individual was not there. People ignored them because they did not know how to communicate with them, did not know whether they were capable of understanding or not. People with dementia were described as being invisible people:

“Well they don’t know what to do do they? It’s not easy. They sort of speak through somebody else, you know, how is he? And he is sat there listening to it all” (Alan, a carer, describing people’s reaction to another gentleman in the SHARED group, Frank)

People spoke over the individuals with Alzheimer’s disease, did not take their feelings or opinions into consideration. The informants with Alzheimer’s disease often felt undervalued and not treated respectfully:

“The doctor never even spoke to me. Never told me nothing. And like when we’re out like people ask Pauline if I want tea or coffee? Why don’t they ask me? They think I don’t know what I want” (Raymond discussing people’s reaction to his dementia)

Mary, a lady with Alzheimer’s disease, also experienced a perceived stigma with regard to Alzheimer’s disease and felt that others treated her differently because of her diagnosis. She felt “degraded” to have the disease, to be associated with the connotations she believed the label to hold:

“Researcher: If you were asked to tell people what it was like to have dementia what would you say?
Mary: Frustrating. It’s frustrating and a bit degrading
Arthur: Oh it’s a pity you should feel like that my love. There’s no shame in it.
Mary: It’s degrading. They think it is an illness and it’s not. Well not an ordinary illness anyway. It’s aging. Natural.

Arthur: Well I suppose the mind does age like the body. We’re not here to live forever are we? It’s pretty obvious. I suppose the mind wears out, dies off a little bit in places

Mary: It would reduce the stigma if people didn’t see it as an illness”

For Mary the reason that having Alzheimer’s disease was degrading was that she perceived others to view Alzheimer’s as an illness. At first I thought that Mary and Arthur’s opinions did not fit the same pattern as the rest of my informants. Mary would rather people saw Alzheimer’s as a normal part of aging, a consequence of an aging brain, rather than an illness that she herself has developed. The other informants seemed to want Alzheimer’s to be viewed as a discrete disease entity, something that was separate to them, something for which they had no control over. Mary did not want Alzheimer’s to be seen as a disease. She did, however, want it to be seen as something that she had no control over, something that just happened rather than something she could be blamed for. For Mary, the illness connotations associated with Alzheimer’s disease were synonymous with mental illness. She thought it was the fact that Alzheimer’s disease was associated with a mental illness that was degrading, not the fact that it was an illness (or a disease) per se. Mental illnesses, in her opinion, were associated with stigma. People didn’t understand mental illnesses, didn’t know if they were really real, didn’t know if the person who had it was to blame. Could they prevent it? Could they cure themselves? Did they have it because they were a bad person, weren’t able to cope? It was this that Mary was reacting to. She wanted to distance herself from the idea of a mysterious mental illness and instead associate her symptoms with something more tangible and natural, an aging, dying brain. For Mary, Alzheimer’s disease was physical in nature: it had a physical cause and therefore should be thought about as such. Linking Alzheimer’s disease with the natural process of aging, was, for Mary, a way of making her symptoms more real, more visible to others and absolving her from blame for her symptoms and behaviour. For the other informants this scapegoat, the thing that absolved them from blame, was a disease, a disease quite separate from aging. This disease was, however, also something physical, something tangible which made their problems more visible to others. All the informants needed a physical disease, whether inevitable with old age or something that could happen to anybody, to absolve them from blame for their symptoms and to reduce the stigma they perceived others to enact upon them.
8 Conclusions & Discussion

One of the objectives of this study was to explore the extent to which the inner subjective experiences of those with Alzheimer’s disease could be explored by a qualitative researcher. As Clare (2003), Proctor (2001), Pearce et al. (2002) and Cohen-Mansfield et al. (2006) reported, I found individuals with Alzheimer’s to be valuable and insightful research participants. I was surprised at how lucidly my study participants expressed their opinions and feelings with regard to how Alzheimer’s disease had affected them and how others treated them. They were open and honest with me and very keen for me to hear their stories. Initially they were surprised that I felt they could have anything worthwhile to say but when I made it clear that I was interested in their stories, how things were for them, they responded with enthusiasm. I feel that both myself and the study participants with Alzheimer’s disease found the process to be a worthwhile and enlightening experience.

This study aimed to explore the experiences of Alzheimer’s disease by an affected individual and a family member with specific attention to notions of personhood and self. The family member in this study was the spouse of the affected individual and it was this couplehood, along with perceiving Alzheimer’s as a disease entity, that was key to the experience of personhood and self.

8.1 Alzheimer’s as a disease

Central to the maintenance of personhood for the individual with Alzheimer’s was the concept of Alzheimer’s disease being separate to the individual. Within the context of the couple, behavioural and cognitive symptoms which could jeopardise the bestowal of personhood upon the individual, things that would question their rationality and independence, were attributed to the disease, not the individual. The couple needed these symptoms to be legitimised as a disease. As Dumit (2006) found in his study of emergent illnesses, having a disease label allowed the couples to legitimise their symptoms to others and rationalise them to themselves. Receiving a medical diagnosis has been depicted as a necessary turning point, or *status passage*, indicating an illness identity (Glaser and Strauss, 1971 in Beard and Fox, 2008). In the case of Alzheimer’s disease, the label formally legitimates the incorporation of forgetfulness into everyday life in an effort to manage social interaction (Beard and Fox, 2008). As Beard (2008) states, individuals must embark on a moral career after receipt of a medical diagnosis and learn how to accommodate diagnoses into their identities. This thesis did not examine identities per se but all study participants, both the ‘carers’ and the ‘cared for’, had to incorporate the Alzheimer’s disease diagnosis into their lives.

Although there was initially ambiguity towards the symptoms experienced, whether or not they were a normal part of aging and the life course, this ambiguity seemed to be eased by the diagnosis process. Although the individuals with Alzheimer’s disease exhibited behaviour which, within society, may still be deemed ambiguous, for the couple the disease diagnosis created some sort of order out of disorder (Hashmi, 2009). This order was not only for the ‘carer’ but also the ‘cared for’. For all couples there was a definite line to be crossed in the process of Alzheimer’s disease, a distinction between normal aging and pathological dementia (Cohen, 1998). The couple’s need for a formal diagnosis came when their symptoms were noticeable to others. They needed a diagnosis in order to prevent themselves and others incorporating these symptoms into a perception of who the individual was. This diagnosis
needed to be in the form of a physical disease, something for which the individual had no control over, something real causing them to behave the way they did. Their symptoms, their behaviour, loss of social skills, loss of abilities could then all be attributed to the disease, not themselves. The spouse of the affected individual used the disease, Alzheimer’s disease, as a scapegoat for behaviour in their partner which they would otherwise get angry about, behaviour that was incongruent with their notion of who their partner was. Through objectifying the symptoms that the affected individual had as due to a disease entity, the affected individual was absolved from blame. The disease was the cause of the problems the couple faced, not the individual. Both the ‘carer’ and the ‘cared for’ individual in the relationship could view a constant selfhood of the affected individual because Alzheimer’s disease did not get incorporated into who they were. They needed a disease label in order to distinguish the symptoms from the individual, to create an individual who had a disease, rather than an individual who was displaying bizarre, sometimes unpleasant and damaging, behaviour. The ‘carer’ was able to treat their partner positively, as a full person, by seeing Alzheimer’s disease as a scapegoat for these symptoms. This in turn enabled and encouraged the partner with Alzheimer’s disease to also view themselves positively.

8.2 Social Context

The Alzheimer’s Society also protected the personhood of those participants with Alzheimer’s disease. I argue that this was achieved, once again, by objectifying their symptoms as a disease. The groups provided positive social interactions for the couples. These interactions treated the affected individuals as persons. The Society perhaps acted as a socialising institution for the couples, somewhere where they learned the biomedical nature of the disease. Beard and Fox (2008) suggest that support groups afforded diagnosed individuals the opportunity to feel useful and promote identity adjustment through focussing on the positive, being pro-active, accepting help and using humour. They proposed that support groups were mechanisms through which diagnosed individuals normalised otherwise foreign and disorderly experiences and were socialised into accepting an illness identity. The couples within the Alzheimer’s Society groups learnt to see their problems as “the disease, not them”. Both the ‘carer’ and the ‘cared for’ began to accept, if they had not already, a disease explanation model for their symptoms. They were socialised into accepting the diagnosis but seeing that it did not have to impinge upon the personhood and self of the affected individual. The Alzheimer’s Society created a safe environment where the couple could be together in a context of understanding. It gave the couple time to be together in a sense of normality, identifying the importance of the couple but also nurturing the couples as individuals. The Alzheimer’s Society groups were places where the couples felt normal and accepted. They enjoyed the solidarity of people in similar situations and were able to form new social relationships. The groups challenged the role of Alzheimer’s victims (Beard and Fox, 2008) and instead fostered a positive environment of social interactions where the couples could overcome the challenges of Alzheimer’s disease with the help of each other.

The couples believed that society as a whole, however, did not view Alzheimer’s disease as a physical disease that was separate to the affected individual. This was believed to be due to the ambiguous and invisible nature of Alzheimer’s disease. The disease was believed to be synonymous with dementia and therefore had connotations of crazy old age and the end of meaningful life. There were still connotations
of senility (Cohen, 1998) rather than a disease process. The couples, both the ‘carer’ and the ‘cared for’, experienced felt stigma: they felt labelled, stereotyped and separated from others (Green et al., 2005). The public were, however, perceived to be fearful of Alzheimer’s disease, lacking understanding and awareness. The couples felt that personhood was denied to the affected individual due to this lack of understanding, assuming that anyone with Alzheimer’s disease was not capable of participating in social situations. The couples felt that the stigma interfered with the affected individual’s ability to participate fully in social life, a form of enacted stigma (Green et al., 2005). Affected individuals, from the perspective of society, were Alzheimer’s disease, people consumed by the disease and its effects, rather than people coping with the disease: their personhood was no longer in tact. The couples felt that if people were educated in the physical nature of Alzheimer’s disease, if it was reified as a disease of the brain, people would be able to understand the effects more clearly. This, they felt, would diminish the stereotyping and stigma that results in depersonifying behaviour. The key to maintaining the personhood and subsequent selfhood seemed to be seeing Alzheimer’s disease as a physical disease separate to the affected individual.

My findings build upon those of Langdon et al. (2007) in their study of people with early stage dementia, their perception of other people’s reaction to their changed condition and social environment. My informants, as was the case with these study participants, disliked the term dementia due to the connotations of senility and madness they believed it to hold. They were happy to share their diagnosis with those close to them but sometimes tried to hide it from others. Importantly, however, my research delved further into the reasons for this: the perceived misunderstanding of the terms Alzheimer’s disease and dementia. The participants were happy for others to know their diagnosis if they felt they would perceive that diagnosis in a similar way to them: as a physical disease which was separate to them and for which they were not to blame. The participants were not wary of people knowing their diagnosis but did not want to be labelled with what they believed to be misrepresentations of Alzheimer’s disease.

The findings of this study support Kitwood’s (1990; 1992; 1997) notion that personhood is not solely linked to cognitive functioning but is socially constructed by and within one’s interpersonal environment: social interactions are key to personhood. Kitwood (1990; 1992; 1997) stressed the influence of interpersonal relations as an essential aspect for understanding the dementia experience. He theorised that as least some of the depersonalisation seen in people with dementia was caused not by the disease process itself but rather how the person was treated. This indeed seems to be the case for my study participants. Within the context of their marriage relationship and the Alzheimer’s Society, the individuals with Alzheimer’s disease were involved in social interactions which treated them with dignity and respect, valued their abilities and achievements and tried to give them as much independence as their condition allowed: they were treated as persons. This sense of maintained personhood within these interactions had a subsequent positive effect upon the individual’s sense of self. However, it was also clear that they were indeed subjected to a malignant social pathology (Kitwood, 1990) where they experienced depersonalising behaviour at times. Those affected with Alzheimer’s disease felt that others behaved as if they were not there, as if they did not understand and often excluded them from social situations: they felt they were denied their personhood. They tried to resist becoming depersonalised, depressed, angry and losing their sense of self worth in the
midst of this behaviour (Scholl and Sabat, 2008). The affected individual was further supported by the ‘carer’ trying to avoid subjecting their spouse to this malignant social pathology, this depersonalising behaviour. This protection and positive reinforcement helped the ‘cared for’ individuals to maintain a positive sense of self. How those with Alzheimer’s disease were perceived in their social context was, however, very important to them. They were aware that there may be incongruity between the way they viewed themselves and the ways others viewed them and were upset by this.

8.3 Paradox of Diagnosis

There is ambiguity with regard to the diagnosis of Alzheimer’s disease. The couples found a diagnosis to be helpful in maintaining their relationship and subsequently the affected individual’s sense of a maintained personhood and self. The diagnosis makes their symptoms tangible and real: there is a physical reason for them. For the couples the diagnosis acts as a scapegoat for changes in the individual which could jeopardise their personhood or self. In contrast, having a diagnosis also leads the individuals towards stigmatising behaviour, or at least perceived stigmatising behaviour. They do not like being labelled with the term dementia or Alzheimer’s disease because they feel the connotations that surround the terms lead them to be treated differently, like people who cannot understand, not like full persons. This is similar to Beard and Fox’s (2008) findings in their interviews with individuals who had a diagnosis of mild cognitive impairment. They found that labels were both a source of social control and resistance. Since diagnoses are simultaneously cultural objects of oppression and processes of empowerment for individuals trying to cope, Beard and Fox (2008) suggest an identity irony in that diagnosis can simultaneously rob individuals of their unique attributes and serve to solidify group identity among those sharing common circumstances. This was indeed true for my informants: the disease label was at once a positive and negative attribute. However, the disease label was more than a collective identity, it was essential to how the diagnosed individuals maintained a constant sense of self and how their partner rationalised a maintained personhood and bestowed it upon their husband or wife. The diagnosis also caused depersonalising connotations socially, however, and the informants felt objectified by the label, something they struggled to prevent influencing the way they viewed themselves, their self worth and agency (Scholl and Sabat, 2008). The couples both accepted and resisted the label of Alzheimer’s disease, the paradox of acceptance and denial (Macquarrie, 2005). The diagnosis was useful because it gave order and reason for the symptoms experienced but at the same time it was resisted because of the depersonalising connotations that the label brought with it. Central to the maintenance of self and feeling that they were bestowed personhood was not therefore gaining a diagnosis per se, but having a diagnosis that others understood to be physical in nature, something separate from the individual and something which they have no control over. The individuals wanted to be absolved from blame for their symptoms and behaviour. This does not seem to be something that is discussed within the Alzheimer’s literature.

8.4 Self

My study participants did not experience a social death (Kontos, 2006), nor an erosion of the self, drifting towards the threshold of unbeing (Kontos, 2005). In contrast to this ‘unbecoming of self’
(Kontos, 2005), the individuals with Alzheimer’s disease experienced an active maintenance of their self. They experienced a self constantly in the making, a process, not a static entity (Charmaz, 1999). They had lost independence, they had lost the ability to communicate as effectively as in the past, they had lost many skills and abilities and in many cases a sense of purpose. They were sometimes subjected to social interactions that made them feel like they were not full persons. I argue, however, that the affected individuals managed to maintain many of their former attributes and sentiments that they saw as defining themselves and reworked their lessened capabilities into these ideals. They were able to see their independence as intact to some extent and managed to rework their poor memory and forgetfulness as not part of them, not part of their self. I argue that the affected individual saw Alzheimer’s disease as separate to themselves and were able to maintain a constant self because of this. They saw their loss of skills and abilities as a consequence to the disease. These did not therefore impact upon their sense of self. The individuals diagnosed with Alzheimer’s disease showed agency, deciding which aspects of identity, roles and attributes should be incorporated into their sense of self (Sökefeld, 1999). Alzheimer’s disease and its effects were not incorporated into the individuals sense of self, and with determination nor were society’s stereotypes and stigmatising behaviour towards these individuals. They manipulated and utilised the Alzheimer’s disease label to maintain their sense of self rather than to let it be diminished. Loss of skills were seen as just that, loss of skills due to their disease, not a loss of their self. The participants could not do the same things but could hold on to the same attributes, sentiments and values which they had always used to define themselves. Anything which threatened these core values was attributed to the disease process, not them and therefore served to maintain a sense of self.

The findings of this study support the concept of a balance between self adjusting and self maintaining attitudes towards Alzheimer’s disease (Pearce et al., 2002; Clare, 2003, 2002). They found that those with Alzheimer’s disease managed a sense of self by balancing their wish to maintain their prior sense of self against their need to reappraise and construct a new sense of self. My respondents had a similar experience, often cocooning themselves from the world until they had managed to incorporate their diagnosis of Alzheimer’s disease into their lives. Importantly, however, my respondents incorporated Alzheimer’s into life and daily coping but maintained their former sense of self, albeit a little adjusted, by attributing changes to the disease, a disease which they saw as separate to themselves.

The participants with Alzheimer’s disease were in a nurturing environment and had positive social interactions within the couple. Their status of personhood was maintained and they were treated as an equal as far as possible. This had a positive impact on the individual’s own sense of self: they were still the same person, they just had difficulties due to the disease process. Maintaining independence was very important to the ‘cared for’ sense of self. This seems to support the notion of Markus and Kitayama’s (1991) concept of the independent western self. All the study participants were able to maintain the idea that they were independent to a certain extent. They had lost independence within their marriage partnership but had maintained independence as a couple. It was this external image of coping, of being independent, that seemed paramount to the couples and especially those diagnosed with Alzheimer’s disease. Through maintaining the image of an independent, coping person to the external observer, the ‘carer’ spouse tried to decrease the chance of stigmatising behaviour towards their partner, preventing them from being denied personhood and enabling their partner’s sense of self.
to be nurtured. The ‘carers’ attempted to ensure their partner still had some control and independence within their marriage relationship, finding a balance between helping constructively and taking over in an undermining way (Clare, 2002). Carers learnt to safeguard their spouses sense of autonomy and therefore self by providing subtle help (Vernooij-Dassen et al., 2006). The ‘carer’ spouse, through the objectification of Alzheimer’s disease and providing positive social interactions, therefore maintained and nurtured the person and selfhood of their husband or wife.

8.5 The Couple

Couplehood became an essential concept in this research and indeed to the notions of personhood and self in the context of Alzheimer’s disease. Within the Alzheimer’s framework most effort has been directed at the study of family caregiving, highlighting the stress and burden that the situation brings to care givers, but few studies have explored the role of a spousal relationship in dementia (Hellström et al., 2007), the positivity which remains in the relationship (Bauer et al., 2001), nor their role in maintaining the personhood and self of their spouse. Couplehood, in this study, was sustained by talking things through, being affectionate and appreciative and making the best of things. Mirroring Hellström et al’s (2007) findings, my couples also sought to maintain involvement of the ‘cared for’ individual within the relationship. As the spouse with Alzheimer’s disease became relatively less able to play a full role, the ‘carer’ spouse helped them subtly whilst trying to ensure that the individual with Alzheimer’s disease still felt like they were contributing; they endeavoured not to jeopardise their partner’s independence. The couples faced Alzheimer’s disease together as a partnership and tried to maintain this couple above all else. Sometimes there was ambiguity as to who was the ‘carer’ and who the ‘cared for’ as they still felt there was reciprocity within their marriage partnership (Hellström et al., 2005). The ‘carer’ spouse was fundamental to the maintenance of the self and personhood of their partner. They protected them from others’ stigmatising behaviour, celebrated their successes, engaged in meaningful interaction and activities, tried to maintain their independence at least externally and to involve them in decision making and social situations. They provided a nurturing environment within which their partner could interact. Maintaining this nurturing environment for their partner, however, came at a high price for the ‘carers’ and they lost a sense of their former self in the process: being a carer became a key attribute of their self.

Hellström et al. (2007) suggest that whilst the concepts of personhood and autonomy are useful they provide an incomplete picture and that, for spousal relationships at least, notions of interdependence and couplehood may be as important. This thesis has suggested that the status of personhood and sense of self was maintained by the social interactions within the context of the couple. Independence for the individual with Alzheimer’s disease had been surpassed by interdependence and dependency within their marriage relationship but independence as a couple was maintained. Dementia often results in a reduction in the number of social relationships and an increasing reliance on a small number of people to sustain a sense of self (Hellström et al., 2005). For these study participants with Alzheimer’s disease, their main source of interaction was indeed their spouse and I argue that they are key to the maintenance of personhood and self in the affected individual. Both personhood and self are formed within the context of social interactions, the way others perceive you has a great influence on one’s sense of self. For my study participants this self and personhood was formed within the context of their
marriage relationship, further nurtured through other positive relationships such as the Alzheimer’s Society, but sometimes hindered by the malignant pathology (Kitwood, 1990) of wider society. Key to this finding of the ‘carer’ as protector of personhood and self is the concept of Alzheimer’s as a disease. Without seeing the effects of Alzheimer’s as a disease external to the individual, I argue that this status of personhood and the experience of selfhood would not be so clearly maintained.

8.6 Contextualising the Findings

The findings from this study were not ones which I had expected. The experiences of my couples, although fraught with difficulties and change, were overwhelmingly positive. A sense of personhood and self had been maintained, despite sometimes stigmatising behaviour from the general public. These findings, however, need to be placed in context. The study participants are nor representative of all couples affected by Alzheimer’s disease. They are a specific group who I made contact with through the Alzheimer’s Society. They are couples who have sought diagnosis, accepted this diagnosis and sought help in coping with its effects. By the very nature of being in a support group the couples show themselves to be treating the situation with positivity, declaring their right to be treated as people needing help and support. The situation may be very different for couples who have not sought the services of an advocacy group such as the Alzheimer’s Society.

All my participants were part of a married couple and the findings of this thesis are relevant to only that relationship. The ‘carer’ in this case was a spouse and so the nature of coping with the diagnosis may be very different for a different relationship of carer such as son, daughter, niece or nephew. Although this thesis has produced some interesting findings with regard to the couple and Alzheimer’s disease, the experience of Alzheimer’s disease by other family members and their relationship and interaction with the affected individual has not been explored. My participants were also all white, working or middle class couples. There were no participants of other ethnic groups and my findings may not be applicable to such groups. Indeed the Alzheimer’s Society as an organisation has difficulty attracting members from black and minority ethnic groups in the UK. These are therefore groups who may not have been touched by the ethos of the Alzheimer’s Society and may have very different ways of experiencing the disease and its symptoms, personhood and self.

The couples in this study were facing Alzheimer’s disease at a mild to moderate stage. None had progressed to severe dementia. Some of the couples did use the services of external carers and cleaners but all were able to cope to some extent as an independent couple. None of the couples had faced the need for one or both of them to go into a nursing home. The individual with Alzheimer’s disease also recognised their spouse on most occasions. The findings of this thesis cannot therefore be generalised to all stages of dementia. It would be interesting to follow these couples longitudinally to see how their experience of Alzheimer’s disease as a couple, self and personhood, alters with progression of the disease and its symptoms. It would also be interesting to explore whether caring partners are as important in helping to maintain a notion of self and being seen as persons when individuals are faced by other stigmatising diseases such as mental illnesses, epilepsy and HIV/AIDS.
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World Health Organisation
A  DSM IV Criteria for Alzheimer’s disease

Criterion A
There should be multiple cognitive deficits which include both:

1. Memory impairment
2. One or more of the following:
   - aphasia
   - apraxia
   - agnosia
   - executive dysfunction: planning, organising, abstracting

Criterion B
The deficits in criterion A interfere with everyday living and represent a decline from previous functioning

Criterion C
The course is characterised by gradual onset and progressive decline

Criterion D
The deficits in criterion A should not be due to:

1. Other diseases of the central nervous system including:
   - Parkinson’s disease
   - Cerebrovascular disease
   - Huntingdon’s disease
   - Subdural haematoma
   - Brain tumour
   - Normal pressure hydrocephalous

2. Systemic cause of dementia
   - Hypothyrodisim
   - B12 or folate deficiency
   - Niacin deficiency
   - Hypercalcaemia
   - Neurosyphilis
   - HIV infection

3. Substance abuse
Criterion E

Deficits should not occur exclusively during periods of delirium

Criterion F

The condition should not be better explained by another psychiatric disorder such as depression

B The Couples

Richard and Carol

I met Richard and Carol via contact through the regional manager of the Alzheimer’s Society. Carol, 58, had been diagnosed with early onset Alzheimer’s disease for four years but the couple felt that the symptoms had started six years prior to that. Carol used to be a nurse and an interior designer. Carol lives with her husband Richard in their own home. Richard, 61, is the main carer but they also have a package of care two times a day to help Carol with washing, dressing etc. Richard had given up his job to care for Carol. The couple have been married for twenty five years. It is both Carol and Richard’s second marriage.

James and Betty

I met James and Betty at the Alzheimer’s luncheon group. James, 85, has been diagnosed with Alzheimer’s disease for five years, although noticed symptoms a couple of years prior to that. His wife Betty, 84, is James’ main carer. They have a cleaner that comes once a week and their two children help when possible. They moved closer to their children due to James’ problems. Betty feels she could do with some more help but James refuses it. Both are retired teachers. They have been married for 59 years.

Arthur and Mary

I met Arthur and Mary through the SHARED group and so had many hours of participant observation with them as well as the in-depth interview. Mary, 85, has Alzheimer’s disease. She was diagnosed two years ago. They had not noticed that there was anything wrong prior to the diagnosis which was first suggested by a social worker. Arthur, 89, is Mary’s husband. He has Arthritis and struggles physically but has no problems with dementia. They manage together at home with help from their daughter. They feel they are not coping too well but do not feel ready to go into a nursing home. Arthur is a retired minister and Mary has always been a housewife. They have been married for 59 years.

Nancy and John

I met Nancy and John through the SHARED group and they also went to the Alzheimer’s cafe and the luncheon group. Nancy, 75, was diagnosed with Alzheimer’s disease one year ago after her daughter had noticed changes in her. Nancy is still very social and involved in the church but is not able to do
as many things as she once did. Her husband, John, 75, has had to take over many of the household chores and accompany Nancy wherever she goes. Nancy is a retired auxiliary nurse, John worked in business. They have been married for 45 years.

**Pauline and Raymond**

I met Pauline and Raymond at the Walk and Talk session. Raymond, 76, was diagnosed seven years ago. He lives with his wife Pauline, 72. They receive no external help and Raymond is very reluctant to accept help from anyone. He has isolated himself from social situations. Raymond is a retired engineer, Pauline has always been a housewife. They have been married for 53 years.

**Bill and Marjorie**

I met Bill and Marjorie at the SHARED group. Bill, 85, was diagnosed with Alzheimer’s disease two years ago but again the couple had noticed symptoms prior to that. Marjorie, 84, is Bill’s wife and carer. They live together and have no help from external agencies. Their granddaughter helps if necessary. Bill struggles with the fact he cannot help as much as he would like. Bill was a miner and then worked for the gas board. Marjorie is a retired nurse. They have been married for 58 years.

**C Information Letter**

Thank you for thinking about helping me with my research regarding experiences of dementia. I am a research student studying for a Master’s degree at the University of Amsterdam and am currently doing a placement within the Alzheimer’s Society. I would like to find out more about you and your partner’s own personal experiences of dementia. This will involve an informal interview between myself and you and your partner at your convenience. I am interested in your experiences as a couple. If you would be happy to talk about this further please don’t hesitate to contact me.

Thank you,

Susanna Graham

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**D Research Tools**

**Interview topic list**

- Demographic Information

- Diagnosis
  
  - symptoms before
  
  - seeking help
  
  - treatment

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• Reaction to diagnosis
• Life with Alzheimer’s
  – effects and limitations
  – change in roles
  – seeking help
  – change in view of self
• Relationships/Interactions
  – marriage
  – sharing diagnosis
  – family and friends
  – social roles
  – impact of diagnosis
• Support group
• Society
  – stigma
  – old people
  – treatment by others

Observation topic list

Support group
• Surroundings
• Building
• Posters
• Group set out
• Involvement of people with Alzheimer’s
• Activities
• Interactions of those with Alzheimer’s with others
• Interaction of couples
• Interaction staff with couples/carers/cared for
• Topics of conversation between different groups
Interviews

- Home layout, decoration
- Involvement of individual with Alzheimer’s
- Adaptive technologies/aids
- Interaction couple and me - welcoming etc
- Interaction between couple
- Sitting arrangements
- Questions asked
- Reaction to difficulties etc.