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'NOBODY REALLY UNDERSTANDS' - DEMENTIA AND THE WORLD OF FAMILY CARERS

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by

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SUMMARY:

'NOBODY REALLY UNDERSTANDS' - DEMENTIA AND THE WORLD OF FAMILY CARERS

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This thesis provides a comprehensive account of the situation of informal unpaid carers of older people with dementia. Dementia is characterised by a progressive degeneration of intellectual ability, leading to impairment of memory, judgement, and perception, and personality changes. There is no cure, and death typically occurs as a result of pneumonia, strokes, or falls, after a duration of several years. The majority of demented older people are cared for at home often at considerable emotional, financial, social, and physical costs to the carer. This exploratory research highlights the carer's situation both within the informal network of care as well as in relation to formal care provision. Qualitative interviews were conducted with spouse carers as well as adult children, recruited through carer support groups in Sheffield. The thesis presents the carers' views and interpretations of their situation and the findings reveal far-reaching misunderstandings and a mis-match between the views of carers and service providers. Overall, an inadequate understanding of the role of carers and of their needs has been identified. Current service provision, which is mainly based on instrumental support such as day care and respite care, has been found to be inappropriate for the majority of carers and their demented relative. The thesis identifies three main areas where reform is needed and suggests improvements for the recognition of dementia, the management of care, and the empowerment of carers.

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CHAPTER 1: INTRODUCTION

This thesis centres on a qualitative study of the situation of informal carers of older people with dementia. The aim has been to examine the implications of family care for the carer and the person with dementia. Several issues are highlighted, such as the role of the carer in the informal sector, the effect of caregiving in terms of physical, emotional, financial and social strains, the carer's relationship to the formal sector, and the current level of service provision. The research shows that the formal/informal interface is affected by misunderstandings and misinterpretations. As a consequence, current service provision fails older people with dementia and their carers. The following sections present the background to the study, the methods employed, the contributions to knowlege, and the conclusions of the research.

Dementia

The study argues that dementia presents a unique challenge in terms of the quality and quantity of care required. The following section briefly looks at the nature of the illness and illustrates why caring for a person with dementia is both difficult and demanding. Not to be confused with normal ageing, dementia is a disease which affects mainly people over the age of 60, but has been reported in people as young as 23 years of age. Dementia causes a decline in intellectual functioning, affecting some, and often over a period of many years all, parts of the individual's brain. One of the most demanding symptoms are the observed personality changes in the person with dementia. For instance, uncharacteristic aggressive behaviour can make the care particularly difficult for family members who do not recognise their relative any longer. The person's short-term memory is first affected with long-term memory staying relatively unaffected until late in the disease. There is no cure for dementia caused by, for instance, Alzheimer's disease. The person with dementia deteriorates over time and in the later stages of the disease has to be cared for 24 hours a day. At this stage, the majority of affected individuals are doubly incontinent and unresponsive. Dementia itself is not a direct cause of death. Death is often sudden, dramatic, and unexpected, following infections such as pneumonia.

There are around 58 different causes of dementia. Some of these are curable, such as dementia caused by diabetes. It is therefore always necessary to eliminate possible physical causes before a diagnosis can be made. Alzheimer's disease is likely to account for about 60 per cent or more of all cases of dementia (Wilcock 1990: 5). The next biggest group consists of multi-infarct dementia or a mixture of both. Multi-infarct dementia is caused by a series of small strokes in the brain. Table 1 shows the prevalence of dementia in the UK:

Table 1: Prevalence of dementia in the UK

AGE (YEARS)	PREVALENCE
40 - 65	0.1 % (1 in 1000)
65 - 70	2.0 % (1 in 50)
70 - 80	5.0 % (1 in 20)
80 Plus	20.0 % (1 in 5)

(Source: Alzheimer's Disease Society (1993) Deprivation and Dementia, Alzheimer's Disease Society, London)

The uniqueness of dementia has repeatedly been written about in the literature and it has been noted that whereas some problems are similar to other diseases, others are specific to dementia. Only in the light of these characteristics, in particular problem behaviour and personality changes, is it possible to understand why caring for a person with dementia is so difficult and demanding. The difference is thought to be mainly due to the fact that no other disease involves 'such a total destruction of the intellect and personality' (Jorm 1987: 15). In differentiating dementia from other diseases three main issues are important for the care requirements of older persons with the disease.

Firstly, the issue of time. From the onset of the disease to a demented person's death the length of the disease can be up to 10 years (or more), of which some form of support and care is necessary for most of the time. Although most older persons can be cared for on a short-term basis by family and friends if the need arises, long-term care is more of a problem. Whereas any amount of burden of short-term care can be endured by the carer in the knowledge that the arrangement is only temporary, a set-up of long-term care without improvement is hard to imagine for most people. Stress in carers arises in this setting when the need for care persists over time (Johnson & Catalano 1983: 618; Schulz 1990: 35). Further, it is not only the length of care needed in terms of years but also the amount of time required daily or weekly to care for a person with dementia that presents problems to carers (Jorm 1987: 18).

Secondly, dementia creates a unique situation due to the mental impairment which makes communication at first difficult and later on in the disease often impossible. Several writers have noted that caring for a person with dementia is the 'reverse' of caring for a person with cancer. For instance Biegel (1991: 149) notes that dementia 'leaves bone and flesh intact while erasing judgement, memory, and the sense of self. Most types of cancer destroy the physical being while leaving cognitive abilities intact'. A similar point has been made by Orona (1990: 1254) who notes that family members caring for older persons with Alzheimer's disease find the personality changes hardest to deal with.

Thirdly, Alzheimer's disease is very hard for carers to understand because there is no predictable course of the disease. Nevertheless, in terms of symptoms of the disease distinctions are often made between three stages: the early phases, the middle, and the later phases of the disease (Biegel 1991: 148-9). I will adopt this model but it should be clear that the differentiation only very broadly shows which symptoms may be expected in which phase of the disease. Appendix 1 gives an account of the various symptoms in two broad categories: medical and physical problems, and problems with activities of daily life; and psychological and behavioural problems. The mentioned problems and behaviours are not necessarily found in every older person with dementia and some problems occur temporarily at a certain point in the disease process.

Method and Design

The field study was based on qualitative methods of research, in particular unstructured interviews. Eighteen carers of older people with dementia were recruited through three carer support groups in Sheffield. The interviews took place between September and December 1996 and the majority were conducted in the respondents' homes. All interviews were tape-recorded and lasted on average just over an hour and a half (around 100 minutes). Of the respondents, five were wives, six husbands, two sons, and five were daughters. The older people with dementia were, in relation to the carer, two fathers, five mothers, six wives, and five husbands (Appendix 2). In addition to the interviews, three feedback sessions were held in the scheduled support groups in April 1997. The purpose of these sessions was twofold. Firstly, it was felt to be important to give feedback to the respondents, while also giving them the opportunity to comment on the findings and discuss possible improvements. Secondly, the feedback sessions served as verification of the findings from the initial interviews by receiving feedback from the participants. The final analysis considered three different sources of data, using the method of 'triangulation' (Denzin 1970): my own interviews, the research literature, and official documents.

Contribution and scope of the study

This thesis brings together within a single account the relevant research literature and my own original interviews. It will be shown that the role of carers of older people with dementia is misunderstood and misinterpreted within the present system and that they consequently receive inadequate support from the state sector. The study breaks new ground in that it provides a comprehensive account of the situation of this particular group of carers. No other research project to date has focused exclusively and in such depth on the carers of older people with dementia, in particular Alzheimer's Disease. Although data has only been collected on a small sample of carers, this extensive data covers the carers' complete experiences, both in personal and individualistic terms, as well as in relation to service provision. Also, the data obtained covers the carers' situation both in the past, and the present, and includes the carers' thoughts about the future. The carers in the study reflect on their experiences and what could have helped them, as well as how they would want their own future, and the future of all carers, to look like.

It will become clear that policy in relation to carers of older people with dementia has a long way to go if it is to balance the views of policy makers, service providers and carers. The study raises several points: to begin with, general misconceptions of who carers are and why they care, need to be addresssed. A vague definition of 'carer' is used in policy (Twigg & Atkin 1991: 4) which does not do justice to carers, nor does it specify which carers are in need of support. Previous research by Lewis & Meredith (1988: 4) found that there is

> an almost universal misunderstanding of the perspective of the carer and the person cared for, which [is] manifested in lack of appropriate support, lack of sympathetic understanding and lack of practical help.

In the context of dementia, 'carers' typically provide extensive, personal and often intimate care for a relative for long periods of time. Furthermore, carers in the study were spouses or adult children, and all of them were sole carers of their relative with dementia. The study highlights the complex relationships between carers and older people with dementia. Moreover, it will become clear that carers are not a homogenous group and should not be treated as such by service providers.

Secondly, there has to date been no consensus about the processes at work that enable carers to cope, and which factors influence the coping abilities of different groups of individuals such as spouse carers and adult children who care for a parent. Quantitative research has provided a wealth of data on the effects of caring on carers in terms of physical, psychological, social and financial strains. However, although these often large-scale quantitative surveys are valuable to form a basis of knowledge, providing information about the situation of carers, there are important methodological flaws in the majority of these studies. For example, Lightbody and Gilhooly (1997: 213-14) have pointed to the confused definition of 'caregiver' and the necessarily arbitrary variables employed to measure, for instance, the relationship between carer characteristics and burden. There is, then, a need for more qualitative research into these issues. The fieldwork undertaken for this study provides an example of exploratory research of these factors that are thought to influence the caregiving relationship. Based on qualitative interviews with carers, this thesis highlights carers' attempts to make sense of their situation as well as their ways of coping with everyday life. From these accounts it has been possible to analyse which factors in the caring relationship influence individual carers and which behaviour patterns are common to all carers. On the basis of this novel approach, the study has been able to suggest ways in which the real needs of three different groups of carers, adult children, older spouses and younger spouse carers, can be addressed.

Thirdly, the study presents a unique account of the carers' own interpretations of their relationship to the formal sector. It has been argued that to obtain data from carers alone creates a one-sided picture with not enough attention being paid to the views of service providers and the inevitable restrictions in terms of resources that are faced (Twigg & Atkin 1991: 2). However, I want to argue that, at the time the research for this thesis was undertaken, a full and detailed account of how carers experience formal care, and how they understand and interpret this experience, was long overdue. There has been convincing evidence that there is a mis-match between what policy makers assume about carers' wishes and needs, and what carers themselves really think (Lewis & Meredith 1988: 4; Twigg & Atkin 1991: 5). A good example of this misconception is the prevailing view that if carers were informed about services and were encouraged to ask for much-needed help, the demand would soon outstrip the scarce resources available (Allen et al 1992: 299). Alternatively, there is the fear that, if good quality care was provided, carers may no longer want to care for their demented relative. This view has been termed the 'floodgate' mentality (Walker 1997: 189-90).

There has been no evidence in my research that carers are not aware of the lack of resources, and it has become clear that what carers expect from the service sector is not unrealistic. I will demonstrate that what carers expect is a better organisation of services. In other words, it was strongly expressed that quality was valued more than quantity of care provision (Chapter 7). Furthermore, it has been found that the support that is given by the formal sector is based on day care and respite care, which is completely inappropriate to all but a few carers. The role of the carer is usually taken for granted and the services are targeted at the person with dementia to keep the latter in the community. A shift of perspective is needed to recognise that carers are as much in need of support as the older person with dementia. The study has uncovered that what this group of carers need most is compassion, sympathy and reassurance. What they frequently get, however, is a cold clinical approach to dementia in which their views are not being taken seriously, although, as far as dementia care is concerned, they are the experts. On the basis of these findings the thesis suggests ways in which recognition can be given to the valuable work of carers, the emotional needs of carers can be addressed, and the voice of carers can be heard without putting yet more strain onto carers.

Finally, the thesis places the comprehensive account of the carers' situation into the general debate on policy. Furthermore, the research findings as well as the carers' own suggestions for change are incorporated into practical proposals for change.Three main issues for reform are discussed: Recognition, Management and Empowerment. Firstly, the process of diagnosing dementia has to be improved so that carers can be recognised and supported before a crisis necessitates a response from service providers. Also, information on the disease and on services needs to be made freely available to carers and professionals. Secondly, more needs to be done to create appropriate and acceptable care provision. This may include developing new services, or adapting the existing services to the needs of older people with dementia and their carers. And finally, it has to be recognised that carers are the experts in dementia care and that potentially, carers have a lot to offer to other carers and professionals. To develop this potential and to enable carers to find their voice, there needs to be more emotional, rather than instrumental, support for carers. This thesis aims to help in the empowerment of carers by promoting their views and giving them a voice.

Contents and organisation

The thesis is divided into eight chapters: Chapters 2 and 3 provide the background to the study in the form of a review of the literature as well as the methodology employed. Chapters 4 to 7 present and analyse the findings based on interview data and literature. Chapter 8 concludes the thesis by discussing the policy implications of the study.

Chapter 2 provides the context for the study in the form of a review of the literature. Dementia has been found to be significantly different to other diseases in terms of the quality as well as the quantity of care required. This chapter presents the clinical picture, and then addresses the issues of informal care networks as well as formal care provision. Previous research has shown that the majority of older people with dementia are cared for by relatives and that caregiving can have far-reaching consequences for carers. Physical, financial, psychological and social strains have been identified. The response of the state has been to provide mainly instrumental support such as day care and respite care at a level which is inadequate in all but a few cases. There is little support for carers' emotional needs.

Chapter 3 explains the method and design of the study. Due to the sensitive nature of the study, qualitative interviews were found to be the most appropriate method for data gathering. Theoretical sampling was employed to obtain a group of carers of older people with dementia taken from three carer support groups in Sheffield. Eighteen interviews took place subsequently and were tape-recorded. To verify the interview data, three feedback sessions were held in support groups after the preliminary analysis of the interviews. The method of triangulation was used to analyse the three sources of data: interviews and feedback sessions, literature on caring, and official documents.

In Chapter 4 the role and status of the carer, and who becomes a carer, is analysed. It is argued that although for other diseases there are often several people who share the care, in dementia care there is usually only one carer. A distinction is made between the situation of adult children who care, older spouse carers and younger spouse carers. Finally, the chapter examines the evidence for the different strains experienced by carers, and concludes that the emotional impact, or subjective burden, is seen as being harder to bear than the physical demands, or objective burden.

Chapter 5 presents the evidence on coping strategies employed by carers. Carers are equipped with different personal and social resources which influence their ability to cope. The chapter highlights the practical and personal coping strategies, and the differences found between adult children and spouse carers. Furthermore, an indication is given of how these two groups of carers attempt to make sense of their experiences by taking each day as it comes and making the best of their situation.

In Chapter 6 an account is given of the way carers come into contact with health and social services. The data uncovered very serious problems with GPs in their role as gatekeeper to secondary services, and with the way dementia is diagnosed. There is a lack of knowledge about dementia and about available services among professionals, which in many cases in the study led to no diagnosis or a delayed diagnosis of the condition. Furthermore, carers themselves were in great need of information, and favoured a frame of reference in terms of early and late stages of dementia. However, the majority of carers had to fight for recognition of the dementia, and had to be assertive to obtain information on the disease and services.

Chapter 7 looks in more detail at the way carers are supported by the formal sector. At present there is an over-emphasis on instrumental support, such as day care and respite care, which is given in response to crises in the caregiving. The provision of these services is patchy and poorly coordinated, and neither was found to be appropriate for all carers and older people with dementia. Little evidence was found of successful care management and the majority of carers have to actively negotiate and supervise the support they receive. Finally, the emotional needs of carers are not addressed adequately in the current system.

In Chapter 8 a summary of the findings of the study is given and the implications of these are presented in relation to the policy debate. Suggestions for improvements are made, based on the carers' own ideas as well as the literature. Three areas need to be addressed: the process of diagnosing dementia and the recognition of the role of the carer, the management of care, and the empowerment of carers. Finally, the chapter also identifies the shortcomings of the study and points out those areas where further research is needed.

Conclusion

The study demonstrates that dementia presents a unique set of circumstances in terms of the symptoms of the disease, and the length, quality and quantity of care required. Current policy fails carers of older people with dementia and the system has been found to be inadequate at every level: diagnosis, assessment of need, information, needs of carers, practical as well as emotional support to carers, management of packages of care, and empowering carers. Three areas of reform are identified. Firstly, it is vital to improve the process of diagnosing and assessing dementia, so that recognition of the status of the carer and information can be given before a crisis takes place. Secondly, the care of the person with dementia needs to be managed appropriately, with both the carer's and the demented person's welfare in mind. Adequate services and a seamless provision of these are required. Finally, carers need to be empowered. The study shows that carers are at present not able to make their own informed choices. Moreover, it has to be acknowledged that carers have a lot to offer in terms of knowledge and experience and that this should be utilised to educate new carers as well as professionals. To conclude, only if these three areas are addressed can the role of carers be acknowledged, their voice be heard, their contribution be valued, and their efforts be supported adequately.

CHAPTER 2: DEMENTIA AND FAMILY CARE

INTRODUCTION

The previous chapter has given a brief insight into the factors that make the care of a person with dementia both demanding and difficult. This chapter gives an overview of the literature in the field. To begin with, the clinical picture of dementia is presented. An account of the clinical presentation of dementia is necessary to explain the complex nature of the disease and the relative lack of knowledge about it. The section below highlights the difficulties in diagnosis and treatment, and the uncertain course of the disease. These unique characteristics of dementia are thought to be the reason for delays in diagnosis and the slow response of service providers. Secondly, the chapter looks at informal care arrangements for older people with dementia and the effects of caring on carers. The majority of demented older people are cared for at home by relatives. These relatives, usually spouses or adult children, often face social, psychological, physical and financial strains. Finally, I will look at the informal carer's position in the formal sector. Support is provided mainly in the form of practical support such as day care and respite care, in response to a crisis in the caring relationship. These services are rarely adequate to relieve the stress of caregiving, and they do not address the emotional needs of carers. Furthermore, the majority of older people with dementia require full-time nursing care towards the end of their illness, and the move into institutional care is often traumatic for carers because this move is rarely planned in advance.

THE CLINICAL PICTURE

The most common form of dementia, Alzheimer's disease, was named after Alois Alzheimer, who first described the disease in 1907. However, Alzheimer's description of one of his cases, a 51 year old woman who showed bizarre behaviour patterns and intellectual deterioration, was not the beginning of dementia. In other words, Alzheimer did not find anything new. Torack (1983: 23-7) notes that the earliest reference to dementia can be found in Greek legal writings in 500 B.C. The influence of what was seen as incompent behaviour due to old age was recognised, while older citizens were generally regarded highly. However, dementia has not always been treated as benignly as this. Although Hippocrates attempted to explain diseases in terms of natural rather than supernatural causes, the most common explanation of dementia much later in the middle ages was witchcraft. Not until about 1793, according to Torack (1983: 26), was dementia recognised clinically, and the first definition of dementia was given in Alzheimer's article 'Über eine eigenartige Erkrankung der Hirnrinde' in 1907. Since then there has been much medical research into the phenomenon of dementing illnesses.

There are a number of reversible medical conditions which can cause symptoms of dementia, for instance delirium, dehydration, depression or an adverse reaction to medication. Three main causes of irreversible dementia are mentioned in the literature namely Alzheimer's disease, multi-infarct dementia, and a mixture of both. Whereas the underlying causes of, for instance, Alzheimer's disease are unknown, the clinical picture shows a degeneration of nerve cells in the brain. In the brains of Alzheimer's disease patients there is a dense pattern of 'senile plaques and neurofibrillary tangles'. These tissue changes can be clearly distinguished from the normal ageing brain which shows only a few of these plaques and tangles (Hauw 1993: 127-8). The main symptom is a progressive impairment of intellectual functioning which involves the loss of all intellectual skills, impairment of memory, often impairment of judgement and perception, and personality changes (Jorm 1987: 2). A certain diagnosis of dementia can only be made by examining the brain at autopsy after the individual's death. However, it should be stressed that it is not just the brain that is affected by change but that the different layers of tissue are responsible for certain skills and functions. For example, in Alzheimer's disease the functions that are subject to deterioration are summarised by Marshall (1990: 6) as memory, language (comprehension and expression), motor skills, visual and perceptual ability, intellectual (eg. abstraction) skills and educational (eg. reading and writing) skills (Appendix 1).

There are a number of factors which, from a medical point of view, are thought to contribute to the development of dementia. The most commonly mentioned is old age, followed by genetic factors, previous serious injuries to the head, Down's Syndrome, environmental factors, and lastly viruses or the abuse of drugs. None of these have been shown to be the sole factor responsible for the development of dementia. There have been quite a number of popular theories about the possible social and psychological causes of Alzheimer's disease. Gender, social class and level of education, life events, loss of former interest, personality and age have been mentioned. Most of these, with the exception of age, have now been considered invalid as causes of dementia. Some might nevertheless play a part in being caused by, rather than being a cause of, the dementing illness and these might therefore influence the experience of dementia.

It is useful to doctors to know something about the individual's background and family history (Marshall 1990: 42). With some knowledge of the person's previous level of functioning, and the problems that have newly arisen, it is often possible to eliminate some causes of dementia such as depression, dehydration or the effect of medication. Psychology has further contributed to the diagnosis and assessment of dementia by providing various screening instruments based on cognitive functioning and intellectual skills. These tests are all designed to detect a dementing illness as a possibility only. They do not provide a full assessment and should be seen as an indication of dementia upon which further investigations are necessary to distinguish between different types of dementia.

Treatment of the dementing illness is not possible, only treatment of various symptoms. For instance some physicians prescribe tranquillisers if wandering becomes too much of a problem or the person is aggressive, or anti-depressants if the demented person is subject to extreme mood swings or shows signs of depression. However, it is necessary to note that this is rather dangerous. Firstly, in older persons even smaller doses are as effective as higher ones and there is the danger of literally poisoning the person, in particular if other medication for infections or chronic illnesses is taken. Moreover, any form of medication might make the confusion of a person with dementia considerably worse.

CARING FOR PEOPLE WITH DEMENTIA AT HOME

The majority of older people with dementia are cared for in their own home or the home of their relatives. The latest available figures on the total caregiving population (Office for National Statistics 1998) reveal that, in 1995, 'one in eight adults was providing care and one in six households contained a carer'. There are an estimated 5.7 million carers in Great Britain, with around 1.9 million caring for someone at home. Of these carers, 3.3 million are thought to be women, and 2.4 million men. The figures further show that the majority (90 %) of carers look after a relative, of which 40 % are parents or parents-in-law, and 20 % are spouses. In terms of dementia, the Alzheimer's Disease Society (1993) has estimated that in 1991 there were 635,735 individuals with dementia and that, until the year 2021, at least another 258,214 people will develop some form of dementia. The following table shows the rough predictions by age (see Table 1 for prevalence of dementia):

Table 2: Predictions for dementia

Year	Prevalence 0.1%	2 - 5%	20%	Total	Total population
	40 - 64	65 - 79	80+	40+	40+
1991	14,665	234,670	386,400	635,735	22.7m
2001	16,133	234,740	453,600	704,473	24.5m
2011	18,279	243,000	512,000	773,279	27.3m
2021	17,789	304,160	572,000	893,949	28.4m

(Source: Alzheimer's Disease Society (1993) Deprivation and Dementia, Alzheimer's Disease Society, London)

This section looks at what caring at home means in the context of dementia, in the light of the requirements outlined in the previous section. Furthermore, the possible motivations of those people who care will be examined.

Caring in the home

There have been numerous attempts in the literature to dispel the 'myth' of a golden past when older people were cared for in their families (Brody 1985: 19; Finch 1989: 57ff). By now it has been established that the picture is not as clear cut and that in fact the opposite may be true. Finch reviews the historical evidence on family support in the past and reveals that firstly, help given was by no means taken for granted and was usually based on reciprocity and seen as a temporary measure (Finch 1989: 69; 76). Secondly, contrary to popular belief, the large extended household was not the norm, and thirdly, older people were as likely to live alone with their spouse instead of residing with their children as they are now (1989: 62-3). It appears that there is no evidence that families in the past supported each other more than in the present (1989: 61; 81). Further, because of the historical cicumstances, the need to care for large numbers of older people simply did not arise. Finch concludes that it is 'meaningless therefore to ask whether people are less willing to look after their elderly relatives than in the past, when this particular dimension of family obligation was simply not put to the test for most people in previous generations' (Finch 1989: 81). Brody (1985) suggests that, at present, not only are more and more people informal carers to their parents and other relatives, but the nature and duration of care has changed as well.

What this means is that long-term care is much more common today than it was in the so-called good old days. Brody notes that despite this finding the myth is still present and rather persistent and that the 'irony of the myth is that nowadays adult children provide more care and more difficult care to more parents over much longer periods of time' (Brody 1985: 21).

Wenger (1984) has developed a typology of different support networks which she found in her research in Wales. She identified five different types of support network ranging from very close local family ties to a wider community based network (Scott & Wenger 1995: 164-5; Wenger 1990b). This typology has been highly influencial for research and policy in recent years. However, despite this evidence of support networks, it should be stressed that caring for a person with Alzheimer's disease at home differs significantly from caring for a frail but mentally lucid person (Gilhooly 1984a: 107; Gilleard 1984: 78). It has been acknowledged that dementia puts a great strain on a person's support network (Scott & Wenger 1995: 159), that these carers are likely to have the smallest network (Nolan et al 1996: 10), and that the concept of social support networks may be too simplistic in relation to dementia (Ell 1996: 174). Caring for an individual with Alzheimer's disease is thought to be one of the most difficult tasks for a carer because of the mental impairment of the person. The latter can cause more problems and put more strain on the carer than the care for a person who is physically impaired. It has also been noted that one of the difficulties arising out of the caregiving is the changing nature of the problems the carer has to face, which necessitate a constant reassessment of the caring situation (Hooker 1994: 391). Finch (1989: 53-55) examines the level and nature of support within families and notes that whereas there can be a lot of assistance between different family members this support is not automatic and requires a certain amount of negotiating. Also, the direction of assistance given is predominantly from the older generation to the younger, unless an older person needs long-term personal care. The latter, it should be noted, is not part of the 'normal' support network found in families and it should be stressed that a disease such as dementia creates a unique situation in terms of the intensity of care and its duration. In this context, Haycox (1983: 440-1) notes a number of conditions for successful home care. The 'ideal' carer would be a family member who has no other commitments and can give the person with Alzheimer's disease all of his or her attention. Further, being female and childless is seen as an advantage. Another condition is that of having enough space in the home to manage the disease and minimise risk of accidents. Finally, a physician who is sympathetic to the caring situation, and an accessible day hospital or day care centre, are seen as preconditions for successful home care. However, the fact that these 'ideal' conditions are rarely met will become clearer in the following chapters of this thesis.

The caregiving population

There has been a large number of studies addressing the 'caregiving population' and the characteristics of the latter. These studies have found, for instance, that the majority of family carers are female, their average age is 57, about 70 % of them are married, one-third are in employment, and around three-quarters of carers live in the same household as the person they care for. Moreover, carers report more ill health than their age group in general, and caregivers tend to have less income than their non-caregiving peers and many are reported to live on the margins of poverty (Schulz 1990: 38).

Table 3: Carers by age

Age	Women %	Men %
16 - 29	9	7
30 - 44	18	12
45 - 64	27	20
65 +	13	14
All ages	10	6

(Source: Fisher 1997: 136, derived from Office of Population Censuses & Surveys 1992)

There has been plenty of research into the processes by which a person becomes a carer and the motivations behind caregiving and it seems that certain factors underpin the decision of who becomes the main carer. In essence, a spouse, if available, usually becomes the main carer. In the absence of a spouse a child takes over responsiblity for the care of the parent, and a co-residing child is more likely to become a carer than a child not living in the same household. Finally, the decision who becomes a carer is gendered, in the sense that women are more likely to be expected to care in a situation where for instance there are both male and female children as prospective carers (Finch 1989: 27-8).

Women as carers

As mentioned above, the majority of carers of older people with Alzheimer's disease are women. This group of women who care has received considerable attention in the literature. It has been claimed that women are more likely to take over the role of caregiver because caring is thought to be a feminine quality which can be found throughout history and is governed by social norms and expectations. Graham (1983 1983: 13) defines caring as a concept 'encompassing that range of human experiences which have to do with feeling concern for, and taking charge of, the well-being of others'. The motivations of women who care are thought to be based on a blend of love and duty, and affection and obligation (Finch 1989: 30). In particular the latter, obligation, has popularly been seen in terms of biology as the foundation of the claim that women should care because it is in their nature, or psyche (Finch 1989: 36; Graham 1983: 26). It has also become apparent that often women seem to have very little choice in whether or not they become caregivers, even though the role of carer compromises other possible roles such as being a wife, a mother, or being employed.

Among feminist researchers and writers there has been a lot of criticism of the justification that women should care for older people because most women are generally those who are already involved in other caring relationships, usually in terms of child-care (Graham 1983: 15). Finch (1989: 40), for instance, notes that it seems that altruism is compulsory for women more so than it is for men. Furthermore, there has been convincing evidence to show that the transition to the status of caregiver is not necessarily smooth. For example Suitor and Pillemer (1994) note that being a carer can have adverse effects on the marital relationship in particular if the spouse does not support, or actively hinders, the carer in the attempt to combine different roles. In practice, whereas the motivations of women may be different and based on feelings and emotions, it should not be taken for granted that women should take on the caregiving role.

In recent years, the finding that most carers are women has been challenged. For instance, the 1995 General Household Survey finding that older male spouses did almost as much caring as female spouses was met with suspicion by feminists (Rose & Bruce 1995: 116-7). However, further research revealed that particulary in the case of older spouse carers and sons and daughters there was little difference in terms of gender and the numbers of carers were almost equal (Pascall 1997: 95-6). There is a real possibility, therefore, that there has been an over-emphasis on women who care in the literature to the detriment of men who care.

Men as primary caregivers

A group of carers often forgotten is that of men. This group has often been ignored in the past or not been seen as significant under the misconception that men are not 'real' carers because they are thought to obtain more outside support than women who care

(Arber 1989: 80; Ungerson 1983: 47). The evidence on this is conflicting and it has been found that men are very capable in caring for their wives and doing those chores in the household which traditionally were seen as female. It appears that in older couples the need to care 'overrides the gendered division of labour' (Baldwin & Twigg 1991: 120).

As mentioned above, the assumption that most informal care is provided in the family and by women has been criticised. The group of men who are primary carers is larger than initially thought and it is estimated that about one third of carers of older persons are men (Zarit 1986: 260; Arber 1989: 73). It has also been acknowledged that there are characteristic differences both in the motives for caring and in the actual care set-up between women carers and men who care. For instance, men are more likely to take on the role of carer gradually, tend to be older, and tend to care for their wives, and consequently live with the person they care for in the same household. In other words, woman carers predominate only in certain caring situations and it has been found that half of all spouse carers are men. For the group of male carers this means that three-quarters of male carers are caring for their spouse, with the majority of the rest being unmarried men caring for a parent (Arber 1989: 73; 77; 80).

Older carers: Spouse and Sibling

It has been noted that there are considerable numbers of primary caregivers who are either the spouse or sibling of the person with Alzheimer's disease and are old themselves. Zarit (1986) for instance looked at a sample of spouse caregivers and noted that their coping response and the level of intervention needed differs from that of other groups of carers. In particular in the case of an older person caring for a spouse there seems to be very little choice in taking on the role of the caregiver (Oliver 1983: 73). On the other hand, many spouse caregivers have reported that they do not regard themselves as carers, as the caregiving is seen as a natural extension of the marital relationship (Wenger 1990a: 213). Similarly, Wenger stresses that the caring experience of older carers usually differs from that of younger carers in terms of the length of care given, the nature of care, and the effect it has on the carer (Wenger 1990a: 197-8). She also notes that despite the emphasis on the plight of adult daughters caring for their parent, the proportion of older carers is significant and should not be overlooked. Older carers are also more likely to be co-residing with the person with dementia, and less likely than a younger carer to ask for help or complain about the burden of caregiving. Although the length of care is shorter than the care given by younger carers, it has been found that the hours spent on care per week was significantly higher than average, and that the care given included more intimate personal care and was often done without outside help (1990a: 197; 199-200; 209;

211). Appropriate intervention is rarely given, according to Wenger (1990a: 212-16), because service provision is based on 'separation', for instance day care or respite care, and is not designed for the different circumstances and needs of older carers.

Filial caregiver systems

In the absence of a spouse as a prospective carer the responsibility to provide care is likely to lie with the children, if there are any. It has also been established that contrary to the popular myth of a golden past children do care for their parents and provide more complex care for longer periods of time than in the past (Brody 1985: 21). Further, Keith (1995: 183) has found that there are several factors influencing the choice of who will become a caregiver. These factors include gender, geographical proximity, other family commitments, personality or health factors, and the history of parent-child relationships. As for gender, female children are more likely to provide more personal care, with male children often acting as financial advisers or back-up. Geographical proximity is another important factor in the sense that those children who live closer to a parent in need of care are more likely to take over more responsibility for the caregiving. Similarly, family commitments, such as very young children, or health problems might excuse a child from active caregiving. Finally, Keith suggests that the history of the relationship between parent and child prior to the illness can influence the decision to care. For instance in the case of a poor relationship and if contact has been broken off, the child might no longer feel responsible for the care of the parent. On the other hand Keith cites an example in which a child which has always had a very good relationship to the parent is brought in to calm a situation or to get the parent to do things, such as take a bath.

There is evidence that in most cases there is one carer, often termed primary caregiver in the literature, who takes on the sole responsibility for the care of an older person with dementia. However, in her analysis of filial caregiver systems, Keith (1995: 179-80) has identified three different options: the primary caregiver, the partnership, and the team. She notes that the choice of system is dependent on the size and gender composition of the particular family. Keith also notes that although in one-child families the set-up is that of one primary caregiver, this should not automatically be assumed for families where there is more than one potential carer. It is therefore necessary to look beyond the principal caregiver to understand the possible involvement of other family members in the care of the older person. In the 'partnership', two adult children share the care equally, including everyday care and decision-making. Other offspring might be involved in the care of the parent but their role and responsibility is limited (Keith 1995: 183-5). In the 'team' on the other hand, each adult child occupies a certain role and the care of the parent is structured around the latter. Keith concludes that although there are primary caregivers in families of all sizes there is scope for other models of care, namely partnership and team, to develop. The two latter might help to reduce the stress and burden of care placed on one carer. At present, however, the medical profession and other service providers are highly insensitive to these other forms of care and still look for *the* primary carer to turn to for decision making and the main responsibility for the care of the older person (1995: 188).

Friendship and care

There has been considerable interest in, and concern about, the issue of older people with cognitive impairment, as characteristic in dementia, living on their own and without immediate family who could provide care. Allan (1986: 1; 3-5) has assessed the usefulness of friends as carers and has concluded that the very basis of friendship is undermined when long-term, unilateral care is required. He states further that friendship is a personal and voluntary relationship which is non-exploitative in nature and is based on equality. Friendships are also not necessarily durable and tend to change, break down, or adapt to new circumstances. What this means in the context of dementia is that this extreme situation puts undue strain on a friendship. This finding has been confirmed by Fischer et al (1990: 130) who found that family-less older people receive considerably less informal care and thus are more likely to be institutionalised. She also notes that in most instances of older people suddenly requiring help there is a vast network of helpers, consisting of neighbours and friends, who react in a crisis situation and provide a safety network in emergencies (1990: 134). However, the main difference between family carers and non-kin carers lies not only in what they do but in their attitude to doing it. In Fischer's study the provision of care was based solely on altruism of the carer but with the clear understanding that no more help than the present level could be given to the older person (1990: 134-7). What this means is that there exists a safety network for older people living alone which works in emergencies. However, the help given is of a voluntary nature and does not extend to systematic, extensive, long term-care (Allan 1986: 11), as for example required by demented older people. As Allan puts it, 'attempts to draw friends into the caring role are unlikely to be successful because this would involve a quite radical shift in their existing exchange basis' (Allan 1986: 10).

EFFECTS OF CARING

Research on the effects of caregiving on the caregiver has shown that many families report some form of burden on different levels, in particular emotional, physical, and financial burden (Biegel 1991: 7). In general, there is convincing evidence that providing care for a person with Alzheimer's disease in the home setting can have 'far-reaching and diverse consequences for the caregiver, negatively affecting various aspects of his/her life' (Raveis 1990: 54). However, it has been acknowledged that it is difficult to measure the extent of burden accurately. One distinction has been made between subjective and objective burden, which has been introduced to assess the experience of caregivers more adequately. Subjective burden refers to the emotional response of the carer to the caregiving situation (Morris & Morris 1993: 251), including morale in general, and more specifically feelings of anxiety, depression, grief, anger, frustration, guilt and shame (Murphy 1986: 51-58; Jorm 1987: 16-17; Motenko 1989). On the other hand, objective burden refers to actual physical nursing tasks, such as dressing and feeding. In other words, objective burden is directly determined by the changes in behaviour of the person with Alzheimer's disease and the effect the caregiving has on the carer's everyday activities and social life (Morris & Morris 1993: 251-2).

A further term that needs to be defined is stress. Generally, stress 'refers to any event in which environmental demands, internal demands or both tax or exceed the adaptive resources of an individual, social system or tissue system' (Chiriboga 1990: 123). In the literature concerned with the impact of caregiving on the caregiver the differentiation is similar to that found in assessing 'burden', in that a distinction is made between subjective, or perceived, stress, and objective stress. Four dominant factors in perceived levels of stress have been identified. Wenger (1990: 200) notes that subjective stress is mainly determined by the nature of the relationship between carer and dependent, the carer's response to the caring role, the presence or absence of family support, and the financial consequences of caring. As far as objective stress is concerned, Schulz (1990: 33-6) summarises the objective stressors as the type of illness (including nature of onset and prognosis), the level of disability in self-care, cognitive impairment, problem behaviour, and patient coping. A further category which is added to caregiving models is that of contextual variables or mediators. It has been recognised that these mediators can determine the way informal carers cope, or indeed whether or not they cope. Mediators are, for instance, demographic characteristics, personality attributes, and the level of outside help and social support (Schulz 1990: 38-40). This differentiation needs to be kept in mind in assessing the impact of caregiving on the carer. The majority of research projects that have been undertaken have been quantiative in nature and are based on comparisons of the different variables in the attempt to find significant relationships between the latter.

Research findings

There has been a huge number of quantitative studies of the effect of caring on the carer. There are some findings which are contradictory, but the majority are consistent with other studies even if the findings seem surprising. For example, no correlation has been found between marital status and supporters' morale or mental health (Gilhooly 1984b: 40; Suitor & Pillemer 1994: 686). Also, no correlation was found between the quality of the relationship prior to onset of the dementia and supporters' well-being (Gilhooly 1984b: 40). However, other studies have found that those reporting close relationships before onset of the disease subsequently felt less burden (Biegel 1991: 154). The level of total support given to the carer has been found to be unrelated to the level of stress, but those carers least satisfied with the present level of help showed higher levels of stress (Gilleard 1984: 80). Generally, this means that the level of service provision shows a positive correlation to the carer's experience of caregiving in terms of strain. However, caution has been expressed because the direction of causality is not entirely clear. In other words, the experience of stress might cause the need for more outside interventions and dissatisfaction with level of services already received.

The majority of research findings agree that there is no significant correlation between a person's severity of symptoms and the carer's wish to institutionalise (Hinrichson 1994: 99). The latter has been suggested to show a breakdown of the family support system (Zarit 1986: 260; 265), a worsening of the supporter's own health, or the fact that there are no relatives who could give care (Gilhooly 1984b: 35). On the other hand, the wish to institutionalise has been shown to be related to the level of outside help given to the carer in the form of, for instance, home help (Gilhooly 1984b: 40). Further it has been found that the nature of dementia means a constant readjustment of the carer to the caregiving situation. What this means is that the total of the reported behaviour symptoms does not increase as the dementia worsens but only undergoes changes so that some of the 'most troublesome behaviours, including wandering, paranoid accusations, and restlessness' are only present temporarily (Zarit 1986: 265). The care for a person with dementia demands shifts over time but the objective burden does not necessarily increase. Other authors suggest that there is evidence that 'the stresses imposed upon caregivers may peak during the intermediate phases of Alzheimer's disease, when the patient is still active and possibly more agitated or belligerent' (Chiriboga 1990: 136).

Somewhat surprising findings have been, for instance, that the severity of symptoms is no guide to the severity of the burden experienced by the carer, as carers differ in their interpretation of burden and in their coping responses (Zarit 1986: 260; Hinrichson 1994: 99). In other words, not all caregivers find the same symptoms problematic to deal with (Zarit 1986: 265). From this it follows that the experience of stress is related to the carer's attitude to the caregiving role and the subjective burden rather than the physical burden (Wenger 1990: 200). A further surprising finding has been that contrary to common sense it appears that the longer the care is given the better the carer's coping and morale, and the carer's mental and physical health outcome. One reasons for this finding has been suggested to be the caregiver's increasing ability to tolerate problem behaviour, referred to as the 'survival effect' (Gilhooly 1984b: 40-2; Zarit 1986: 265).

There has been some criticism of the research methods employed to get these findings. Generally it has been suggested that quantitative research methods may not show the whole picture and leave certain areas untouched (Gubrium 1988: 197). Also, the research instruments used have been criticised for not being sensitive enough. For instance, measures to assess burden would make no distinction between a person being upset about the mental and physical decline of a loved one or being upset about the time and effort it takes to care for that person (Schulz 1990: 38). Furthermore, despite the wealth of data obtained, it has been noted that it is difficult to analyse the findings of these studies because health generally may be an important factor in the decision as to who will take on the main responsibility for the care of a person with a dementing illness (Schulz 1990: 43). Moreover, it has been suggested that the analysis of physical and mental health might not be adequate because the effects of long-term caregiving could lag and only show after the care recipient has died (Schulz 1990: 43).

Finally, a neglected dimension has been that of the possible positive effects caring can have. There has been little research into the rewards of caring, probably mainly because such feelings of satisfaction seem doubtful in the light of the overwhelming evidence on the stress of caregiving. Nolan et al (1996: 82-106) review the research evidence and report that it is a further sign of altruism that carers may experience a sense of satisfaction. Furthermore, it appears that the rewards of caring are not easily recognisable to an outsider to the caring relationship, as they can involve the ‘little things in life, those apparently trivial and mundane events that can assume great significance’ (1996: 103).

Psychological strain

The impact of caregiving on the carer has been described in terms of psychological, physical, and social strain of caregiving. The psychological or emotional strain carers experience can show itself in several ways. The emotional consequences of caring for a person with dementia can include 'increased levels of depression, anxiety, helplessness, hopelessness, emotional exhaustion, low morale, distress' and 'feelings of isolation' (Raveis 1990: 54). Depression in particular has been found to be alarmingly common in carers of older people with dementia (Schulz 1990; Cohen & Eisdorfer 1986; Oxlad 1996; Morris & Morris 1993; Jones & Vetter 1984; Jorm 1987;

Gilleard et al 1984; Brody 1985; Biegel 1991; Bibbings 1998). Anger and frustration can arise out of the caring situation in particular if a person with Alzheimer's disease shows repetitive behaviours, attention seeking, or night-time wandering. Feelings of guilt may accompany or follow anger in particular if the carer feels he or she should cope better but does not know how to.

Financial strain

The financial strains carers face have been well documented. There are several factors which are thought to influence the financial situation of carers of older people with dementia. Hancock and Jarvis (1994: 5-7) note gender, residence, the type of care that is given, and the amount of time spent on care. Of these factors, gender has been identified to be the factor which causes the greatest variation. Women are more likely to suffer more than men because they are more likely to be carers. They are also more likely to give up work to care for a relative, or work part time. Both of these scenarios mean that women face lower pay and that their pension entitlements are inadequate. In particular for daughters who care this means that they may face financial insecurity in their own old age (Bibbings 1998: 175-6; Ungerson 1998: 173).

Loss of employment has been associated with more than the loss of a current income. In particular for younger carers, employment has been found to have a psychological dimension. As Gilhooly (1986: 170) has pointed out, work can be a carer's social life. However, this need for some form of social life can cost carers in the sense that any employment invariable necessitates outside help. In other words, carers have to fund the care their relative requires in their absence (Baldwin 1995: 127).

Furthermore, caring for a person with dementia has been associated with extra costs. For example carers may be faced with costs for bedding, clothing, laundry, transport, moblity aids, housing adaptations, heating, and speacial food (Twigg & Atkin 1994: 42; Baldwin 1995: 129). There is no guarantee that carers receive help with these costs.

Physical strain

Caring for a person with dementia has been recognised as being more demanding than caring for a person with physical rather than cognitive impairments (Gilhooly 1984a: 107; Gilleard 1984: 78). The physical strain involved in caring for a person with dementia can be considered in two different ways. The first is the obvious area of the amount of physical strength necessary to give care. This includes in the later stages of the disease tasks such as bathing and dressing the person. The effects of these nursing tasks on the caregiver make up the second category of physical strain. The carer may feel muscular tension, tiredness and general exhaustion (Mace 1992: 223). It has also been noted that the psychological strain experienced can manifest itself in actual physical symptoms such as headaches, nervousness and irritability (Riordan 1990: 87) or clinical conditions such as heart disease, hypertension, and a compromised immune function (Schulz 1990: 41).

Despite the finding that the severity of the patient's symptoms is not significantly related to either the mental health of the carer or the wish to institutionalise (Hinrichson 1994: 99), there has been an attempt to explain the differences in outcome. The first hypothesis is termed 'wear-and-tear', which denotes that both carer and care recipient deteriorate in their functioning and coping ability. The second, the 'adaptation' hypothesis suggests that the carer learns to adapt to the caregiving situation. The third hypothesis mentioned is termed 'trait', and describes a situation where the carer manages to maintain a 'constant level of adaptation over time' (Morris & Morris 1993: 253-4).

Social strain

Social strain covers the effect of caregiving on the social life of the carer. This strain can become evident in different areas of a carer's life and can have psychological and physical strain as a consequence. I will briefly look at three different areas in which social strain can occur, namely time constraints, constraints on social life in general, and the effect of caregiving on family life. To begin with, caring for a person with Alzheimer's disease means a time commitment both in terms of long-term care (in months or years) and in terms of the amount of time spent on actual care per day or week (Jorm 1987: 18). This kind of commitment inevitably means that the social life of the carer suffers as a consequence. Moreover, the disease in itself can cause social strain and put restraints on the social life of the carer. For instance the person's 'unsociable' and inappropriate behaviour may be a source of embarrassment to the carer and prevent him or her from meeting friends. One reason for this is thought to be that the knowledge about dementing illnesses is often poor so that many people do not know much about the disease and may not know how to respond. This in turn can gradually lead to social isolation of the carer (Riordan 1990: 89). Finally, a third area of social strain is the general effect of caregiving on family life. It has been acknowledged that some carers find it difficult to negotiate their role in the family, in particular if they are required to be carer, spouse, parent, and even employee, all at once. Trying to take on numerous roles can lead to conflicts within the family and can cause considerable distress (Gilhooly 1984a: 124; Suitor & Pillemer 1994).

FORMAL CARE PROVISION

Home care is still regarded as best for older people with dementia and the preferred choice of the majority of both older people and their carers. It is also the most cost effective option for the state. At present it is estimated that around 80 % of older people needing care receive this care in the home setting from members of their families. However, it has been noted that this setting is no longer the norm because the composition of the family has been changing. The increase of single parent families, divorce and remarriage, women's employment patterns, increased geographical mobility and other phenomena of 'modern life' mean that potential cares are not readily available. The changes in the family have led to large numbers of older people living alone. In the case of healthy people this is less problematic but there is an alarming number of older people living alone with dementia. The dangers of this have been summarised by the Alzheimer's Disease Society (1994: 5; 11) as accidents and the risk of self-neglect, injury and exploitation.

Family carers are therefore vital to the present system. Without these carers community care would not exist. However, there is evidence that the contribution of this group of carers is very often taken for granted. In 1989 the Department of Health noted that the 'bulk of community care is provided by friends, family and neighbours' (DoH 1989: 4). On the basis of this assumption the White Paper called for 'packages of care' and 'case management' (1989: 5). Although the idea behind these concepts is ambitious, the recommendations of the White Paper have been criticised. For instance, Caldock (1995a: 106) has expressed the view that the system is based on 'middle class life-styles and resource assumptions'. Furthermore, Walker (1997: 211) has noted that managerial and cost-cutting strategies appear to be behind these recommendations.

To clarify the carer's position vis a vis the formal sector, Twigg and Atkin (1994: 11-15) have suggested four models: carers as resources, carers as co-workers, carers as co-clients, and the superseded carer. The first model, carers as resources, represents the taken-for granted situation of many carers and little thought is given to the carer's needs. As far as the care of an older person with dementia is concerned, this model seems to be the norm. In the second model, carers as co-workers, professionals aim to work with the carer to provide both instrumental and emotional support to the carer and the person for whom they care. This scenario would be the ideal situation for dementia but appears to be rare. It also harbours hidden dangers in that carers may be further exploited as resources under the guise of co-worker. To make this model work, carers would have to be truly regarded as the experts in dementia care, without being forced to take too much responsibility for the actual management of care. Also, the needs of carers themselves, for support, independent of the caring context, are neglected in this approach. The third and fourth model, carers as co-clients and the superseded carer, either treat carers as patients in their own right, or enable the carer to give up caring. These two models seem an unlikely choice for carers of older people with dementia. In both cases a crisis is most likely to necessitate institutionalisation of either carer or the person with dementia, so that effectively the matter is taken out of the carers' as well as the professionals' hands.

The following two tables briefly summarise the main sources of formal care provision (excluding the voluntary and private sector). However, this is an ideal typical situation and does not mean that all these services are necessarily available to carers. On the contrary, most carers will have to cope with very little support, as will be seen below.

Table 4: Health Service Provision

Primary Care Team	* *District Nurse* * *Health Visitor* * *Incontinence Advisor* * *Community Psychiatric Nurse* * *Chiropodist* * *Clinical Psychologist*
Acute Hospital	* *Geriatrician* * *Neurologist* * *Psychiatrist* * *Psychogeriatrician* * *Others, specialising in other areas eg. the heart*
Non-medical Personnel	* *Physiotherapist* * *Occupational Therapist* * *Speech Therapist* * *Clinical psychologist* * *Nursing Staff*
Long-term care	* *Long term or 'continuing care' ward* * *'Community Care'*

Table 5: Social Services

Personal Social Services	* *Home Help Service* (Help with getting up, dressing, general housework) * *Aids and Adaptation Service* (Walking aids or wheelchairs, bathroom aids, dressing aids, feeding aids) * *Welfare Rights Service* (Information and assistance with benefits, entitlements and services available)
Residential and Day Care Services	Providing day care facilities, homes and 'relative relief' or 'respite care' (short term stay to provide a break for caring relatives)

(Adapted from Riordan J. (1990) Living with Dementia, Manchester University Press, Manchester; Chapter 8)

The provision of these services have been found to be patchy and poorly coordinated. The majority of carers first approach their GP for help if they believe something is wrong with their relative. In Britain, GPs are recognised as gatekeepers to more expensive secondary services (Hill 1996: 119). There has been evidence that while good GPs can make a real difference to carers' lives, some GPs are unable to deal with a diagnosis of dementia. As a result, dementia may go undetected, or it may be mis-diagnosed, or diagnosed late. Few older people with dementia are referred for clinical assessments, due to resource restraints, and the remainder usually only come into contact with social services when a crisis takes place in the caregiving. Indeed, Qureshi and Walker (1989: 25) note that crisis intervention appears to be the main aim of social service departments. In other words, due to an acute lack of resources, there are no preventative services and emergencies are dealt with as and when they arise. This approach to service provision has been criticised for failing older people with dementia and their carers by putting them unnecessarily at risk by only responding to emergencies. It has been recognised that early intervention can improve the situation of carers (Killeen 1998: 13-14) but this finding is rarely acted upon by service providers. Moreover, carers are expected to not only provide all the care but to act as care managers as well if they do receive support from health or social services (McAuley et al 1990: 206). What this means is that carers have to negotiate and manage the services they receive. There has been evidence that this puts some carers, namely the more passive carers, at a disadvantage because only the more active and assertive carers are successful in negotiating and organising support at an appropriate level (Zarit & Pearlin 1993: 307). However, at the same time carers have very little say in service provision and very little control over both the quality and the quantity of the care they receive (Allen et al 1992: 325).

Service provision for older people with dementia and their carers is mainly based on instrumental support, rather than emotional support (Stephens 1993: 262). Examples of instrumental support are day care and respite care, with permanent institutional care seen as a last resort. A degree of emotional support is provided in carer support groups which are either tied to day care or provided by voluntary organisations such as Age Concern, and the Alzheimer's Disease Society. These suport groups provide carers with the opportunity to talk about their experiences and to meet others in similar situations. They also provide carers with information on dementia and on available services. Additionally, carers can voice their views, and effectively develop their voice, in a supportive environment. This function of support groups as a means to empowering carers should not be underestimated. Empowerment, in this sense, means enabling carers, through information and emotional support, to have a say in the provision and level of support and to inform service providers of their real needs. Unfortunately, the potential of this dimension of support groups is not fully understood to date (Chapter 8).

Day care and respite care

Day care has generally been seen as a positive intervention, giving carers short-term relief. Several problems have been mentioned. For example Lewis & Meredith (1988: 14) have reported problems with regard to the punctuality and reliabilty of the ambulance service that takes older people with dementia to the day care facility. As for the actual service itself, Gilhooly (1984b: 39) found that in some cases there appeared to be a lack of communication which led to resentment because day care staff viewed some of the demented people as less impaired than the carer.

Respite care is used to provide a break for carers by placing the person with dementia into an institution for short periods of time, usually one or two weeks. Nolan and Grant (1995: 51-4) have identified three different types of 'beds': crisis beds, holiday beds, and rota beds. Respite care is not appropriate for all carers. It has been suggested that spouse carers in particular feel uneasy about the physical separation necessary (Wenger 1990a: 212; Gilhooly 1984a: 125).

It has also been noted that respite care often has negative effects on the person with dementia, who may become more confused and anxious (Newton 1997: 89; Nolan & Grant 1995: 52). Other problems that have been mentioned are the inflexible allocation of respite breaks (Nolan & Grant 1995: 57), the lack of communication between staff and carers (McAuley et al 1990: 209), and concerns about the safety and quality of the care provided (Mullan 1993: 244; Grant & Nolan 1995: 59-60).

Nursing care

Almost all older people with dementia require full-time nursing care in the later stages of the disease, and many will have to be institutionalised. For carers, this is a prospect they find difficult to face. Many carers, in particular older spouse carers, regard formal care as equivalent to the workhouses of the past. This irrational fear has been commented on repeatedly (Cohen & Eisdorfer 1986; Nicholson & White 1993; Ungerson 1987; Victor 1995). These fears are not alleviated by reports that the care provided in some establishments is inadequate (Walker 1997: 202), and that carers' wishes and views are often ignored by staff (Mullan 1993: 244; McAuley et al 1990: 209; Nolan & Grant 1995: 59-60). Additionally, letting a spouse go into permanent care has been seen as equivalent to getting a divorce (Oliver 1988: 75; Ungerson 1987: 99). Younger carers, mainly adult children caring for a parent, on the other hand, are more likely to organise care in recognition of their own family and career commitments (Gilhooly 1986: 166).

CONCLUSION

This chapter has given an overview of the literature on the situation of carers of older people with dementia both in the informal as well as in the formal sector. To begin with, the clinical picture has been presented and has highlighted the difficulties in diagnosing and treating dementia. It has become apparent that dementia presents a very different situation to other diseases, in terms of the symptoms, the lack of treatment options, and the length of time that care is likely to be required.

Secondly, the issue of home care has been addressed. The majority of demented older people are cared for in their own home or the home of a relative. There is evidence that in the majority of cases there is only one carer, and that this carer may have a very limited support network. Due to the confusing definitions of 'carer' there are different ideas about the nature of the caregiving population. There may have been an over-emphasis on women who care, effectively presenting a one-sided picture and ignoring the needs of the considerable number of men who care. Although is has now been acknowledged that gender is not the main factor in the decision as to who becomes a carer, previous research has revealed that different groups of carers experience their caregiving differently. For example, it has been indicated that there are differences in coping behaviour between adult children and spouse carers. Rather than focusing on gender alone, it may therefore be beneficial to look at groups of carers according to their stage in the life course. In the rest of the thesis three distinct groups will be highlighted: adult children who care, younger spouse carers, and older spouse carers.

Thirdly, the effects of caring on the carer have been investigated. There is evidence of psychological, financial, physical, and social strain on carers of older people with dementia. It has also been found that the subjective burden of caring is harder to bear than the objective burden. These findings are mainly based on quantitative studies and the methodology of some of these has been criticised as being flawed. Nevertheless, these often large-scale projects have provided an important basis of data on caring which is essential as a background to more qualitative research.

Finally, the carers position in the service system has been highlighted. Community care is still the favoured option but research has shown that the level of service provision is inadequate. The assistance that is given is mainly based on instrumental support and only provided in crisis situations. Day care and respite care are not appropriate for all carers and only available to few. There are no clear guidelines on the provision of emotional support to carers.

To conclude, carers of older people with dementia are placed in a difficult position. Long-term care for their relative is needed, which most carers provide at home. The impact of this situation can have far-reaching consequences in terms of strain on different levels. Their efforts are rarely recognised until a crisis takes place which necessitates intervention from the formal sector. The level of service provision is inadequate and few carers get the support they need, when they need it. Kitwood (1997b: 3-4) has summarised the situation in the following words

> Those who have dementia, we can say without a shadow of doubt, need to be cared for in the true and original sense. In fact, however, this need is very rarely met, either when they are being looked after by members of their family or in formal settings.

With the research evidence in mind, this thesis provides a clearer picture of the situation of informal carers of older people with dementia. For this purpose, qualitative interviews with spouse carers, as well as adult children caring for a parent, were conducted. The following chapter presents the methodological considerations and design of the study.

CHAPTER 3: METHODOLOGY

INTRODUCTION

As the previous chapter has demonstrated, the majority of demented older people are cared for at home often at considerable emotional, physical and financial cost to informal carers. The research highlights the carer's situation both within the informal network of care as well as in relation to formal care provision. The main aim was to examine the implications of this care set up and suggest ways to enable the person with dementia to be cared for at home, while ensuring the relative well-being of the carer.

Any research into dementia inevitably touches on sensitive topics by asking participants about their personal experiences. Although there were many similarities in the carers' accounts, as will be seen in the following chapters, each case was unique and had to be treated accordingly. For this reason qualitative methods, in particular focused interviews, were considered to be the most appropriate approach to information gathering. The thesis uses three different sources of data: interviews, secondary data, and official documents. This chapter provides an overview of the methods employed in the attempt to get a comprehensive view of the carer's situation.

METHOD AND DESIGN

Qualitative unstructured, or focused (Denzin 1970: 125), interviews were considered to be the most appropriate method for this study for several reasons. To begin with, the nature of the study called for qualitative methods rather than quantitative methods. As Strauss and Corbin (1990: 19) have pointed out:

> Some areas of study naturally lend themselves more to qualitative types of research, for instance, research that attempts to uncover the nature of persons' experiences with a phenomenon, like illness... Qualitative methods can be used to uncover and understand what lies behind any phenomenon about which little is yet known.

Qualitative research methods differ from quantitative methods in that data are gathered in different ways and the subsequent analysis is not based on mathematical procedures (Strauss & Corbin 1990: 17). Interviews are the most popular form of qualitative data gathering. Burgess (1982: 107; 1984: 102) has noted that any interview is a 'conversation with a purpose'. There are different forms of interviews and normally a distinction is made between structured interviews, semi-structured, and unstructured interviews (Patton 1990; Burgess 1982 and 1984; May 1993; Ely et al 1991; Denzin

1970). The term 'unstructured' is slightly misleading. For instance, Ely et al (1991: 58) note that every interview has a structure but in the 'unstructured' interview the shape of the structure evolves in the process of interviewing. In other words, the interviews were structured in terms of the research problem but allowed the interviewee the freedom to introduce new material at any stage (Foote Whyte 1982: 11).

As the study aimed to discover the carer's perspective on caring, the issue of whether to interview individuals with dementia did not come up. However, it should not be assumed that it is impossible to interview confused older people. What is crucial is the severity of a person's confusion as well as the nature of the research objectives. In the case of dementing illnesses it will be doubtful whether a person can give reliable information on his or her present situation and care (Butler 1990: 163). The danger is to regard all older confused persons as incompetent from the onset and underestimate a person's 'discourse abilities' (McIsaac 1995: 4-5). In this context it is worth mentioning that no interview for this study was conducted in the presence of the demented person, out of respect for the person, and precisely because the level of confusion could not be estimated. The carers agreed that they would not feel comfortable to 'talk over someone's head'.

The unstructured interviews were approached with a set of themes and topics to form the questions in the course of the conversation (Burgess 1984: 102) and to give the interviews a framework. Very briefly, the themes covered the past, present, and anticipated future situation of the carer and the person being cared for. As a starting point in each interview carers were asked when they first noticed something was wrong with their partner or parent. The majority of carers automatically followed these themes in telling their own story in their own words (Patton 1990: 24). Thus, they played an active part in determining the direction of the conversation while I was able to ask for more detail about certain topics which were of particular interest to me. Burgess (1982: 107) has noted that this approach provides an:

> opportunity for the researcher to probe deeply, to uncover new clues, to open up new dimensions of a problem and secure vivid, accurate, inclusive accounts about informants that are based on personal experience.

Another reason for the choice of method was what could be called personal inclination and the conviction that qualitative methods would yield the best results for the study. As Kellaher (1990: 122) has phrased it, qualitative methods are more likely to give the researcher a 'holistic view of phenomenon'. Similarly, Burgess (1990: 109) notes the benefits of unstructured interviews in saying that:

> Without allowing people to speak freely we will never know what their real intentions are, and what the true meaning of their words might be.

Seeking information about the care of someone with dementia needed to be done sensitively, in the knowledge that social relationships were potentially being interfered with and privacy was invaded, and with the intent to avoid harming the participants in any way. The interviews were scheduled to be 90 minutes long, which has been suggested to be the optimum length for a focused interview (Burgess 1984: 120). The interviews were complemented by a certain degree of observation in support group meetings, as well as feedback sessions which were about 90 minutes long and took the form of a 'group interview' (see below).

THE STUDY

As the project was an exploratory study my intention was to discover new concepts instead of merely testing existing theories. I used the method of grounded theory (Glaser & Strauss 1969). Within this approach, termed 'theoretical sampling', the sample was not selected randomly but on the basis of certain characteristics which were important in the process of generating new data (Strauss & Corbin 1990: 176-93). Specifically, I wanted to interview carers who were currently caring for a person with dementia, or had cared until very recently.

Access

The study was based in Sheffield. I initially attempted to get access to carers of older people with dementia through one hospital ward. However, this was discouraged by hospital staff who felt that those carers whose relatives had been admitted to hospital would be too distressed to be interviewed. In other words, I was refused access. Due to the sensitive nature of the research topic it was then decided to recruit participants through support groups rather than hospital wards. The leaders of support groups I then contacted were much more welcoming and very helpful.

Eighteen carers were subsequently taken from three support groups, one hospital-based and two which were run by the Alzheimer's Disease Society. One support group was led by social workers, another by volunteers who had been carers in the past, and the third by volunteers who had not cared for a person with dementia. Due to the person or persons leading the groups, incidentally all women, the dynamics within the groups were observed to be different. The first group, led by a social worker, was attended by spouse carers as well as adult children. The focus in these meetings was mainly on general information on dementia, with guest speakers regularly being invited to talk about new developments and sources of assistance for the carer. The second group, led by two former carers, was attended by spouse carers only. The meetings were used exclusively to exchange experiences and let carers talk about how they felt. Due to their own caring experiences the two group leaders were able to give their personal opinion and advice. The third group was led by two volunteers who had no previous experience with dementia. This group was attended by adult children who cared for a parent and the meetings were based on very specific practical information requested by the carers, in particular regarding financial affairs such as funding full-time care and arranging for a power of attorney. The possible reasons for, and implications of, these different group meetings will be considered further in Chapter 5 and 7 respectively.

I obtained permission to attend the support groups as an observer after the carers had been asked whether they would mind someone sitting in. At the beginning of the first meetings I introduced myself and explained the nature of the study, asking the group members whether they would be interested in being interviewed. To help them in their decision and to ensure informed consent (Butler 1990: 165-6) I distributed handouts which stated clearly on one page who I was and where I could be contacted (at university), what the study was trying to achieve, and how the carers could contribute. It also specified that the interviews were confidential, would take about 90 minutes and that, if possible, I would like to use a dictaphone to record them. The carers were free to ask questions about the nature of the study and the method before the meetings carried on as normal. I believe that this personal approach enabled me to get enough participants for the study in a relatively short period of time and it also enabled the carers to know exactly who and what they were dealing with. Two main questions concerning my motives were asked by the carers: who was I (PhD Student) and why was I interested in dementia (my grandmother had dementia), and would I want to do more research into dementia after completing my PhD? It has been noted in previous research that such issues are important to potential respondents (Oakley 1981: 45). No doubt these questions could not have been addressed adequately by recruiting participants in any other way. Several carers approached me immediately after the meetings to volunteer their names, telephone numbers and/or addresses, expressing their willingness to be interviewed. Others contacted me by telephone (at university) to arrange an interview, and a third group of carers took the handouts home to consider their participation and then came back to me in the next group meeting, asking whether they were still needed. There was only one person in each of the three groups I approached who decided not to take part in the study. The majority of the interviews were subsequently arranged over the 'phone, choosing a time most convenient for the carers.

All the carers in the support groups were white, and came from different parts of the city (see below). The groups run by the Alzheimer's Disease Society seemed to attract carers from all social groups, whereas the hospital-based group had a catchment area in the South West of the city, usually associated with more affluent residents. Overall the distribution of my sample seemed to be fairly varied in terms of income of the carer and level of education.

One consequence of obtaining a sample from support groups was that this particular group of carers may have had different characteristics to the total population of carers. For instance it has been noted that any sample recruited through organisations or societies may be biased in the sense that it is a certain type of person who joins a society (Pearlin & Zarit 1993: 164). However, what exactly this means is inconclusive. It has been suggested that those carers who are members are facing more problems with the care of their relative, and need more support. Although it was not possible to analyse this claim in the context of this study due to lack of a control group, the carers in the sample did not give the impression of generally having severe problems. The carers' situations were varied, ranging from those who got a lot of support from the formal sector to those who got no support whatsoever.

It has also been claimed that members tend to be more aware of what dementia is and are more articulate and more active within a society, wanting to learn more about the disease and new developments in cure or treatment. The latter claim may be relevant for the chosen sample since all interviewees expressed the need for more information. However, again, it could not be determined whether this was an unusual characteristic of this particular group of carers. Judging on the evidence from previous research studies (Chapter 6) this is likely to be a more general finding among the majority of carers. Thus, despite the restriction of recruiting carers from support groups, the main aim was to introduce a wide variety of carers into the sample (see below).

Ethical considerations

There were several prospective ethical problems which had to be considered prior to the interviews with carers. To begin with, the carers could have found the issues covered in the interviews too sensitive. For various reasons they may not have wanted to disclose information about themselves and the person for whom they cared. However, the study has shown that those issues which were regarded as sensitive by the researcher, such as issues around incontinence, were not necessarily perceived to be so by the carers. Those carers who had to deal with incontinence were familiar with the topic and felt no shame in detailing their tasks. Lee and Renzetti (1993: 5) note that it is not uncommon to approach a topic with caution only to find that the fear of offending the interviewee was unfounded. On the other hand, seemingly harmless questions provoked a surprising response. For instance, one carer who talked at length about the problems in his sex life at the beginning of the interview reacted mildly offended when, at the end of the interview, I inquired about his age and the age of the person being cared for.

Secondly, one complaint about interview practice that has been noted by Butler (1990: 168), has been not so much the invasion of privacy but the issue of 'overburdening' the interviewee by asking for 'too much' information. In the context of this study it appeared that the nature of the interview provided a certain safeguard against asking questions that were too intrusive. The possibility of overburdening the carer was only encountered in two interview situation. I ended one interview early to protect the carer who was very recently bereaved. In another interview the carer burst into tears once, explaining, rather than accusing, 'You are making me cry.' Fortunately, at least for the researcher, it had been observed in previous support group meetings that this particular carer cried easily, and stopped as quickly as she started. The situation was diffused by distracting the carer and, for the time being, changing the topic. In all other interviews the carers seemed to use the interview situation to 'unburden' and to talk to someone who knew something about dementia (albeit based on the literature in the field rather than personal experience), was interested in their story, and had the time to listen. Some carers commented how much they enjoyed being interviewed, subsequently referring, for example, to 'our lovely long chat'. Thus, the fear of overburdening the participants was largely unfounded and it appears that in the majority of cases it seemed 'to him or her an agreeable form of social intercourse' (Quoted in Burgess 1984: 102).

Finally, the good rapport that was achieved in all interviews presented a very different problem, namely a possible danger of becoming over-familiar with the participants (Denzin 1970: 138-9; Oakley 1981: 33-4). Indeed, all the carers that were interviewed were very friendly, very welcoming, and eager to tell their stories. Rather than unnecessarily burdening the carers, I faced the prospect of burdening myself. Butler (1990: 169) has noted that:

> it is all too easy to be drawn into a lengthy and emotionally demanding session when the role of researcher is abandoned in favour of concerned listener.

All interviews were experienced as draining but the effect was counteracted by never conducting more than one, or a maximum of two, interviews a day. Also, care was taken that the interviews did not exceed the time specified and no interview was allowed to last more than two hours. The timing of the interviews was achieved with accuracy by using two standard tapes. The first one, a 90 minute tape, presented the ideal length of the interview. The second tape was a 60 minute tape, of which one side was used if the interview was not completed. This second tape signalled to the researcher that it was time to bring the interview to an end and gave the option of recording any concluding comments.

The way access was obtained, as has been detailed above, meant that the carers in the study were in no doubt about my position as a research student and I was at no time mistaken for a social worker, psychiatrist, or other professional. Nor was I expected to pass judgement or give advice. It has been noted that age is one characteristic that can influence the position in which the researcher finds him or herself in relation to the person being interviewed (Burgess 1984: 105). In several cases I was similar in age to the carers' grandchildren or own children, some of which were in higher education. My status as research student was therefore accepted and understood. In other words, the interviews reflected that the carers themselves were the experts on the topic and talked about their own experiences, educating me in the process.

Interviews

Eighteen interviews with carers of older people with dementia took place between 22 September and 2 December 1996. Only one interview was cancelled and re-scheduled due to a crisis in the carer's household. In many cases the diagnosis was not clear to the carer or not available but it appeared that there was an equal proportion of Alzheimer's disease and multi-infarct dementia present, and possibly a mixture of several causes in some cases (Chapters 2 and 6). One person being cared for had been diagnosed as suffering from Binswanger Disease, a dementia caused by a viral infection.

On average, the interviews lasted just over an hour and a half (around 100 minutes). No interview was longer than two hours, and one interview was slightly shorter than the specified 90 minutes due to the very recent bereavement of the carer, as mentioned above. All interviews were tape-recorded with the permission of the interviewee. Several observations were made in relation to the equipment used. The dictaphone and separate microphone were provided by the researcher and were of poor quality. In one interview the first ten minutes were not recorded because the record button was not pressed correctly. On the positive side, the dictaphone was useful in that it switched off audibly as soon as the tape ended. This was invaluable as the conversation was usually too animated for the researcher to keep an eye on the tape. Few texts on methods discuss these potential problems although Burgess (1984: 120) mentions the need to be familiar with the equipment used. However, ideally, good quality dictaphones should be used. It was, for example, observed that the majority of people lower their voice when they talk in confidence, about something personal. In these cases, a poor quality dictaphone gives a poor quality recording, with the danger of losing important data. Thus, in this research study, minor problems which made parts of some tapes difficult to transcribe included hissing gas fires (in two cases), the sound of hail against a window, a very friendly as well as a hostile dog, and a playful cat (long cord for microphone).

Of the eighteen interviews twelve took place in the carer's home at a time most convenient for the carer, which was usually mid-morning or early afternoon while the person with dementia was attending a day care facility. I arrived exactly on time for each interview, believing this to be the first step towards good rapport. Having to rely on buses, careful planning was needed to achieve punctuality. In other words, rather than to risk being late I was very frequently early, and after locating the carer's home, went for walks in the neighbourhood. Furthermore, for my own security I left the interviewee's address in a sealed envelope with my landlord.

Two interviews were conducted at the carer's place of work. These two carers were adult children in full-time employment who used their lunch breaks to be interviewed. One interview took place at the Alzheimer's Disease Society in Sheffield, where a room was 'booked' in advance. The carer in question did not receive any formal support at that time and felt that we would be unable to talk freely in the presence of his wife as there were profound problems with his wife's behaviour generally and in particular towards strangers. Three other interviews took place in my house. In all three cases the locations were suggested by the carers, who were adult children caring for a parent. The reasons were a combination of full-time employment (in two cases), the need to meet in the evening, the distance to the carer's house (one in the Peak District), and severe weather conditions (two of the interviews took place in late November). All three carers felt that, as they had cars, it would be unacceptable for me to travel on public transport to remote parts of the city after dark, and offered to come to my house instead to be interviewed.

There are several issues which have not received enough attention in the literature. For instance, there have been guidelines about the way the interviewer should behave (Foote Whyte 1982: 111). Researchers should be sympathetic, interested and patient. They should also avoid giving advice, entering into arguments, passing judgement, or upsetting the interviewee. As useful as this advice is, the literature on research methods fails to instruct those researchers who go into the respondents' homes to be prepared for what they may find there. The exact location, usually a living room, of the interview was of importance. More precisely, the position of the researcher and the respondent in a living room was found to be of significance. Three examples from this study serve to illustrate this point further: One interview took place in a long narrow living room with the interviewee and researcher sitting at opposite ends. This situation provided a dilemma in terms of taping the interview because there was too much space between the two speakers. I opted for placing the dictaphone close to the interviewee, although this meant that I could no longer hear myself on the tape. In the second example the respondent invited me to sit on the sofa and then sat next to me, leaving very little space for dictaphone, microphone, cups of tea, and biscuits. It was also difficult to talk and keep eye contact by looking sideways at each other. After a short time I suggested that maybe it would be better to sit facing each other. The third example provides a similar, but yet qualitatively different, scenario. The carer in question offered me the most comfortable armchair in her living room. However, this armchair was specially adapted for a person with dementia and therefore very high. The carer seated herself on the sofa which was considerably lower than my position. In effect, I was looking down on the person I was interviewing, which felt wrong. Making an excuse, in this case playing with a kitten, I moved down to sit on the floor instead. To conclude, it is important for researchers to be prepared for anything when conducting interviews in a person's home. It is further important to observe that person's privacy, while ensuring that no unequal power relationship is encouraged, as could potentially have been the case in the third example mentioned above.

Carer Profile

Interviews were conducted with five wives, six husbands, two sons, and five daughters. Those being cared for were (relationship to the carer) two fathers, five mothers, six wives, and five husbands (Appendix 2).

Of the older people with dementia ten were alive and cared for in their home or the home of the carer (co-residing with the carer), one was alive and periodically living alone (that is, living with an adult child for short periods of time when needed), two were alive and in permanent nursing care, and five were deceased.

In the spouse carer group the ages ranged from 57 to 81 for the carer, and 58 to 85 for the person being cared for. The average age of the carer was 71, and for the person being cared for 72.

Among the group of adult children caring for a parent the youngest carer was 43, the oldest 60 . The parents being cared for were between 72 and 94. The average age of the carer was 49, and for the parent being cared for it was 80.

At the time of the interviews, all carers had cared for a considerable period of time. However, in some cases it was difficult to establish the exact length of care because the disease was not recognised for years. Most carers gave two estimates, one giving the length of care since a diagnosis was made (if a diagnosis was made) and a second suggesting what they considered to be the first signs of the disease and what caused them to finally ask for help or advice. The shortest time of care was reported as 15 months (since diagnosis), the longest eight years.

As already mentioned, the carers responded positively to the interview situation and all of them were willing to be interviewed again in case further information was required. All of them agreed that it would be beneficial if I could come back to the support group to offer some feedback on my research. In the event, a second interview was not conducted due to the wealth of data obtained in the initial interviews and the feedback sessions took place in April 1997, as will be discussed below. I attended all support group meetings until December 1996 and all carers and those people ('gatekeepers') who were of assistance in getting access to carers received a letter before Christmas 1996. The letter thanked the carers and gatekeepers for their help so far, reminded them of a possible second interview and of the feedback I planned to give to the group. As everyone was very friendly and helpful I also felt that it was appropriate to wish carers and gatekeepers a pleasant Christmas and to wish them well for the New Year.

ANALYSIS OF DATA

All interviews were tape-recorded and transcribed. The tapes were numbered and pseudonyms were used on the tape cover as well as in the transcripts. Furthermore, I transcribed the interviews myself and the tapes were, and still are, stored safely to ensure confidentiality. This seems particularly important to protect not only the carers and their families but also the identities of several social workers, GPs, and hospital consultants.

Transcripts and coding categories

The data was generated through the method of constant comparison throughout the data collection period. In other words, sampling, data collection and analysis took place not one after another but simultaneously. Due to this approach only the first seven interviews have been transcribed fully and the emerging themes noted. Data was then analysed by identifying provisional coding categories from these first few data sets obtained (Strauss & Corbin 1990: 65-6). These themes evolved into the final category by being tested in subsequent interviews. The remainder of the interviews were transcribed selectively in the light of these categories, which were revised, added to, and eliminated as necessary (Strauss & Corbin 1990: 97, 108-9). In this way the categories obtained were generated by the data itself.

The quotations used in the following chapters were chosen on the basis of their 'quotability'. Quotability means that some carers were better than others in articulating the general points in the clearest, most direct, and succinct ways. In other words, all interviews were treated as equal in their information value, but quotations were predominantly used from those respondents who were more 'perspicacious, informative and talkative' (Fennell 1990: 71). Furthermore, the quotations used to illustrate points are verbatim. Breaks in the quotation are noted as ...[...]... indicating that not the full conversation is given. Natural thinking breaks (Ely et al 1991: 60) which were longer than, for instance, a pause caused by the respondent trying to find the right words, are indicated as ...[Pause]... Pseudonyms have been used throughout.

Interviews with the carer of a person with dementia had advantages and disadvantages. The obvious advantage for this study was to get a first hand account of what it was like to care and how the carer felt about the caring situation. It was also possible to get information about the person with dementia which may otherwise not have been accessible. The main disadvantage was that there was plenty of scope for individualistic accounts, incaccurate factual information and, in general, a very one-sided picture of both the carer's and the demented person's situation. Whereas I could not determine the extent to which I obtained a one-sided picture of the caring situation, an attempt was made to verify the information that was obtained in the interviews. To avoid the danger of having been given a modified account, in a negative or positive sense, in the interviews, I attended the support groups for several months. It was observed in these meetings that carers repeated certain events and how they felt about their situation, the same way they had presented this information in the interviews. I therefore consider it unlikely that any participants systematically falsified their accounts.

To analyse the interview data the method of triangulation (Denzin 1970: 300-301) was used. The concept of triangulation suggests that by using a wide variety of evidence it is possible to obtain a complete picture with more certainty and less doubt. Kellaher et al (1990: 122) have noted that:

> Triangulation is not a simple combination of different kinds of data but the attempt to relate these different kinds of data so as to counteract the threats to validity identified within each.

Triangulation therefore serves to test the validity of a given study. In the context of this study, data, observation, feedback, and literature on the topic were combined in an attempt to describe and analyse the situation of a spouse or adult child who cared for a relative with dementia.

Feedback

One way to verify findings, and to involve carers in the research beyond the interview stage, was through the feedback sessions which took place in April 1997. These sessions were incorporated into the scheduled support group meetings. The aim of this was to guarantee maximum attendance because a large number of carers made care arrangements for the person with dementia to be able to attend meetings at this particular time. The sessions were announced in the meetings previous to the feedback sessions. For those carers who had not attended these meetings, a notice appeared in the Alzheimer's Disease Society Newsletter (Sheffield branch), and I 'phoned several carers who I thought were unaware of the feedback sessions. From the eighteen carers only two were unable to attend one of the three feedback sessions, in both cases due to illness.

The purpose of these sessions was twofold. The main aim was to give the promised feedback to the carers and present them with the findings. The second aim was to verify these findings by getting feedback *from* the carers. I presented the main themes that had been identified in the preliminary analysis and each point was then discussed by the group, with carers being encouraged to voice their doubts, approval, and personal opinion. For example, it was generally agreed that very little information on dementia and on services was available to carers and that only more assertive carers managed to get enough information from professionals. Other topics discussed were the difference between objective and subjective burden, the impact of the caring relationship on different groups of carers, coping mechanisms, and the carers' relationships to the formal sector in terms of problems with diagnosis and assessment. Furthermore, suggestions were made by the carers about how the situation could be improved. Again, this opportunity to comment on the findings ensured a high level of involvement of carers throughout the research process. The three feedback sessions were tape-recorded but have not been transcribed as they mainly served to clarify some issues and verify the findings of the study.

CONCLUSION

To summarise, the study has used qualitative methods of research to obtain a comprehensive picture of the caring situation from the carer's perspective. It has already been noted that obtaining the sample through support groups may have influenced and biased the findings. One consequence of the sample characteristics has been that all participants were white and the majority were middle class. The latter was due to the catchment area of the particular support groups that were approached. The former, however, reflects a more important issue namely that *all* members of these support groups were white. Further informal questioning of social workers and carers support workers revealed that carers from ethnic minorities generally did not make use of those support groups which I accessed (Chapter 8). This is an issue which could be investigated in more detail in further research to establish the needs of this group of carers.

Another consequence of the sample selection was that the study did not touch on the financial consequences of caring much because the interview focused more on the problems perceived as most severe by the carer. Two possible reasons may be responsible for the lack of data on the financial effects of caring. On the one hand it is possible that in this particular sample the financial aspect of caring was indeed not the most pressing issue for the carers. On the other hand it may have reflected a natural reluctance of carers to explain their financial situation to a stranger, despite the fact that other, more personal, details were related without hesitation. It may have been possible to obtain more information on this particular aspect of caring if a structured interview schedule had been used. However, if the interviews had been more structured I may not have secured such a wealth of data and such vivid and highly personal accounts of the carers' situations. In sum, I believe the choice of method was appropriate for the study and should have given me the best possible information and a very comprehensive account of the carer's situation. Moreover, the high involvement of carers throughout the research process, through the use of qualitative interviews and feedback sessions, has gone some way towards helping to empower carers and giving them a voice. This theme will be developed further throughout the thesis. The following four chapters present my analysis of the data obtained.

CHAPTER 4: THE WORLD OF THE CARER

INTRODUCTION

As Chapter 2 has illustrated, caring for a person with a dementia has been found to be significantly different to the care given to a person with a physical disability. One of the factors that make dementia care specific is the length of the care required, which in the study covered between two and over 10 years. Secondly, the demands on carers changed constantly due to the changing symptoms the person with dementia displayed. And thirdly, dementia is difficult to diagnose and there is as yet no cure, nor effective treatment. Due to these unique characteristics of the caring situation a closer look at the world of the carer is needed.

This chapter is based on the findings of the research and attempts to illustrate the situation in which carers found themselves. To begin with, the role of the carer will be looked at in more detail and an analysis of the principles underlying the decision to become a carer for a person with dementia will be attempted. Secondly, I will examine the attitudes of different groups of carers in terms of their stage in the life course (Chapter 2). The situation of adult children who care, older spouse carers, and younger spouse carers will be analysed and it will be determined how far these groups experience their caregiving differently. Thirdly, this chapter will highlight the extent of the strain the care situation puts on carers and I will distinguish between the physical, financial, psychological and social impact of caregiving.

BECOMING A CARER

The precise ways in which a person becomes a carer are not fully understood but several models have been put forward (Johnson & Catalano 1983: 612; Finch 1989: 28). To begin with, Qureshi and Walker (1989) have suggested a hierarchical decision model, listing relatives in order of preference on the basis of traditional (Western) normative values and beliefs (Walker 1991: 98). Finch has adapted this model and has outlined several principles which appear to determine who becomes the main carer. In the first instance a spouse will take on the caring role. This was the case for the majority of respondents in my study. Although in some cases adult children were living close by it was the spouse who provided all aspects of care. Secondly, where no spouse is available there is usually one adult child who takes on the caring role, including practical caring and decision-making. Finch notes that this process is highly gendered with daughters being more likely to provide care than sons (Finch 1989: 28).

Thirdly, those of the first two categories, either spouses or adult children, who share the same household are more likely to take on the main caring role than those not living with the person with dementia. Indeed, the several daughters and one of the sons in my study felt that they had no choice because while they were living with their parent they were expected to take on the caring role. In one case a husband was not given formal support because his daughter still lived at home and was thus deemed available to care for her mother despite having a full-time job.

Other studies have focused on issues of proximity and distance. For instance, Ungerson (1987: 43) notes that proximity of kinship as well as geographical proximity can influence who becomes a carer. Furthermore, it appears that the quality of the relationship between different members of one family determines who is most likely to be seen as a carer, or rather, who is not seen as a carer (Ungerson 1987: 51). Examples from my research include an adult daughter still living at home who had enjoyed a good relationship to her mother, and at the other end of the scale a son who was excused from caring due to a very difficult relationship with his mother in the past.

Who cares and why?

The reasons for caring have been explained on the basis of two different motives: the egoistic or self-serving motive, or empathy and altruism (Schulz 1990: 29-30). The former has been associated with 'expectation of payment, gaining social approval, ...complying with social norms, seeing oneself as a good person, or avoiding guilt'. The latter shows a different view of social interaction with the emphasis on altruism and empathy with the goal being that of benefiting 'the other and not the self, even though benefits to oneself may be a consequence of helping'. Although both types of motives may be present in the care for persons with Alzheimer's disease, Schulz suggests that altruism may play a greater part in the earlier stages of the disease and may then be replaced by more egoistically motivated care later in the disease (1990: 31).

However, this model may be over-simplified in the sense that motives may not be the same for different categories of carers. Furthermore, my research has found no evidence of egoism. On the contrary, caring for a partner or parent with dementia seemed to be based on empathy and altruism alone. This again may suggest that caring for a person with dementia is significantly different from caring for a person with other illnesses. One interesting point was raised by a daughter caring for her mother, who said that she thought that some of those people who care have always, even before their caregiving, had a caring personality. Indeed, the personality of the carer (as well as the personality of the person being cared for) has been mentioned as one factor contributing to the choice of who is most likely to become a carer (Keith 1995: 183). Lewis and

Meredith (1988: 19) refer to personality and suggest that caring may be 'central to femininity'. However, this view of a 'caring personality' has to be approached with caution. The literature appears to explain the involvement of women alone as the result of them having the 'right' personality for caring, whereas the respondent quoted above referred to both male and female carers. The idea of 'caring personality' may refer to no more than the finding that for many carers the person with dementia was not the first person for whom they had cared. Seven carers, three husbands, two wives, a daughter and a son, had previously looked after other relatives either with dementia or other conditions such as cancer. The daughter had cared for as many as five other people, related and unrelated, before she began caring for her mother. In this sense to refer to 'caring personality' could be seen as a way to rationalise the position of the carer, rather than as a factor in the decision to *become* a carer. Moreover, personality has been mentioned as an important factor in relation to a person's ability to cope with the care of a relative with dementia (Hooker et al 1994: 386). This line of thought will be developed further in the next chapter which focuses on coping mechanisms among carers.

Despite the word of caution that caring should not be seen as a natural component of femininity, and that the presence of carers other than women should not be ignored, there has been evidence that 'altruism is compulsory for women in a way it is not for men' (Finch 1989: 40). This means that in some situations the selection process of carers is thought to be highly gendered, with women much more likely to become carers than men. A good example of this are adult children who care. Finch and Mason (1997: 98) have reported that normative beliefs do exist and that children are generally seen as obligated to their parents. Moreover, Finch and Mason (1997: 103) found that there are

> some situations in which gender does seem to have a clear impact upon people's normative judgements: daughters are rarely chosen as the appropriate people to provide money, and sons are rarely chosen as the people who should provide care for an elderly woman.

What this means for the choice of carer for an older person with dementia is that daughters may feel under pressure to accept their filial obligation due to a 'public normative consensus' that it is their role to assist their parent. A similar normative belief is found in the case of spouses who care. However, these beliefs are thought to apply equally to men. Spouse carers, whether male or female, are often regarded as the natural choice of carer (Wilson 1995: 111). This lack of choice in spousal caring relationships will be discussed further below.

Looking in more detail at the reasons family members might have for not caring for a relative with dementia, it has been suggested that 'it is legitimate for someone to refuse help to a relative if they are unable to provide assistance, rather than able but unwilling' (Finch & Mason 1993a: 98). In their discussion of 'legitimate excuses' Finch and Mason mention employment, other family commitments, competence, geographical distance, and lack of resources as possible reasons why a relative may be excused from the role of carer (1993a: 102-110). Examples from my study are spouses who reported adult children who were ill themselves (diabetes), or had their own family to support, including young children who were suffering from illnesses such as asthma, eczema, and Crohn's disease, or simply lived too far away to be available.

Focusing on filial caregivers, Keith (1995: 183) adds the history of child-parent relationship, personality or health factors, and gender, to this list. Again there was evidence of all these factors in my study where excuses made for the lack of support from other family members varied. Some of those mentioned were siblings who denied that there was a problem or were reported to be too selfish to care. The following account given by a daughter caring for her mother illustrates the complex family relationships that may be present:

> There are four of us and I am the second eldest. There is a brother older than me who doesn't come near not because there is strife any more but because there has been strife [in the past] and he simply, he just... you know, he is there but we don't actually communicate an awful lot. But there is no negative feeling.... as such! I have a sister who is younger than me, who doesn't have children, is very much like mother in nature, is not a carer... except for herself! And I have a younger brother who has two children and a wife who is quite possessive and quite forceful. And he doesn't feel he has an awful lot of time to spare so I don't lean on him. Which means I am pretty much alone in doing this.

To summarise, there appear to be patterns in what is considered a valid reason for not providing care as opposed to unreasonable excuses. However, there could still be a certain degree of variation between families, based on the family's general history of relationships. Furthermore, in some instances care was provided despite the fact that the carer had a legitimate excuse, such as a full-time job. This demand on a particular family member was rationalised with the explanation that a close family member was always seen as preferable to a more distant family member. Likewise, any family member was seen in preference to someone unrelated to the person with dementia, and overall, female relatives were preferred to male relatives (Walker 1991: 98).

Overall, those situations seen as reasonable excuses included young or ill children, or the prospective carer's own failing health. In one case a sibling's difficult past relationship with the parent was cited as reason enough to avoid getting involved in the care. Another reason for not helping with the care of the person with dementia was geographical proximity. Several carers noted that their children or siblings were supportive but from a distance because they lived too far away to be of any practical use. Those situations not seen as reasonable seemed to cause a lot of bitterness. Usually in this scenario there was a child or sibling who refused to talk about the disease or was considered too selfish to care. Underlying all these reasons were normative beliefs about what was right and wrong (Qureshi & Walker 1989: 131), which became particularly clear in the group of spouse carers and will be discussed below.

Spouse carers

It has been noted that while the majority of carers do not really face a choice about whether or not they take on the commitment to care for a person with dementia, this applies most strongly to spouse carers (Oliver 1983: 73). Indeed, being a spouse of a person with a dementing illness makes it almost impossible to refuse taking on the caring role. My study showed that not only was the spouse expected to be the natural choice of carer, but it was also striking that none of the spouses felt they had a choice to begin with. For the spouse carers in the sample the role of carer was seen as an extension of their marriage:

> I married him for better or for worse, didn't I?
>
> You know, you do marry for better or for worse.
>
> If you love someone you want to look after them.

This attitude was expressed most strongly by older spouse carers but was also mentioned by the three younger wives in the study (aged between 57 and 66). Thus marriage was regarded as the 'supreme caring relationship' (Ungerson 1987: 51) with marriage vows being taken seriously and literally meaning 'in sickness and in health' and 'until death do us part' (Gilhooly 1986: 169).

Further, the spouse carers in the study remarked that they believed that their children should not have to care for their parents:

> I wouldn't want to involve them.
>
> Family-wise, ahm, my daughter always says, 'You know where I am, mum', but again you don't want to burden your kids, I mean, come on, you don't.
>
> You don't want to burden your kids.

> He's busy (son)...besides which I've got to be truthful with you...I really don't think it is right to call him out. I do if it is an emergency but I really don't think that while I'm here the children should be responsible for him (husband)... I just don't think it's right so while I'm able I'll look after Alan myself, so that's it.

The idea that children should not be involved with the care of a parent as long as there is a spouse (Murphy 1986: 62) seemed to have to do with a certain amount of pride and wanting to be in control and to be seen as being able to cope. In the study, female carers in particular did not want to be seen to accept help from their grown-up children and sometimes refused well-meant offers of support, whereas male carers, while equally reluctant to ask for help, were extremely grateful for all the help their children were willing to offer voluntarily. This phenomenon has been noted by Ungerson (1987: 59-60) who remarked that for husbands 'the obligation of gendered kinship will cross-cut and contradict the obligations of marriage'. In other words, male spouses were more likely to receive help from others, while wives may have been left without support for longer.

Several carers also felt that there were certain things about the care of a spouse which could not be discussed with their own children, because 'they are the children'. This applied in particular to issues of partnership and intimacy, and also to the more personal aspects of care given to the spouse with dementia, such as dealing with incontinence. Nevertheless adult children, or siblings, usually got involved when decisions about the care of the demented person had to be made, in particular when permanent care had to be considered:

> They're quite supportive from a distance, you know, I get lectures on what I should do, oh yeah.

Adult children caring for a parent

In the case of a child caring for a parent it was unclear why one child took on the caring role in particular if there were several other siblings who could have participated in the care. The study has shown that all adult children were primary carers who took sole responsibility for the care of their parent. This finding contradicts previous research studies. For instance Matthews and Rosner (1988: 185-9) expressed the view that if there is more than one adult child, filial responsibility is shared and everyone is involved to a certain extent in the care of the parent. The different degrees of involvement are termed routine, back-up, circumscribe, sporadic, and disassociation. However, two issues warrant clarification. The study by Matthews and Rosner does not appear to be dementia specific and therefore only partly applicable to the unique care situation in cases of dementia. Unlike other diseases, dementia creates a situation where extensive care has to be provided for a long period of time, often over several years. The temporary care needs of an older person who is, for example, recovering from an operation, is both quantitatively and qualitatively different. Furthermore, in the light of my findings on the demands of care it would not be satisfactory to talk about 'participation' if siblings provided sporadic or back-up support only.

A similar, but likewise flawed, model was proposed by Keith (1995: 180) who found in her analysis of filial caregiver systems that there is scope for two other options apart from the primary caregiver set-up. In the 'partnership' two adult children share the care equally, including everyday care and decision-making, while in the 'team' each adult child occupies a certain role and the care of the parent is structured around the latter. Again, Keith's study does not appear to be specific to dementia which suggests that although the three different set-ups do exist, they may be rare where adult children care for a parent with dementia.

There is, then, convincing evidence that there is typically one person who takes on the role of primary carer (Horowitz 1985: 200; Johnson & Catalano 1983: 612; Jones & Vetter 1984: 514; Baldwin & Twigg 1991: 120-1; Lewis & Meredith 1988: 6). Unlike Keith's suggestions that the medical profession has introduced the notion of the 'primary caregiver' to simplify procedures (Keith 1995: 188) it would appear that there is indeed almost always one person solely responsible for the older person with dementia. Moreover, this finding may be unique to the care of a person with dementia, with other diseases showing a higher level of participation from more than one family member (Keith 1995; Matthews & Rosner 1988). Further, once one person has been identified as main carer very little support was given from other family members, as will be seen below.

Informal support

A surprising finding of my research has been that the role as carer did not seem to be questioned despite the fact that there were others, usually siblings or the carer's own children, who could have been available to take over or at least participate in the care. This applied particularly to spouse carers who saw their caregiving as part of their marriage, as mentioned above. Adult children were more likely to explain how they came to care for their parent, but all of them accepted that they were the best person to care. This phenomenon has been observed before (Qureshi & Walker 1989: 132) and it has been commented that certain perceived norms mean that there is no explanation or justification necessary. Furthermore, once one person has been established as the main carer of a person with dementia and is recognised as such there is very little support available from other family members and friends (Johnson & Catalano 1983:612;

Gilhooly 1984a: 24; Finch 1989: 27; Allen et al 1992: 300). For instance, Gilhooly (1984b: 39) notes that in her study there was no evidence of a great amount of either practical or emotional support from relatives or friends.

This finding goes against the concept of social support networks developed by Wenger (1984). Wenger identified five different types of network (Chapter 2) which are influenced by factors such as 'the availability of local close kin', 'the level of involvement of family, friends and neighbours', and 'the level of interaction with the community and voluntary groups' (Scott & Wenger 1995: 164). There has been some indication that the notion of a social support network may not be without problems in relation to dementia care. To begin with, it has been acknowledged that dementia does present a unique situation. Carers of older people with dementia have the smallest networks of all carers (Nolan et al 1996: 10) and there is a lot of strain on this network (Scott & Wenger 1995: 159). Secondly, it has been noted that a *support* network is not necessarily the same as a *social* network (Nolan et al 1996: 8) and that the two should be distinguished to avoid confusion. Whereas carers of older people with dementia certainly have a social network of family and friends, it does not follow that actual support is given (Nolan et al 1996: 11). Finally, Ell (1996: 174; 178) has criticised the emphasis on the perceived benefits of social support as too simplistic. Rather than being 'static resource banks', families are a potential source of stress and conflict. This problem is particularly acute if long-term care is needed, as is often the case in dementia.

The small sample size does not allow me to dismiss the concept of social support networks. However, there appeared to be very little evidence of such networks in my research. The picture that emerged instead showed that the main carer often received some amount of help from other family members but rarely from people who were not related, such as neighbours and friends. This finding is consistent with Allan (1986: 1, 5) who noted that apart from it being a rare occurrence for friends to care, the basis of a friendship is undermined when long-term, unilateral care is required. In other words, whereas 'friends do care about one another and are concerned for each other's welfare this is not synonymous with providing practical care' (Allan 1986: 7). However, the research has shown that, in emergencies, there were neighbours and friends who were willing to provide short-term support. An example included a neighbour who contacted a daughter when her father had failed to open his curtains in the morning. Indeed, Fischer et al (1990: 134) found in their research of family-less older people that something like a safety network did exist when immediate help was needed in a crisis situation.

On a more permanent basis, however, the on-going help that was given to respondents by family members usually consisted of practical help such as shopping, house maintenance, and the provision of transport:

> He [son] was very good, when we moved into the house he and his friend put all the central heating in the house and rewired the house, so in practical terms he is very helpful. And, you know, if something goes wrong with the car he deals with the car for me. I mean, he does a lot of odd jobs for me, but he's never done anything physically for his dad.
>
> My son, ah, with regards to his dad's illness, he doesn't really want to know. He's very very good, with anything else, he'll do any job I want. He's built the wardrobes here, he's... He'll do anything I ask him to do job-wise. Him and his wife will come and they work ever so well together and they just get on with it and get the job done, and they're wonderful.

There has been no evidence of actual hands-on caring such as help with bathing, dressing and feeding, unless in emergencies. The reasons for this lack of support are difficult to understand but it appears that many carers are reluctant to accept help even from other family members. This reluctance may stem from the nature of family relationships. Finch (1989: 54) has noted that 'there are very few situations in which support from relatives is totally reliable in the sense that it would be given automatically, and without further thought, when need is identified'. Finch adds, and my research supports this view, that 'the real significance of reliability... is the reliability of knowing that there is something to fall back on, with family support acting as a safety net if really needed'. All carers in the study felt that those family members who did not actively contribute would provide practical assistance in emergencies or in a crisis. Furthermore, in those instances where one or more crises had taken place this security backup seemed to have been adequate in the short-term.

CARING FOR DEMENTIA

Although carers of older people with dementia face similar situations in their everyday care there are important differences between individual carers. It is necessary to realise that 'carers' are not a homogenous group (Allen et al 1992: 305) and that they experience their roles differently. In previous research, distinctions have often been made on the basis of gender, between women who care, men who care, carers unrelated to the person with dementia, and filial caregivers. However, to highlight the differences in how carers in my research experienced their caregiving situation it has been necessary to distinguish between three main groups based on their stage in the life course; adult children caring for a parent, older spouse carers, and younger spouse carers (Chapter 2). The following outlines the unique situation of each of these groups of carers and considers the attitudes and needs which arose out of these different care set-ups.

Adult children caring for a parent

Role changes were likely to take place when a child cared for a parent. One carer reported that she now had to have three different roles in relation to her mother. The first was the role of a husband in terms of taking responsibility and providing security. The second was the role of the daughter, in terms of being small and obedient:

> And what I frequently get is 'I'm the mother here!' You know, as if to say 'I'm the one that controls things'.

The third was the role of the 'mother's other self', in terms of being in control of situations and people. Another daughter reported that her mother saw up to five different persons in her, and that she, as a carer, learnt to respond appropriately to whatever character her mother thought she was. This included being shut out of the house because she was a 'stranger'.

Being a 'parent to your parent' was stressful for the carer in particular as there did not seem to be one clear cut role change between parent and child. As the examples above show there were several changes and the positions had to be re-negotiated constantly. One daughter said that she no longer knew how to talk to her father after he became demented:

> I try to talk to my Dad as my Dad but he can't see the logic.

Children often felt that they had a duty to look after their parent but found that they had to make many sacrifices:

> It's not because I resent it, although I do in a way.... It isn't because you don't want to care because you do and you want the very best for them... because I've given up three and a half years of my life and when I finish this I'm gonna be a funny sort of age for having any sort of life of my own.

In particular those children who had their own family to support found that a 'chunk' was taken out of their life (Chapter 5). In particular if the relationship to the parent had been difficult in the past, there was likely to be resentment. A daughter explained that her mother was now getting a lot more love and attention than she, the daughter, had ever received from her mother in the past, and that she felt this was unfair:

> I'm angry that all these things have happened... And the person who's been instigating all this is now demanding and getting the utmost care that anybody can possibly get... But

> she gets all that as a reward for very unloving behaviour and that to me doesn't seem fair.

It appears that adult children caring for a parent had to cope with a very complex situation and were faced with potential problems in their relationship with their parent, their siblings and their own families. How these issues influenced their coping ability will be discussed in Chapter 5.

Older spouse carers

A slightly different situation was found in the spousal relationship where the role change that took place had to do with traditional values being turned upside down. Husbands reported that initially they found it difficult to be faced with having to take over the housework and do things they had never thought about previously such as cooking and cleaning and doing the laundry. All of them appeared to have adapted very well although several noted that they missed their wife's cooking and more importantly baking. Similarly, several wives found it difficult to take over paying bills and maintenance work in the house. A wife said that she found this particularly stressful as she had never been involved with their finances:

> We reversed roles... I've got to do everything now.

On the other hand, another wife reported that to her own surprise she had enjoyed taking over and got a great sense of achievement and satisfaction out of being able to handle their finances.

More frequently mentioned were the lack of emotional support, lack of a partnership, of intimacy and affection:

> She's not the person I married.
>
> It's not my Harry in there any more.
>
> She was so outgoing, and used to drag me with her. She used to be so full of life... We had some happy times like. You see, all that's gone now.
>
> The marriage is over if you like, you know. Ahm, it's... it's not the same person that I married... Ahm, when I say the marriage is over it... we're not having, as you can understand, a normal married life, I mean, normally we would be out and about and all this, that and the other, and I mean it's... it's frustrating.

A loss of sexual intimacy was only expressed directly by two husbands caring for their wives.

> Sexually like, it affected her almost straight away. I mean, our sexual relations were very good like. Then suddenly one night she said ‘No, that’s dirty’, you know, ‘That’s dirty’. That were... That was the end of it, you know. So I mean, it were all part of that... part of that disease.
>
> I mean sometimes, even at 76 you have... not so much sex, you have a need for affection, you know, and that and I try, I say, you know, come on, lets go to bed with me tonight. No chance..

However, there have been other studies which confirmed that this had the potential to cause a problem in the relationship (Oliver 1983: 78; Gilleard 1984: 67; Archibald 1997: 217-21; Archibald & Baikie 1998). What was expressed strongly by the respondents in my sample was the lack of more general signs of affection on the part of the person with dementia. Several carers tried to make the best of the situation by showing their partner as much affection as he or she would tolerate. Usually the person with dementia did not instigate a hug or a kiss, but in some cases they appeared to enjoy it if their partner showed them affection.

> He’s still affectionate, ahm, he needs affection, he needs you to put your arm around him and you know, give him a cuddle and a kiss. You know, he does appreciate this so that’s one of the positive things really. What happens is you have to go and be the affectionate one, you have to go to them and give them a cuddle.
>
> She enjoys it like when I kiss her like, you know. You know, ‘Come on, give me a little kiss’ like, and I kiss her in the morning or even sometimes when I get her to table like, for a meal, ‘Come on, give me a cuddle’ and I put my arm around her like.

In several other cases, however, the person being cared for physically withdrew from the carer or stiffened up when approached for a cuddle.

> Sometimes, you know, I pick her up, I say ‘Come on, let me have a cuddle’ but she’s very rigid, her body is very rigid like.

Spouses seemed to find it difficult to understand what was happening to the person they had often known since childhood, and had been married to for up to 60 years. One wife said that she tried very hard to understand and wished she could 'look into his head' to see what he was thinking. A husband remarked that he believed that to a certain extent he knew how his wife felt because of the way he had felt after suffering a mild stroke several years ago.

It is clear that in all the cases where a spouse cared for a partner, the relationship was affected by the dementia. In how far this lack of intimacy and partnership influenced the carer's ability to cope will be discussed further in Chapter 5.

Younger spouse carers

A third group of carers, that of younger spouse carers, is of importance. Three wives in the study were aged between 57 and 66 at the time of the interview (with the latter being under 65 at the time of her husband's death). These carers faced problems which could be found in both of the other two groups of carers. For instance the loss of the partnership was as critical as for older spouse carers but the younger spouse carers additionally felt that they were losing out on their retirement. In common with this finding, Oxlad (1996: 226) found that younger wives seem to be the ones most to suffer.

In contrast, several of the older spouse carers in my research expressed the view that although the dementia was hard to bear they felt that they did not lose out on too much.

> We've had a good life, we're not bitter about this illness. You see, I've accepted it because we've done all we wanted to do.
>
> We had ten good years of retirement, and really, a lot of people aren't blessed with that.

Moreover, similar to adult children caring for a parent, younger spouse carers seemed to be more likely to worry about the future and future financial security. In all three cases, financial worries were paramount, in particular for one of the wives whose husband had been made redundant because of his illness.

An additional problem that seemed to concern this group of carers most was that the relatively early onset of the dementia was more likely to be dismissed by doctors as being caused by stress or depression (Cox 1997: 194). Two of the wives were told, respectively, that there was something wrong with the carer's marriage, or that the husband was illiterate (Chapter 6). It appears that, whereas most carers had problems in having the dementia recognised, younger spouse carers seemed to fare worst because early onset dementia is still rare.

Furthermore, as far as service provision was concerned, problems were uncovered in the use of day care and respite care (Cox 1997: 194). Both of these services were designed for older people with dementia and it was pointed out that younger people with dementia did not fit into these groups. Furthermore, the three wives in the study felt left out and isolated because most support groups catered for either spouse or child carers and that they did not really fit into either category, feeling ‘too young’ for the former and ‘too old’ for the latter (Chapter 7). Also, it appeared that, even in the literature available to carers, only a general distinction was made between the two main groups and that there was little information directly relevant to younger spouse carers who felt they had unique problems and worries.

Attitudes to care

The carer's attitude to care results from the differences in the caring relationship. Several things have been observed, for instance children caring for a parent tended to be better informed about the disease as well as about services. This was partly so because they were more likely to demand more information from professionals. Spouse carers appeared to be more reluctant to ask for information and were also more reluctant to accept help when it was offered. Several reasons were given for this behaviour. Older spouse carers in particular had never been encouraged to question professionals or to ask for help. Younger carers suggested that older people were also reluctant to accept what they considered to be 'charity'. In other words, there was a generational factor involved which gave younger carers, such as adult children, an added advantage in getting more information and more services because they did not hesitate to be critical. This finding will be discussed further in Chapters 6 and 7 in relation to formal support.

Furthermore, adult children were more aware of their limits, due to other demands on them such as full-time work or their own family, and thus were more likely to accept respite care and to consider permanent care for their parent (Gilhooly 1986: 167). Spouse carers, on the other hand, regarded permanent care as a very last resort which was often only considered if their own health broke down. Again this may be explained in terms of the different relationship between spouse carers as opposed to adult children looking for a parent. Some of the spouses in the study reported having been married for nearly 60 years and that they had not been parted once in all these years. Not surprisingly they found it unbearable to even consider respite care or permanent care because this was regarded as letting their partner down (Chapter 7).

Adult children, on the other hand, did not have such an intimate bond and often needed to think about the welfare of their own families. Several children caring for a parent were very clear about the stage when they would consider permanent care. In practical terms, incontinence was a development which was commonly felt to be beyond the capability and commitment of these carers. Surprisingly, however, those actually having to deal with incontinence did not find it to be such an obstacle. Both spouse carers as well as adult children reported that they gradually got used to the physical demands of caring. The following quotation is taken from an interview with a wife and shows how she gradually adjusted to the physical demands of caring for her husband:

> You get used to it, it grows on you [Laughter]. Well, it does, because you find yourself from doing small things to what I'm doing now, is having to er, ... dress him, undress, ahm, between us we manage washing and shaving, and I certainly have to shower him, he can't manage the shower, ahm, and you know, you gradually find you're doing more and more, and that's all acceptable really. And there's lots of things like that.

Other carers reported that incontinence was just one more adjustment in this process of increasingly demanding tasks.

For older spouse carers, the emotional level of the care relationship seemed more important as a factor in the decision to institutionalise their partner. Several mentioned the inability of the demented person to recognise the carer as the point where institutionalisation would be regarded as a possibility:

> As I say, I'll never let her go into a nursing home until it's absolutely necessary. When it comes to time when she doesn't know who I am or anything like that, then I might consider it.

Younger spouse carers again appeared to fall in between the two main groups. The following thought was expressed by one carer regarding full time nursing care for her husband and illustrates how the carer was torn between her marriage vows and the demands of the rest of the family:

> They [carer's children] said, enough is enough Mum, you've done this now for a long time and there's no point in going on until you crack up, what's going to happen then. That'd be two of you [Laughter]... I feel I owe it to them...

Finally, common in both spouse carers and adult children caring for a parent was the idea that they did not want their own children to look after them in their old age. Usually this took the form of verbally instructing their children not to look after them, and in a sense giving them permission to abstain from the caring responsibility. A daughter, only half-jokingly, proposed to take care of the situation herself and explained the reasons why she felt this way:

> I said to my son, I said, you know, 'I don't want you living near me, I don't want you feel responsible for me... when I get that I'm not gonna function properly I'm gonna take me car on top of a cliff, over top of the cliff, done it... Don't tell anybody else, it's gonna affect the insurance'...[Laughter]... He must think his mother's a madwoman. But I don't want him to feel he must look after me, no way. I mean, just do

> not want it. And I said it now when I'm of very strong mind, you know. Just don't wanna... I just don't want him to do it because I feel that strongly how destructive it can be, you know.

A number of carers were more specific about this and remarked that they had already made arrangements for the possibility that they may have to be looked after at some point in the future.

To conclude this section, it seems that not all carers faced the same difficulties in the care of the person with dementia. Some of these difficulties were based on different attitudes to care among spouse and adult child carers. In addition, younger spouse carers were in the unique position of sharing attributes of both groups, making the caring situation even more difficult for them. Carers of the two main groups had different needs, which may lead to different problems in the caring situation, and which require a very different response if the impact of caring is to be addressed.

EFFECTS OF CARING

There is clear evidence that carers of older people with dementia face some form of strain on different levels (Chapter 2). It has been recognised that providing care for a person with dementia can have negative effects on various aspects of a carer's life (Raveis 1990: 54). The main distinction that has been made is between the physical, emotional, social and financial strain a carer experiences (Biegel 1991: 7; Brody 1985: 22).

While it is difficult to assess the actual level of stress experienced by carers at any point in time, it is nevertheless useful to distinguish between what has been termed subjective and objective burden. Subjective burden refers to the emotional response of the carer to the caregiving situation (Morris & Morris 1993: 251), including the carer's general psychological well-being (Gilhooly 1984b). Included in this category is morale in general, and more specifically feelings of anxiety, depression, grief, anger, frustration, guilt and shame (Murphy 1986: 51-58; Jorm 1987: 16-17; Motenko 1989). Objective burden, on the other hand, refers to the practical nature of caring and the actual physical nursing tasks involved, such as bathing and feeding.

In all the cases in the study there was evidence of at least one crisis in the caring situation (Chapter 6), usually precipitated by a carer's physical and/or emotional breakdown. More often than not a crisis appeared to be due to the psychological strain felt. Many respondents reported that they found it hardest to cope with the emotional impact of caring:

> A lot of times it's not the physical problems that you're dealing with, it's the emotional trauma and the never knowing which symptoms you are gonna be having to deal with. And that's quite wearing.

Indeed, Wenger (1990a: 200) refers to a study conducted in the Netherlands which found that 'stress was more closely related to attitudes to care rather than the physical burden to care'.

However, in several cases it appeared to be the *physical* side of caring which was most likely to finally lead to institutionalisation of the person with dementia.:

> Despite of all the help that I've been able to have we are now looking at full-time care because he's... physically I can't cope any longer.... I mean he doesn't get out of bed, I have to get him up, and now it takes two of us to get him out of bed and into the bathroom and into the shower. You know, you can only go on doing that for so long and then it gets too much.

Therefore, the physical tasks in caring for a person with dementia may not be experienced by the carer as the most difficult side of caring. It can nevertheless be the main factor that leads to the person being admitted to full-time nursing care because this is a legitimate reason to give up caring and the point at which intervention is usually taking place (Chapter 6). The physical strain of caring can also contribute to the stress carers feel which in turn may worsen any existing physical symptoms. The carers' own view on this (Feedback sessions) was that the stress of caring had either produced their physical symptoms such as chest pain or else considerably worsened their conditions, such as arthritis and diabetes. Thus, these findings seemed to suggest that many carers could cope to a certain extent with the nursing tasks involved but that the latter could cause symptoms of stress. In other words, there was clear evidence that the 'subjective burden' of caring was more damaging to the carer's well-being than the 'objective burden' (Bibbings 1998: 173). Furthermore, as Jones and Vetter (1984: 513) concluded, the social impact of caring can be seen as a 'curtailment of [the carers'] social life [which] distressed them more than the actual tasks they had to perform'. The following briefly summarises the evidence for the different strains identified; physical, financial, emotional and social, and the importance given to these by the carers.

Physical strain

Generally, it has been noted (Chapter 2) that caring for a person with dementia is more difficult than caring for a person with physical rather than cognitive impairments (Gilhooly 1984a: 107; Gilleard 1984: 78). To begin with, carers reported symptoms of exhaustion due to the physical tasks involved in caring. For some the difficulty of providing nursing care was aggravated by shame or embarrassment, not for themselves but for the person with dementia. A wife expressed her uneasiness in the following words:

> The thing that I find the most difficult thing is all the toileting. And it's, you know, what it means to me, that's upsetting in a different way really. It's not that I can't do it, I can do it, I just feel it's so undignifying, you know, it must be...what I'd like to know is does he realise what I'm doing.

Fatigue and exhaustion, recurrent flu and colds, back and elbow problems, and arthritis were mentioned. All of these could be regarded as the direct effect of the physical strain of caring, such as bathing and feeding a person with dementia. The following powerful account was given by a daughter who cared for her mother:

> I do have a lot of problems, she actually... If I put her in the shower room and she stands there... I'm climbing up on the toilet seat, I'm climbing all over the place like a contortionist in trying to get the water round her and she won't budge... she stands and she stiffens up and she's solid as a rock. So you've got this huge woman in this little confined space - 'cause it's not meant to be a shower room, you know, and you're literally swinging off the ceiling and all sorts of things to try and rinse her off, yeah? She stands... I know they have bunions and stuff like that but she... she almost stands on the balls of her feet with the toes curled up, so she's very rocky. So you say to her open your legs a bit and stand squarely to get your balance. She can't do that, she must have her feet together, everything is... everything is, you know, confined and tied in kind of thing, so you try washing somebody that's standing like that, that won't budge. You can't get her under the shower and yet you can't get around her because she's like totally solid like a rock and immobile, it's really difficult. It's very... I do manage but it's very difficult and I come out of the shower and I'm absolutely drenched and I'm totally shattered. But then you have to forget all that because she has to get dry. She won't dry herself, although she hates being wet she won't dry herself. She wants every part of her body drying which is quite difficult... I mean it's poxy but then I think there's some bits she ought to be drying herself - it's a lifetimes' body so she knows where everything is, you know, and you could resent it but then you think, well, she's got to be dry, you know. So then she's got to be wrapped in a nice warm robe and then you've got to take her and dry her hair immediately otherwise she will scrub at it with her towel as if she's going to die of pneumonia if it is not instantly dry... so you must dry it and you must make her a cup of tea to settle her down because she is so agitated... And all the time you're dripping wet and absolutely shattered. And when that's all done which takes sort of, you know, half an hour then you can go and get changed and get dry yourself... It's quite tiring, you don't look forward to it. But that's the only other alternative to trying to wreck your back trying to get her out of the bath... if she insists on that technique of

> moving her feet forward and head... and I said 'Push your head forward, push your weight forward, you're not falling over if you push your head forward'... no way, no way. It's really really difficult.

Also, the person with dementia often showed a tendency to have sleep disturbances (Mace 1992: 223), which contributed to the exhaustion felt by carers:

> I think it's a bit like the Chinese water torture, it's the steady drip on your nervous system, you know, lack of sleep, it builds up, it builds up.
>
> We had very disturbed nights... You can't cope with it all day and all night.
>
> 'Cause you get so tired, it's the tiredness that floors you really.

Further, and more alarming, symptoms caused by the stress of caring have become evident, such as headaches, sweating, chest pain, shortness of breath, hypertension, early menopause (aged 36), and stress related impotence.

> I had to go to hospital because I got pains in me chest and they said, well, that's... that's... that is stress and nothing else.

It has been acknowledged that the psychological strain experienced by carers can manifest itself in actual physical symptoms such as headaches (Riordan 1990: 87) or more seriously in clinical conditions like the ones mentioned. Biegel et al (1991: 160-3) have referred to the carer as 'the hidden patient' and note that the link between stress and physical illness, in particularly respiratory disease, hypertension, and cardiovascular disease, has been well established.

In more general terms, a compromised immune function was found in carers of older people with dementia (Schulz 1990: 41). Possible evidence of this may be the finding that according to the carers in the study medical conditions such as diabetes, asthma, angina, strokes, bronchitis, and advanced prostrate cancer, which were present prior to the onset of the dementia in their relative, were thought to have become worse during the course of their caring.

Financial strain

The carers in the study were reluctant to talk about their financial situation (Chapter 3) but several hinted that they either struggled to make ends meet or were glad to be comfortably off. A wife noted that, in a way, she was glad that they had not saved but had used their money to go on holiday several times a year. She felt that if they had saved up for their retirement, her husband would not be able to make the most of it:

> I mean now, as things have turned out, I'm glad we didn't save for our old age 'cause if we had done what would have been the point? The situation that we're in...[...]... so it would have been a total waste of time but we enjoyed it while we were earning it and now, and I think back and I think thank God we did because otherwise David wouldn't get any enjoyment out of the money he earned over the years.

Several factors are thought to influence the financial circumstances of carers. Hancock and Jarvis (1994: 5-7) mention gender, residence, the type of care provided, and the amount of time spent caring. All but one carer in the study co-resided (or had co-resided prior to the demented person's death), and provided long-term, full-time care. They were therefore all in a similar position in terms of experiencing negative effects on their income. However, as far as gender was concerned, there was some indication that there were indeed differences in the carers' financial circumstances, with female spouses and daughters more likely to report their difficulties. Due to the small sample this finding is not generalisable. Other research studies, however, have acknowledged that women suffer more financially than men because they are more likely to become carers, and are more likely to be employed part-time (Hancock & Jarvis 1994: 6). As a result, female carers, in particular daughters who care, face lower pay and inadequate pension entitlements (Chapter 5 and 8).

In addition to the overall depressive effect of caring on a person's earnings, dementia care has been associated with extra costs such as transport, laundry, bedding, clothing, housing adaptations, and heating (Baldwin 1995: 129; Twigg & Atkin 1994: 42). With some of these extra costs, such as incontinence pads, one husband in the study obtained help from social services. Other costs, however, such as special food (replacement meals) or convenience food, or transport costs had to be met by the carer. Some carers were more fortunate than others in this respect and found that being able to pay for these extras made their life more tolerable:

> I use taxis a lot. I mean, we are very well off since we gave up the car, you see, and the thing is I use taxis a lot.
>
> But I tend to get, ahm, very lazily, prepared food from Marks, you know, pasta and things like that, microwave, so he doesn't have to be kept waiting.

For others, a lack of adequate funds meant that they had to budget very carefully. One carer in particular found it difficult to pay bills as his wife hid and lost money and he felt unable to stop her having access to her pension. Another carer reported that she did not know how to buy Christmas presents for her grandchildren because she did not feel she could spare the money.

Some carers had to go without things they would normally have been able to do. A daughter, for instance, noted that ideally she would want to pamper herself when her mother went into respite care but that this was impossible due her lack of resources:

> I don't actually have any means to actually say, right, I'm going to book into a hotel for a few days... I don't have that kind of money to do it with...

A number of carers experienced a sudden drop in income because they had to give up their jobs, such as the daughter quoted above who cared for her mother. Others experienced redundancy or had taken early retirement to care for the person with dementia:

> So money, you see, as well, we're both on pensions now, so the money is not there that used to be there.

However, the loss of employment had a further dimension than the financial one. Several carers spoke very fondly of the jobs they left behind. One of the younger spouse carers felt that she had missed out on enjoyment and a sense of satisfaction by having to retire early to care for her husband:

> I'm sixty. I was sixty [recently]. I'm retired but I always meant to work to 65 because I don't feel sixty, I don't feel I ought to retire, I don't feel I'm ready to retire...[...]... So I've always wanted to sort of carry... I love working, I mean I do like working, I'm a person who's always liked work, ahm, and you know I really would love to be able to... work, but I can't. I just can't any more, you see, that's the difficulty...[...]... I've always been a person that's enjoyed going to work, I do like working. I like the independence of working, I like meeting different people, you know, I would like to work but... obviously, I mean, if I hadn't got David to cope with now, I mean nobody is gonna employ me at this age anyway because they've got so many young people without jobs now, they're not going to take me on in any case.

Similarly, a husband felt that because he was forced to take early retirement his circle of friends had decreased dramatically:

> I used to have a lot of fun at work - oh, yes, I enjoyed work.

Thus it appears that losing their employment had more than financial consequences for carers, in that they were affected psychologically (Gilhooly 1986: 170; Baldwin 1995: 127). For adult children, this psychological dimension appeared to be strong enough to warrant their continued employment. Five out of seven adult children carried on working, despite the care demands they experienced, and referred to their jobs as their social life without which they felt they would not be able to cope (Chapter 5).

Furthermore, whereas older spouse carers worried about their present financial situation, younger carers were more concerned about their financial situation after the end of their caregiving:

> And it is so important to carers this kind of security because when you spend a length of time caring and you've no work and you've no savings of any sort, what do you do when you stop caring? When you...I mean, I will be 50 this year, so there is not an awful lot of earning potential left by the time I finished caring.

As this quotation of a daughter shows, younger carers were particularly worried about their future financial security, in terms of pensions, in their own old age (Baldwin 1995: 125; Bibbings 1998: 175-6; Ungerson 1998: 173; Hancock & Jarvis 1994: 5-7).

This situation was not alleviated by benefits, such as attendance allowance, which is designed to compensate for a carer's loss of earnings. However, few carers were aware of these benefits and their entitlements, and few claimed (Twigg & Atkin 1994: 42-3; 1991: 8; Bibbings 1998: 172; Baldwin 1995: 134). This issue will be discussed further in Chapters 7 and 8.

Psychological strain

The emotional responses to caring for a person with dementia varied but all carers reported feelings of anger, frustration, distress, and depression at some point of their caring relationship. Some of these emotional responses were due to the behavioural problems of the person with dementia. One example of very disturbing behaviour was related by a wife who found her husband's suspiciousness and accusations very distressing:

> And of course these personality changes carried on and on... oh, I was... now what was I... Oh, I was a slut, and been frigid all out married life according to him, but all of a sudden I was a slut and then a friend and I, again, a friend and I who'd been to school together, so she was my bridesmaid and I was hers, I mean, friends all these years and living close together, and then, all of a sudden we were a couple of lesbians, and that's why we'd been friends all those years and been friends the four of us, you know. My friend thought he was joking and of course... and of course she didn't realise he was serious, because she was laughing, 'Oh, David, big joke', you know, it was the type of joke David would make. But of course he was deadly serious and she couldn't believe it after all these years, but he was.

Another symptom of dementia that almost always caused distress in both carer and the person cared for was the tendency to suffer from hallucinations:

> You know, they [hallucinations] were getting very very bad... she didn't... she didn't really know who I was and various people used to be coming to stay and then they'd be in the bedroom and they'd climb out through the window and they'd climb up onto the roof to go home.
>
> And then the children would be... the babies would be asleep on the settee here, she tucked them up, you know, brought blankets down and tucked them up with a cushion or something like that... and she spent hours tucking the children up in their beds at night, you see. And I mean, this was getting very very wearing and it was distressing her as well.

Further, an all-pervading feeling was one of loneliness and hopelessness, affecting a carer's general morale:

> It was as if he just went into a world of his own.
>
> Happiness has gone.

However, while feeling lonely and isolated many carers at the same time experienced a lack of privacy which in some cases was very hard to tolerate:

> He's terribly restless. He follows me around, my shadow, that's what I call him... He's my shadow and I get very cross.
>
> I can't write a letter when he's here, I can't read when he's here unless he's asleep.
>
> At the moment she treads very heavily on my psychic space... I am not allowed to be anywhere in the house before she comes looking for me... 'Cause I can't even sit and think my own thoughts... she won't have it. This is what I mean by being on my psychic space.... I need to do this and I need to cut my toenails even, or whatever...
>
> He needs watching all the time, it's very difficult to go away from him for any length of time when he's in the house because you just don't know what he's doing.
>
> Well, it's very difficult because, ahm, I have to tell him every time I leave the room and he is sitting here, and I have to say, well, 'I'm going to take the washing out', 'I'm going to get the washing in', 'I'm going to the toilet', and well, 'I'm going to make the beds', or 'I'm going to get washed, I'm going to have a shower', or... I can't actually have a shower when he's about because, well, he's in the bathroom, he's wanting me, and there I am having a quick shower and he pulls the curtains aside, 'Oh, there you are, I wondered where you were', and of course I had only left

> him less than five minutes before, and then we get water all over the place.

Clinical depression was found in the sample in several cases and treated with anti-depressants.

> He drives me mad! He does, literally.
>
> I feel very sad all of the time.
>
> Things overpower me in my mind.
>
> I'm on anti-depressants at the moment, ahm, ...I went to the doctor...and I said 'I've had it up to here to me eyeballs', you know, and he said 'You're suffering from clinical depression', and that really put me through the floor, you know, but he said 'We can alter that' and he put me onto those anti-depressants.

Several other research studies have shown convincing evidence that there is an increase in the number of negative mental health outcomes such as depression and mental exhaustion among carers of older people with dementia (Raveis 1990: 54; Schulz 1990: 40; Cohen & Eisdorfer 1986: 199; Oxlad 1996; Morris & Morris 1993: 255; Jones & Vetter 1984: 513; Jorm 1987: 19; Gilleard (et al) 1984: 176; Brody 1985: 22; Biegel 1991: 153; Ell 1996: 175; Bibbings 1998: 173). This increased risk of negative mental health outcomes for carers as a result of the caregiving has been referred to as one of the 'hidden costs' of caring for a person with dementia at home (Jorm 1987: 19). In fact, it has been suggested that carers of older people with dementia show higher levels of depression than the normal population and that women tend to suffer more than men.

The majority of respondents reported periods of feeling tense and tearful, ranging from simply feeling sorry for the person with dementia to finding themselves on the verge of a nervous breakdown. It has been suggested that seeing a person deteriorate mentally may be the single most difficult thing the carer has to face (Riordan 1990: 86). Worst affected by this is thought to be a spouse living with a partner with dementia and witnessing the deterioration of a loved one (Murphy 1986: 52). A husband reflected on the change in his attitude to his wife:

> You've got to sit back and really think what you're doing and you're treating her as a patient rather than a wife. You know, it's not that I don't... It's not your wife any longer... it's not a partner any longer, and I think that a very hard thing to bear.

Several respondents likened the care of the person with dementia to that of a small child and one carer found she treated her husband like she would treat a sick animal:

> It's rather like a sick animal, okay, you do your best for them, make them comfortable. You just hope... He will never get better.

> 'Cause I sometimes have to scream that I can't get through to him and ahm, I do shout and he does jump to attention quickly then, you know, he realises that he's got to do as he's told. You know, look, I'm handling a man of 75 who is rather like a two or three year old. And my way is to treat him rather like a two or three year old child.

> Part of the time she's like a three year old, you know... she's like a helpless three year old.

> It's like looking after one of my grandchildren, it's like looking after a child.

Common to all carers, whether spouse carers or children caring for a parent, seemed to be a sense of guilt. Feelings of guilt may accompany or follow anger in particular if the carer felt that he or she should have coped better but did not know how to. Similarly, shame and embarrassment were common in particular if the person with dementia showed socially unacceptable behaviour in public (Murphy 1986: 57). Several carers recalled such incidents, which led to further isolation of the carer because he or she felt they could not take the person anywhere. This issues will be dealt with in more detail in the following section.

Social strain

The social impact of caring on the carer relates to the carer's own life as well as the effects the care situation has on family and friends. Brody (1985: 22) summarised the caring situation in the following words: 'The family is affected by interference with its life-style, privacy, socialisation, vacations, future plans, and income'. The impact on the family can have repercussions on the carer's situation, which then again affects the family. Many carers in the study reported a complete breakdown of the social life they enjoyed prior to the onset of the disease. Because of the demands of full-time care they no longer had the time or energy for friends and hobbies:

> I was very resentful at first, ahm, because my life has finished, ahm, my freedom has finished.

Spouses found that they could no longer pursue hobbies they used to do as a couple, such as dancing, because of the demented person's deterioration:

> We used to enjoy dancing, we had some lovely times like that, you know, and as I say, that's all gone now, you see.

In some cases the person with dementia became so withdrawn that he or she did not tolerate strangers, or even family members, in the house, or refused to talk to anyone but the carer.

Adult children caring for a parent found that they sacrificed 'a large chunk' of their lives. One daughter never married because her mother became confused while she was considering settling down with a partner and she found herself as the main carer instead. A divorced son who cared for his mother believed he had no chance to have a new relationship and to have a family because the care for his mother and a full time job took up all his time. Furthermore, adult children reported that they had given up hobbies, such as Italian lessons, and holidays abroad because of their care commitment.

One of the main problems of caring for a person with dementia has been mentioned as being the lack of social contact and the isolation felt:

> Something I've noticed, we never get any visitors now... It would be nice if somebody just once in a while would come and had a little talk, you know. That's the worst part, as I said, as much as I love Nora [wife] and everything, I get bored stiff. I mean you can't be watching television all the time, and eventually you get fed up with reading. I mean, you have nobody to have a conversation with.

Carers were often isolated from the family circle as well as from friends and neighbours. The carers noted that 'Nobody really understands' what dementia is and what it is like to care for someone with dementia:

> People just don't understand.
>
> As far as friends are concerned I think most of them are, ahm, don't understand it, they don't visit as much as I thought they would. Ahm, and as I say, whether it is that they don't understand or they're frightened of it or what it is. I've sort of given them open invitation to come anytime and spend an hour with us, but they don't.

Two processes seemed at work. One was that 'people gradually fade away' and 'don't know how to handle it'. One carer likened this to the experience of a death in the family, when the name of the sufferer or the condition the person suffered from is consciously not mentioned among family and friends. Similarly with dementia, according to this carer, people did not want to talk about it:

> But people just drift away when you sort of say Alan has got dementia, you know.

This stigma penetrated into a carer's social life. All the carers in the study reported that their friends 'gradually faded away' or withdrew from them when, due to the caring situation, they were no longer able to participate in activities such as dancing, tennis, or going to church. One carer was very bitter about this and reported that she now knew who her 'proper' friends were, namely those who still came to visit her and offered emotional support to her. Other carers remarked that their friends stayed in touch but only by telephone because they did not know how to approach the person with dementia. Generally people failed to understand what was happening and did not show sympathy:

> They don't realise what's wrong with her.
>
> I mean if he were to be here now, oh yes, he'd say hello and... you know. Ahm, and then when you're gone he'd say to me 'Who were that?' and if I told him he'd say, 'Oh, all right'. But tomorrow he wouldn't know you'd been. You know, and I would say 'That young woman who was here yesterday...' and he'd say 'What young woman?'. You know, see what I mean? And I'd say 'There was a young woman here when you came home'... 'Was there, I don't remember that'. You know, but that's how it is. So this is what people say, you know, they see him and say, 'He's not bad is he?'... See what I mean? 'So he's quite good, isn't he really'. So they have no idea. Because tomorrow he won't even know he's seen anyone, you know [Laughter] I mean it's as silly as that really... Oh, it is a strange thing this disease.

One carer felt upset that her friends withdrew from her when her husband had to be admitted into full time nursing care following a fall. According to the carer, her friends regarded this as her attempt to 'get rid of him' and accused her of giving up on his care.

The second process was the *carer's* withdrawal from the circle of family and friends, usually for the same reasons mentioned above. Carers felt disappointed with the reaction of friends or in some cases felt too ashamed of what was happening in their family. Some actively withdrew because they felt they did not want to bother others, including those people who had volunteered to help:

> Ahm, for one thing with the way Alan is at the moment I wouldn't want to put the responsibility on to them [friends]. I don't think it's fair because it can be difficult.
>
> I mean, I know they [Support group organisers] said that they would get someone to come and sit if you can't get [to the meeting] but I thought I don't really want them to strain their back and get someone. I'd rather cancel than sort of at this stage bring in a stranger.

One respondent felt that there was very little support available because of a lack of understanding of what was involved in caring for a person with dementia:

> You've got to understand to give emotional support and not many people understand it. They don't understand what the carer's role is. People make noises... and they say, 'Oh, it must be hard'. And it's very kind of them but you're left with a feeling of, unless you've done it you don't really know what it is... you've got to experience this emotional confusion and you've got to experience the physical effects of that confusion before you can actually begin to understand.

Another carer said that he was very disappointed that his local church made no effort to keep in touch with him. He stopped attending church with his wife after she shouted out 'Who's making all that bloody noise!':

> The vicar was giving this sermon, and she'd say 'Who the hell is making that bloody noise?'... 'Who's making all that bloody noise!'... quite loud!... You have to laugh at these things but it weren't half embarrassing at time. Well, the vicar, he must have heard her 'cause everybody else in church heard it.

The carer explained that this incident was very much out of character and very upsetting to him as she had never sworn in her entire married life. A daughter with nursing experience reflected on this not unusual behaviour of a person with dementia:

> We often had this on the ward and we used to find it amusing but you get... you get the most delightful little old ladies that were really genteel and spoke very well, you could tell... they'd come up with the most appalling language and you couldn't believe they'd ever heard things like that... And apparently, his [psychiatrist] explanation was that, er, if they, in their past life they'd actually been brought up to believe that, you know, it was wrong to swear and things, were more likely to do it as a result of dementia. Now, my Mum had always sworn, not badly, but she'd always sort of swear a little bit so actually her language didn't get any worse. It's quite interesting. But you get the most sweet little old ladies and they come up... I've never heard language like it!

In several cases where grown-up children seemed to withdraw from both the demented parent as well as the parent who cared, the carers explained that they thought this was due to the lack of information that was available. One reason why some sons and daughters did not want to talk about dementia was the possibility that there was a hereditary factor involved:

> But Simon [son] seems to want to bury his head in the sand about when the illness is concerned, right from the very start when there was a possibility that it was what it was going to

> be, the first thing he said was, 'It's hereditary, that, you know'. So you know why he's burying his head in the sand, don't you, he doesn't want to see that prospect, you know.

For those who withdrew completely it seemed possible, according to the carers, that a child was afraid of not being able to remember the parent as he or she had been, if they witnessed the deterioration:

> He [son] sort of said 'Oh, yes' and 'Oh, dear' and then we would go straight on to something else... and his problem was that he was afraid of not being able to remember what his dad used to be like.

As for neighbours, the majority of carers in the sample had little or no contact with their neighbours, even if they have lived in their present home for a long time. If there was contact it was limited to help in emergencies, in the form of transport or looking after the person with dementia for a short while. One daughter reported that while her father was still living on his own a neighbour had tried to contact her whenever her father failed to open his curtains in the morning. No respondents had neighbours who were actively involved in the care. One daughter said that she had no time for the neighbours because there had been problems at an earlier stage in her mother's illness:

> When I first went to look after her... she went round telling the neighbours I was taking her pension and spending it all; going out and buying clothes... And all I was doing was bringing my stuff in from where I used to live, but... to be honest I don't give a damn because I got pretty sick of it all and I thought, stop it, you don't need this, you know... I say 'Good Morning' in passing but I have no contact with them at all and that's the way I like it.

A wife explained that their neighbours did not know what was wrong with her husband and that she had no intention of telling them because 'they would not understand'.

It appears that there is a stigma attached to dementia, in the sense that many people still do not know what it is and label a person as 'mad' or even see the person's behaviour as a result of drinking. Gilhooly (1984a: 124) observed a similar pattern, noting that any existing relationship with neighbours was of a superficial nature and that it was 'the stigmatising nature of dementia [which] frequently reduced contact even more'.

Finally, many of the carers found that friends and family failed to recognise the problem while on a short visit. This experience was due to the demented person's ability to put up a front for short periods of time. One carer reported that several friends told her that her husband was normal, and that this made her very angry. Similarly, a daughter remarked that for a long time her siblings denied that there was a problem:

> There is a lot of denial about it. Ahm, they only go on what they want to see and because they don't see her very often... it's something they will see and go 'Oh, no, she's just awkward, that's all'.

CONCLUSION

This chapter has highlighted the situation of the carers in the study. It has become clear that there are complex processes at work in deciding who becomes the main carer for the person with dementia. Very little evidence of social support networks was found and once one person had been recognised as the main carer, there was very little support of both practical and emotional nature from relatives, neighbours, and friends.

Furthermore, it has been illustrated that there were different groups of carers, whose attitudes to care and experiences of caring for an older person with dementia were fundamentally different. Adult children caring for a parent, for instance, were concerned with the effects the caregiving had on their own social and professional life, whereas older spouse carers felt the changes to their marital relationship most strongly. Younger spouse carers shared attributes of these two groups but were often hindered further by the stigma attached to dementia. In other words, it is important to realise that carers are not a homogenous group and that they experience their caregiving in different ways.

Finally, this chapter presented the physical, financial, psychological, and social effects of caring on the carer. It has been argued that the effects of caring varied from one carer to another but that overall the subjective burden of care was experienced as more negative than the objective burden. Although carers found the physical care tasks demanding, it was expressed strongly that the emotional and social strain of caring was particularly hard to bear and that they obtained little, if any, support from the informal or formal sector in alleviating this situation.

There is evidence, therefore, that the caregiving situation isolates the carer due to the stigma attached to dementia. This worked in two ways. On the one hand, family, friends and neighbours sometimes drifted away as a result of a lack of knowledge and understanding, while on the other hand, the carer actively discouraged contact because he or she began to believe that others did not understand and did not want to know. Invariably carers found themselves in what has been described as a vicious circle (Riordan 1990: 89). The following chapter looks at how the carers in the study attempted to make sense of their situation and how they tried to cope with the care of the person with dementia.

CHAPTER 5: MAKING SENSE OF DEMENTIA

INTRODUCTION

The previous chapter has shown that there is usually one carer who is very much alone with the care of his or her relative, and that the subjective burden of caring can far outweigh the objective burden. Furthermore, it has become apparent that the effects of caring on the carer can vary greatly, with some worse affected than others by the physical, financial, psychological and social impact of caring. Nevertheless, despite these differences in individual responses to the caregiving situation, it was possible to find common features in the way carers attempted to make sense of their situation. This chapter looks in more detail at the coping responses of carers in the study.

To begin with a definition of coping will be given, outlining the different recognised ways of coping. Secondly, I will look at the personal and practical coping strategies employed by the carers in the study. This will include social and psychological resources available to the carers, as well as specific coping responses. Thirdly, the difference in coping ability between spouse carers and adult children who care will be highlighted. The final part of this chapter attempts to evaluate the identified ways in which carers try to make sense of dementia, including the stages carers go through on their way to acceptance.

PERSONAL COPING STRATEGIES

Coping has been defined as 'the things that people do to avoid being harmed by life-strains' (Pearlin & Schooler 1978: 2). Whereas generally speaking people cope with many different things every day of their life, there are specific events and situations that precipitate a certain coping response. Among others, such life strains as divorce, or the death of a loved one have been mentioned. In the context of Alzheimer's disease, however, the ability to cope takes on a new and more severe form. As Chapter 4 has established, caring for a person with dementia can have far-reaching and serious consequences for the carer's physical and mental health.

Of particular relevance for carers of persons with dementia is the fact that the period of time over which care is given cannot be anticipated (Chapter 2). In the study it covered anything from two to over 10 years. Schulz (1990: 35) has commented that 'all things may be endurable if the demands are finite'. This highlights the plight of carers of older persons with dementia who can find their coping abilities stretched to the limit.

Moreover, the demands of caring change constantly with the changes in the person's condition, so that any coping response that has been employed has to be replaced by a different response when the carer is faced with different problems. Research into the strain of caring has found that stress levels in carers peak half way through the disease (Chiriboga 1990: 136; Biegel & Blum 1990: 36). This finding is strongly associated with the severity and type of the symptoms which the person with dementia displays. Respondents in this study reported that, although in the later stages the physical demands of care were greater and more difficult for them to deal with, caring generally got easier as time went by because there was less resistance on the part of the person with dementia (Chapter 6).

There are a variety of coping mechanisms which have been described in the literature. The general consensus appears to be that carers have two main possibilities, one is to distance themselves from the problem and the other is to engage with the problem and attempt to deal with it. These have been referred to as distancing or enmeshing techniques (Johnson & Catalano 1983: 919). Developing this theme, 'problem focused coping', 'emotion focused coping', and 'social support coping' have been described (Hooker 1994: 387; Hinrichson 1994: 95). All these, and the significance of each, will be discussed in the next two parts of this chapter which addresses personal and practical coping strategies that have become apparent in the study.

Although most carers were faced with very similar situations there were important differences in the ability of carers to deal with any emerging problems. The explanations of some of these differences in coping ability can be found in an individual's personal life history and relationships. There are two main categories which will be highlighted in this section: social resources and psychological resources. To begin with the social resources to which a carer had access will be looked at in an attempt to show how different carers had different chances of coping from the outset. Based on this background of factors influencing coping ability is the analysis of psychological resources, those aspects of a carer's own personality which appeared to be of some importance in the way carers coped with the care of their relative.

Social Resources

According to the carers in the study family contact was very important but, as the previous chapter has shown, sadly deficient in terms of actual support. However, it appeared that those carers whose family and friends were understanding and supportive, even if only on a practical level, found it easier to adapt to the caring situation.

Past family conflicts (Silverman & Huelsman 1990: 177) on the other hand were found to be a factor that could negatively influence the ability to cope. This applied in particular if the relationship between carer and the person with dementia had been poor in the past:

> I have to say a lot of negative things about mother, right? She chose to rule by divide, which means that she wasn't happy when family members were united, she liked to set one off against another. That's the way of control and it happened a lot.

Further mentioned as a factor in a carer's ability to cope has been a carer's possible past caregiving experience (Silverman & Huelsman 1990: 178). Those seven carers who had taken on a caring role in the past found it easier to adapt to the present caring situation. This applied equally to those who had cared for a relative in the past and those who worked as carers:

> Within three weeks of me retiring my mother was taken ill into hospital, in and out of hospital for about a year, until that year [of retirement] about November time, and they said, well, 'We can't do anything else for her now, she will ... she will not see Christmas'. I remember that, 'She will not see Christmas', ahm, you know, 'Will you have her at home?'. Well, you know, I said, 'We can't possibly nurse her at home, you've got two nurses here to administer morphine.... we can't be trusted to do that on our own'. But they said we would be perfectly alright. Anyway, we made a little flatlet down here to bring her home, and she gradually got better and better and better. And we had her and we nursed her here...[...]... I mean we were stuck at home and we never went out for two years, not at all...[...]... I mean, my mother died in the third year, I retired in '81 and she died Christmas Day '84. So we had those three years out of our lives in a way.
>
> Well, because we... doing the job we were doing, dealing with retired people, of course we used to have people on our campus who had Alzheimer's, so I mean we have dealt with Alzheimer's, you see.

Some of these carers not only knew how to cope with caring, they often also came to their current caregiving with a good knowledge of dementia and of how to obtain help. How far this previous knowledge was advantageous for carers will become clear in Chapter 6.

Finally, there has been some indication in the study that the financial situation of carers influenced their ability to cope. Having sufficient resources could, for instance, relieving the stress of caregiving (Chapter 4), in the sense that carers could 'buy' comforts such as ready made meals, or taxis for transport.

Psychological Resources

As much as each person with dementia is unique, so are those people who care for them. Each carer responds differently to the caring situation and it appears that there are different thresholds in terms of what a person can cope with before finding it an intolerable strain. In other words, what some carers perceive as a problem may not be noticed by another carer (Blom & Duijnstee 1997: 251). Edwards (1994: 159, emphasis in original) noted that 'even when caregivers experience common behaviours among patients, they will not all perceive a problem. Where the behaviour *is* seen as a difficulty, all caregivers will not agree on its severity. What constitutes a burden to an individual caregiver, then, is a personal matter'.

Similarly, the carers' own personality appeared to influence the response to the caring situation (Hooker 1994: 386). Several carers reported that, although they tried, they could not remain calm and pleasant all the time but did lose their temper at times, feeling guilty in the process. It was however, as one carer remarked, a kind of safety valve for them:

> I mean, I can handle it my way, I've got to live and I have to handle it my way and I did tell my doctor... oh, he did tell the doctor that I shouted at him and he said, 'Well, did she shout at you before you were ill?', and he said, 'Yes'. So the doctor said 'You are used to it then, it obviously doesn't do you any harm' [Laughter] and the psychiatrist said to him, 'It doesn't do you any harm, does it?', and Alan said, 'No, but I don't like it'. He said 'Well, it's probably quite good for her so let her get on with it', sort of thing. [Pause] ...[...]... I don't know how else to handle it. I mean, a friend's husband was like it for eight years and she was the most calm and collected person, very well spoken, very polite voice. She did normally, you know, and that's how she coped with her husband, but you see, I can't do that, because I've never been like that.

On a more positive note, other more specific character traits, such as the ability to see the funny side in what the person with dementia did, helped greatly to cope with more serious problems. Humour was important to the majority (all but one!) of carers in the study. Some carers reported being able to make the person with dementia laugh either by laughing with them about something they did or said, or by acting in a funny way and pulling faces:

> [Regarding laughter] This is what's good for them.

> I mean yesterday she was quite good, quite reasonable - doing all the silly things of course [Laughter - Pause] I mean...[...]... you've got to laugh.

> She used to hide things... [Pause] Egg slicer! I found that in dressing table drawer...[Laughter]

Some carers were convinced that laughter, along with affection was what demented people needed most to stay content.

PRACTICAL COPING

A lot of practical advice on coping with the actual care of a person with dementia can be found in the literature, much of which was written by carers for carers. For instance Mace and Rabins (1992: 121-2) list the six Rs of behaviour management, consisting of guidelines on how to cope with problem behaviour. Other sources, such as Micklewood (1991), give a variety of tips on how to cope with everyday care, based on the author's own caring experience. Some carers in the study had had access to this literature but the majority had managed to devise their own strategies by trial and error, responding to each problem as it occurred. The following gives an overview of the findings of the study in relation to hands-on care, emotional coping, and helping the person with dementia.

Hands-on care

More practical help in coping with the actual care were for instance handrails (in some cases for the use of both cared for and carer) on staircases, landings, and in the bathroom. One carer resorted to having a 'child gate' at the bottom of the stairs to prevent her husband from wandering and possibly falling:

> He is much less sure of the stairs, he needs helping up and down the stairs. Except that I've got a child gate to stop him from going upstairs on his own. Or trying to stop him going upstairs [Laughter] I'm afraid I don't always succeed because I take the gate off to take something upstairs and by the time I've done that he's halfway up the stairs behind me.

One carer invested in an electric wheelchair to be able to take his wife on long walks in the country.

The kitchen was another problem area, in particular for carers of women with dementia who seemed to want to use the cooker at every possible opportunity:

> She's a fascination for the gas cooker... and I've had an... had an isolating tap put on that which puts a lot of onus on me, you know, er...you've got to remember to turn it off and remember to turn it back on because we... it's an automatic one and we put a meal on to cook whilst we're out the other day. When I came back in I could hear this clicking noise and I thought, oh no, I've turned the gas tap off... so the timer... the timer was just trying to start the whole time

> with there being no gas there... so, ahm, that put paid to that.

In a number of cases a lack of balance in the person with dementia became a profound problem early on in the disease and other means to cope with the care at home had to be found. Examples included a zimmer frame and specially adapted high armchairs. To help with washing and bathing several carers had a shower fitted or adapted, and complemented this by a shower stool or bath seat.

To make mealtimes easier a number of carers had bought a microwave which helped them save time in preparing and cooking food and made it easier to heat prepared meals. Five carers reported that they relied very much on convenience foods and ready made microwave meals.

Emotional coping

Some of the things carers mentioned as helpful in trying to cope with the caring situation and, as one carer put it, keep their sanity, were related to hobbies and leisure activities. For instance books and reading were mentioned, or an interest in alternative medicine, or cooking. Sports such as dancing and swimming helped carers to 'get out'. Going to the Pub, and on holidays when the person with dementia was in respite care, were also popular. Another carer enjoyed looking after a number of cats, and walked the neighbour's dog on a regular basis. Finally, one carer took solace in nature:

> Then again there are compensations because this week, Monday, Tuesday, Wednesday, the mornings have been beautiful, sunny, and there's been dew on the fields and dew on the garden and outside there on the patio... and there's nothing more beautiful, I love the autumn and, er, you know, that is compensation for being here.

Interestingly, four carers kept a very detailed 'diary of care', partly to come to terms with their experiences, partly to note subtle changes in the condition of the person for whom they cared, and partly to provide a 'guide' to the care they saw as appropriate in case something unexpected happened to them and someone else had to take over (Chapter 6).

All the carers in the study found that they tried to consciously take each day as it came because they had no way of knowing what would happen to them, as a carer, and the person being cared for. However, while the disease was so unpredictable, they were aware that the situation would not improve:

> But now I just learnt to live for each day, what can you do.

> I don't think about this, every morning you wake up and it's another day and you've got to get through that day. That's the future. Really, it could get you down I suppose, but there is no point in worrying too much because it's gonna be there, it's not going away.
>
> I think one tends to live from day to day, but I know the future is not going to get any better.
>
> We don't know what's coming, really is a good job we don't know what's coming 'cause what would we do. I don't think we'd cope if we knew what was coming. It's hard to cope when it hits but to know it's coming would be dreadful. You have to live for the day.

One carer gave an account of how he consciously had to try to remain calm in situations where he could not get through to his wife and could not get her to respond in what he deemed the appropriate manner:

> Ahm, I get tight-chested if I get a temper, get a little headache and I think, oh, I've got to calm down. Just occasionally I am so utterly frustrated because she can't do anything and won't do anything. I said to somebody, you know, you just call it dumb insolence because, you know she just won't take any notice. You're talking to her and she just wanders off. I mean, quite obviously she's switched off, completely switched off, you can say what you like, she's switched off, she just won't take any notice, she will do what she's gonna do. Absolutely frustrating, and you're wanting to go out, you see, and you come in here and she says, 'Mind that the kids are all out, you're not going to lock them all in, are you'... So getting her ready to get her out to the ambulance in the morning...this morning was quite frustrating again. She... she started with cereals, so I got them ready for her and then she stopped halfway through, 'I can't have these, I can't have these now', so I asked 'Why not?', 'I can't have any food', and I said 'Well, you're not going to the dentist, you're not going into hospital'... er, so I coaxed her to do that, then I got her tea and toast ready, and she wandered off upstairs, so I said, 'Come, your tea and toast is ready', so she came down, did something else, wandered off upstairs again, started to get her shoes on, and I said 'You haven't got your tights on yet', so I was halfway through my toast then. So I had to bend down and get her tights on, got those on, then she wanted her shoes on, straight out into the hall, hat and coat on. Meanwhile she had put a very thick cardigan on and she had the thickest coat on and I said, 'Look, you will be boiling by the time...' this was a quarter to 9, the ambulance doesn't normally come until a quarter to ten, so I tried to get her coat off. She went upstairs, messing about, doing anything but having a breakfast. Finally I just gave up and thought you aren't having any. So she went out without it. Not even a cup of tea this morning.

As the above quotation shows, the carer had learned to be tolerant of his wife's more erratic behaviour, which in turn enabled him to feel calmer in difficult situations.

Helping the person with dementia

Most of the carers in the study tried to help the person with dementia as much as possible and employed very individual and personal strategies. These included attaching large notes in the home such as 'TOILET' and 'YOU ARE HOME', or trying to remind the person with dementia to do certain things, such as eat while the carer was out. In some cases these notes appeared to be effective until the person with dementia lost the ability to read and understand them.

The majority of carers attempted to make the best of the person's remaining mental abilities and tried to keep them involved, occupied, and content. The extent to which this was achieved varied. One daughter reported that she was keeping her mother's 'whole' occupied at all times, employing what has become known as reality orientation as well as reminiscence therapy:

> I believe that there is a case - and we can't do it because it is too labour intensive- but there is a case that Alzheimer's or mentally deficient people of this type... can be helped if they could be in a situation where they were getting constant stimulation and that's what I do and that's why it's so very difficult because I'm there 24 hours a day with total responsibility. And it's very hard keeping your mother's whole occupied for that length of time... apart from when she is asleep. Because it's not a question of every hour doing something - it's every minute of every day where she actually expects me to be doing something with her.

A wife used distraction as a way to keep her husband content, which involved giving him a purpose to get up every day:

> He always has to have a purpose to get out of bed since he's had this dementia, there has to be a reason...[...]... So every day I have to do something, right? To Bakewell market... more in these last three or four months than I've ever been to... I have never been to Bakewell market before but I've been to Bakewell market regularly on a Monday because I can't find anything else to do [Laughter]... So Bakewell market it is on a Monday, very often... I mean yesterday he was going to have his hair cut so that was the reason to get up, today of course, it's the day centre, Wednesday's we always go in town, we pay the rent, you know, and anything else that needs doing. Thursday he goes to the day centre, and Friday, we always meet our daughter...[...]... So, you know, Saturday I always go to the hairdresser's and take David with me, Sunday, well, he just gets up because I don't [Laughter]. But he always has to have a reason to get up...

Other carers were more specific about the level at which they kept the person with dementia involved. More individual approaches included using the demented person's interest in literature, quiz programmes, and sport, to attract attention and occupy the person for short periods of time:

> And I mean I do the crossword in the Times every day, not the big one, the concise one, and it is a bit tough and sometimes I'm doing it before he goes out and I say to him 'What's so and so?'. Especially if it is to do with literature. And he will give me the answer! Because it's back in his memory, you see.
>
> I turn over to Countdown and that is a quiz programme, you see, and he's alright with that and I say to him 'What do you know of that?', you know, and things like that... Oh, and we've got Sky television so I zoom through all the programmes to find something 'cause he likes sport and er, I can very often find sport on... or quiz programmes otherwise.

There was only one case where the person with dementia decided that 'That's it' and refused to do any housework from then on, leaving her husband to take over completely, which very much puzzled him at the time. All other husbands reported that their wives had always been very house-proud and were difficult to keep out of the kitchen because they felt they should provide for the family. Several carers responded to this dilemma by finding little jobs in the kitchen for their wives to do. Although, as one carer put it, it frequently was 'a mess-up', the wives appreciated being involved in the preparation of food or in the washing up. However, one husband was less lucky and found it very difficult to deal with his wife who insisted on continuing to cook for him:

> 'Don't tell me', that's her saying, 'Don't tell me I haven't made you meals'... mostly I only had snacks on purpose so I don't put her under pressure 'cause she gets all worked up doing it... she gets worked up in her head, I can tell, you know... she will sit there and say, 'I don't know,' and when she brings it to me she'll say, 'I can't cook same now', and I always say, 'You can'... and then potatoes, sometimes they are... they're not proper cooked but I eat 'em and don't say anything because I know what's like to have your confidence destroyed and that, you know... I don't... I won't humiliate her like that, you know... and then... and then she goes on to me, you see, and this... sometimes, you know, I just can't eat it, they're just too hard and so I will throw them away and then she'll say 'I don't want to cook meal for you, you don't want it', and I say 'Yes, you're doing fine'...[...]... I try to, I say to her... 'I'll do the tea today', she'll say, 'No, aren't I capable?'

The carer commented that he felt fortunate he had not yet caught food poisoning as a result of poorly cooked food, but found it impossible to convince his wife that he could cook at least occasionally.

One example of a very individual coping response was provided by a husband whose wife used to get distressed about the fact that she did not have any money of her own:

> I mean, it's same as, she says 'I got no money', like, you know. So there's her handbag there, like, with her purse in, so I put her twenty pence in there, two ten pence. She's quite happy 'cause she's got some money, you see... It seems simple, little things but quite effective, you know.

The carer solved the situation by giving his wife a purse with two ten pence pieces in it, after which she ceased to be agitated and was quite happy to have her own money. A similar strategy was employed by a wife who managed to involve her husband in the gardening by doing something badly, either on purpose or because she had never done it before, which prompted him to join her.

Another often mentioned way of calming a person with dementia was by the use of music. It had been observed that even those who did not communicate any longer, could still hum or sing along to church hymns and enjoyed certain types of music, in particular classical music, in the home:

> Music seems to get through to him.
>
> One of the things we used to do, we'd play music. And when we were having a difficult day and she'd snapped and she as being difficult, ahm, I'd either...[...]... she still liked music and, ahm, on a Sunday night when we'd had a difficult day I used to put 'Songs of Praise' on and amazingly, because although both my parents went to church regularly as teenagers... really once they got married they never really bothered going to church... [...]... But she remembered the words of every hymn verse by verse.

Music was used by several other carers to calm the person with dementia. For instance one carer knew that if her mother was very agitated and restless it worked without fail to go for a short drive in the car and play her some music on the way. Previous research has shown that music had another significance in that it may aid the demented person's memory (Foster 1997: 6). Whether this element was involved in the situations reported by carers is not clear but the above quotations show that music appeared to make the person with dementia feel more secure.

Finally, several carers agreed that affection, if the person with dementia tolerated it, could make a difference (Chapter 4). Some carers reported that kisses and cuddles had helped to settle an agitated and restless person. This physical contact was thought to be important not only in marital relationships but also in instances where a son or daughter cared for a parent.

DIFFERENCES IN COPING BEHAVIOUR BETWEEN SPOUSES AND ADULT CHILDREN AS CARERS

Although each carer's coping response can be regarded as unique, a common pattern emerged for different groups of carers. The study has shown a difference between two broad groups, that of spouse carers and that of adult children caring for a parent. These two groups faced very different circumstances which influenced their coping responses. Previous research studies have confirmed that some carers struggle more than others. For example Raveis et al (1990: 57) noted that there are:

> indicators that the caregiving experience is different and less stressful for adult sons than daughters, husbands than wives... and there appear to be sex-linked differences in the types of caregiving tasks performed.

To investigate the full extent of the above finding, several issues are highlighted in this section which looks at the differences in coping behaviour between spouse carers and adult children caring for a parent.

Spouse carers

It appeared that spouse carers not only had a different attitude to the care of their relative, as discussed in the previous chapter, but also that their attitude and their caring relationship influenced their coping abilities. Wenger (1990a: 199, 210-11) noted that the care spouses give differs significantly in both its meaning and duration, and in the actual care itself. In other words, spouse carers appear to care for shorter periods of time but are more likely to provide more intimate care than adult children caring for a parent. Furthermore, the care spouses provide for their partner is based on the marital relationship and thus tends to become the focus of their lives.

Men versus women

Previous research has found that husbands seem to be less affected by the caring situation than wives and that the latter suffer more (Jorm 1987: 19; Gilhooly 1984a: 125). It has been suggested that this is so because male carers receive more support from other relatives and have more social contact because they are not as reluctant to go out and leave the demented spouse alone (Gilhooly 1984a: 125). On the other hand, research by Wilson (1995: 108) found that women keep their social life when they become carers, whereas men are more likely to find their social life reduced.

My research confirmed that, as far as clinical symptoms were concerned, female spouses appeared to suffer more: all those taking anti-depressants were wives who cared. However, on the whole, my research agrees with the findings of Wilson (1995), in that wives were the ones most likely to keep outside interests such as swimming and dancing, and were more likely to go on holiday on their own while the person with dementia was in respite care (Chapter 7).

> What do I do when he's in respite? Ahm, I usually go away for part of it. The last time I went to my son's [near London] on the first weekend...[...]... and the second weekend I went to my son in [near Sheffield] and was there for the weekend. When I say weekend, I went from Saturday to Tuesday to [London] and to [near Sheffield] I went from Friday to Monday. I find it helps me enormously.

Husbands, on the other hand, were more reluctant to leave their spouse in the care of others:

> Kate [daughter] said, 'Look dad, put her away in a home', she says, 'it's all she deserves how she's treating you now' and I said, 'But I can't 'cause she thinks still'...[...]... I said I couldn't do it...[...]... I don't think I'll be able to do it, such a softie really and that.

However, due to the small size of the sample in my study this finding is not necessarily generalisable.

Although there was no indication that men suffered the loss of the partnership less, it was apparent that the wives in the study were much more articulate on the loss they felt:

> I mean I have always been a very independent type of person but yet David's always been the strength in it for all, people sort of think, you know, seeing him and me, they always think, well, she's the boss in their house. Well, but I never was. You know, I was just sort of well, yeah, I suppose I am, but my friend used to say, 'Don't you, don't, who you're kidding', David would never let anyone boss him for starters, you know. Well, you know, that was... that's the way it was. And now of course, you know, you have to make all the decisions, 'Whatever you think love', you know, 'I don't know love', and he's [Sic] say, 'Whatever you think love, you know, you know better'. And you know, you haven't got that strength at the back of you, you know, you're the strength, you've got to be the strength for them. You have to be the strength for them, not the other way round, you know, whereas they have always been there wherever you turned, to lead it, and that's all gone.
>
> If anything went wrong and I needed a shoulder to cry on the shoulder was there. That I miss terribly, 'cause I've always had somebody to turn to when I needed

> it...[...]...He's always been there, he's always been the anchor, you know.

This finding has been confirmed in previous research studies and it has been noted that the older the couple the harder the loss of the partnership is felt by the carer (Gilhooly 1984a: 125). However, it should be noted that the length of a partnership is not equivalent to the quality of the partnership. This point will be discussed in detail below.

Another idea that has been expressed in previous research is that spouse carers do not feel the restriction on their social life, which the caring situation inevitably presents, as much as adult children caring for a parent. For example, Jones and Vetter (1984 514) noted that older people, due to their age, had a greatly reduced outside life and naturally enjoyed less social activities than younger carers.

My research has shown that this view lacks foundation and is rather ageist. All older respondents in the study had, prior to the disease, enjoyed a full and very active social life, including hobbies such as swimming every day of the week, walking in the Peak District, sequence dancing, and going on holidays several times a year. A number continued these activities despite now being in their 60s and 70s, trying to involve the demented spouse as much as possible. The oldest respondent in the study was a husband, aged 81 at the time of the interview, who took great pleasure in travel and also walked his neighbour's dog every day. It appears, therefore, that there is no conclusive evidence that husbands and wives were differently affected by the caring situation, and there was no evidence that older carers were less affected by the restrictions in their social life, as compared with adult children who care.

Children

There has been some evidence in the study that a carer's relationship to his or her children can change due to the demands of the caring situation. The following two cases illustrate firstly, how a wife felt guilty because she thought she was not giving enough attention to her own children and grandchildren, and secondly, how a child got emotionally involved without actually helping her father with the care of her mother.

In one interview a wife who cared for her husband commented that she had discussed with her children whether it was about time for her to find a nursing home place for her husband. The reason, it appeared, was not so much her inability to cope but her feelings of guilt towards her own children and grandchildren:

> Someone said this to me only the other day, don't forget you've got four children and six grandchildren and they need you as well. So, and you know, if you're sensible they are

> right, you know, you shouldn't run yourself into the ground when you don't have to.

The second example is taken from one particular interview in which it became apparent that the carer's daughter felt she had a great deal to contribute in terms of advice and telling her father what to do but that her advice was not practical - 'Kate said' was used by the carer repeatedly throughout the interview. In other words, the daughter interfered considerably, as the following quotations will show, but did nothing to help her father with the care of her mother. On the contrary, the daughter blamed her father for not coping better. One of the main issues the daughter got involved with was money:

> I mean she's [wife] got a little sum of money, about two thousand pounds in the [Building Society], she's lost that book now! I had it safe but she started shunting about with it and I felt guilty... Kate's given me hell about that, 'You silly devil, dad, look now what's happened!'.
>
> Kate and I... in her [wife's] absence and that, when she had been... we've searched from top to bottom, right from the attic right down to the cellar and we cannot find that money.
>
> I said 'We're gonna be using two lights', two... we haven't got [central heating] so we use two gas fires, and two televisions, two lights, those other lights we use, and then other things.. .and she won't... 'I don't care, I'll pay 'em'... so Kate said 'You will let her, she must have that money somewhere', she said, 'and if she's taking that attitude you let her pay them'...[...]...because gas bill come in and she paid thirty of it and I only paid twenty, you know. And Kate put it that way, 'You know, dad', she said, 'you ought not to do it because', she says, 'she must have it', she said, 'because she proves it because she finds it, doesn't she?'

Another topic which came up repeatedly was the daughter's opinion of her mother's behaviour in the past, and how she should therefore be treated in the present:

> Like me daughter says, is... she says, 'But you've always argued, haven't you dad, and you know that'. And she said 'That's been the trouble with our childhood', she says, 'we loved you, and I certainly couldn't have had a better father', she told me that, she said, 'but there was always arguing'.
>
> Our Kate said that last time she were round, 'You must be boiling' 'cause she [wife] talks to me as though she's talking to a dog.

And finally, the daughter appeared to not want to talk about the carer's own illness, and despite the demands the care of his wife made on him, she still used him as a babysitter:

> Sometimes I'm feeling down, what with me illness [prostate cancer] and all that, sometime I'm feeling down...and she [daughter] said to me, 'Dad, if I come and fetch you could you possibly look after the kids'...[...]... and I'll say yes, although I don't want to. I do 'cause I love kids so much....[...]... But I always say yes 'cause I wouldn't deny them kids anything because they'll think... we were talking one day about this and I said 'I don't know but I only have another two or three years, right'. She said 'Don't talk like that, I want you to watch these kids grow up'.

As these quotations show, the relationship a carer has with his or her own children can be complex and can either help or hinder the carer in coping.

Importance of grandchildren

To date there have been no conclusive findings on the role of grandchildren in the caring situation. The following section reflects on some interesting findings of my research and shows the importance of grandchildren to the carer, how children cope with a demented grandparent, and finally, how the person with dementia reacts to the presence of young grandchildren.

To begin with, all those carers whose children lived in or near Sheffield spoke with pride of their grandchildren and usually had a 'favourite' grandchild. All spouse carers in the study had grandchildren, with one carer having as many as 12 grandchildren who all lived in Sheffield. The following quotation shows clearly how important a grandchild can be for the carer as a source of pride and joy.

> The oldest is ten, oh, she's a darling...[...]... she comes on the phone and she'll... gay chatter and all that, you know and then she goes... right at the end she'll say 'Granddad I miss ya and I love ya'. Every time she says it! One thing I can always remember that got me about her was that she's always wanted to be a doctor. I hope she does... I ... that's partly because I gave up my gambling to save up enough money for them...[...]... Anyway, one day on television, we were all sat there watching telly when lawyers come on, about lawyers, and I said to Alice [granddaughter] I said, 'That's what you want to be, they get the money, lawyers'. So she said, 'Granddad, I'm not interested in money, I want to care for people'. And she were only seven then!

However, several carers expressed sorrow about the fact that their grandchildren lived too far away to visit frequently and that in many cases they were unable to travel due to the spouse's deterioration. Train journeys in particular proved problematic, as the following quotations of a husband and a wife with similar problems show:

> Er, but we used to go to our daughter at [Northern England] three or four times a year, maybe more sometimes when

> weather were nice, and we used to go on train so we went on same trains each time so I knew exactly the time of the train, where to get on, where to get off, it were no problem. But Margaret started saying, 'Are you sure this is right train? Are you positive?'... 'Of course it is, it's all right, it's right train, let's get on this train'. And we'd get on train and she'd ask other passengers, 'Is this train going to [Place name], is this train going to [Place name]'. 'Cause I used to get quite angry 'cause I didn't realise it was illness, you see.

> We usually visit him [son] but unfortunately last year when we went down it upset Alan a lot, the long train journey and all that, so they are coming up to visit. Usually we have one or two visits a year but Alan has got to that stage now where I don't really want to take him on a train, you know. Oh, when we came back from [South of England] that time we were stuck forty minutes in a tunnel just outside Sheffield and he really... well, just outside Derby actually, and he really got very panicky. And the train was late anyway and we came home very late and he just sort of deteriorated as it were from there. And when we went to the psychiatrist on the following Thursday I told him about it and he said 'Never attempt that again'.

One carer felt that this lack of contact meant that he did not really know the grandchildren who lived away from Sheffield:

> I mean, the other three... I could love them just the same... I do love them naturally, 'cause they're my grandchildren but I ain't seen them since Christmas Eve so... you don't get the... I mean if you see them every fortnight and you see all the little tricks and you watch them grow as they get older and older you get this affinity but if you only see them about every eight or nine months, you can't get that affinity.

Secondly, it has been observed that children can be surprisingly understanding and supportive. One carer recalled that she found it difficult to explain the disease to her grandson, aged 8. To her surprise, however, this 'favourite' grandson reacted with total sympathy despite his young age, and not only tolerated his grandfather's teasing but offered to 'look after granddad' so that his grandmother could do some housework. This finding is consistent with other research studies who found that especially young grandchildren can and do form close relationships with a person with dementia, especially while the dementia is not too advanced (Wilcock 1990: 124; Finch 1989: 41). How this finding has been utilised in formal care provision for a person with dementia will be discussed in Chapter 8.

Similarly, older grandchildren could be very understanding and supportive:

> I've always had a strong sense of humour and it's coming out in him [grandson] as well like. And everybody says he takes after his granddad for that. So when he chats to me like

> it's always with a bit of humour in it like, you know, we're never serious about... In fact, he rang me up last week.. and we were chatting away for about twenty minutes and I said to him 'Thank you for ringing' and he said 'Oh, that's alright, granddad' he says, 'it's always good to talk to somebody who's got a wicked sense of humour like me'... [Laughter]

Some grandchildren were even able to help with the care of the person with dementia in emergencies. A wife relied on her 16 year old grandson to assist her in emergencies when her husband fell in the shower:

> I mean, one night we were showering and he [husband] fell three times in the shower. Twice he fetched the curtain rails and curtains down and the third time he was totally on the floor and I had to get me grandson down and help me to get him up. I often do... you know, to get him up. He lives with me my grandson, so I often go to him and say 'Granddad is on the floor again, can you help me get him up' and he says, 'Oh dear, pass me the bathrobe, nan' [Laughter].

However, there has also been evidence that some grandchildren find it very difficult to cope with the change in behaviour in the person with dementia (Cohen & Eisdorfer 1986: 214; Gilhooly 1984a: 123). For some younger grandchildren more bizarre changes in behaviour can be frightening:

> Kids can't understand sometimes. I know their mother explained it all to them, both of them, but ... but as Alice [granddaughter] was saying, she'll say 'Hello grandma' and she'll not answer. Kate [daughter] said, 'Dad', she said, 'kids are not so anxious to come now', she said, 'it's not you, they still talk about their granddad, why doesn't granddad come here, but they're not so keen on seeing me mum, they either feel sorry for her or they can't understand', you know...

Finally, whereas the presence of grandchildren was always a positive experience for the carer, in some cases the demented person found their presence very hard to tolerate:

> Well, they used to visit us fairly regularly and stopped, but now we couldn't cope with them stopping any longer because it was upsetting Helen [wife] so much.

Similarly, one carer reported that her husband could not cope with the noise their twelve young grandchildren made, and another carer felt that his wife responded negatively to her grandchildren's presence out of jealousy, as she was no longer the focus of attention.

A very different problem was faced by another carer who could not see his grandchildren often because his wife was prone to chest infections and she had caught infections from her grandchildren on several occasions in the past:

> Nearly every time when they've come to stop, that was early on last year, Helen had finished up with a chest infection, so they said, you know, 'We will not come to stop again, and we will not come if any of the grandchildren have a cold'. So, er... they weren't able to visit very much last year, and it was the same at the beginning of this year as well, because either Helen was poorly or they were poorly, so we missed out.

Love and affection

It has been acknowledged that love and affection are one of the most effective factors influencing a carer's coping response in enabling him or her to keep going (Motenko 1989: 166, 171; Murphy 1986: 65; Cohen et al 1983: 446; Wenger 1990a: 201). For instance Wenger noted that a history of intimacy in a sound relationship almost always resulted in a positive attitude to caring (Wenger 1990a: 199). My study has confirmed this finding, with many carers speaking very fondly of their partner (Chapter 4), trying to remember what they used to be like, and trying to make the best of the current situation:

> Yeah, I do [miss the company], very much so. Er... personality changed in respect to affection, very much so I think. Just occasionally I get a spark now and again, sort of... she will respond to a bit of a hug or something like that. You have got to try and you know, try and keep at it, even that gets a bit difficult sometimes. I think on my part as well, you are struggling so long, you know, you tend to forget that they want a bit of a hug and affection and...

The feedback sessions further revealed that some carers felt it would be impossible for them to cope without love:

> You can do a lot in the name of love.

A husband remarked that the love he felt for his wife had changed due to her dementia. He now felt a different kind of tenderness for her which had not been present before.

However, nothing proves the importance of love and affection more than the following quotations from a husband who has had a very difficult relationship with his wife:

> In more ways it's been good, but it was definitely a dreadful mistake, two people definitely not meant for each other, to be honest, even though I loved her, in fact I think I still do to a certain extent but it just didn't work. Begin with, she's very cold, she's not demonstrating...[...]... I mean the

> whole point was if she was in the mood she could be very passionate and very nice to me but it wasn't all there... I bet that... I am not kidding you, I would never go with anyone else, I had opportunities but but I thought about her and the kids... I bet that kids that are twenty or twenty-one have more sexual experience than I have, you know... that's been the point of bitterness with me, you know, but I've got to say this for her, in every other way she's been good, she's always kept me clothes clean.
>
> I can't talk.. if I talk to her she snaps me head off. Yeah, always... she never speaks to me, she speaks to the kids and that but...

It appeared that while a good marital relationship can and does promote wellbeing and enables the carer to cope better, a not so sound relationship has the potential to do a lot of damage (Qureshi & Walker 1989: 22, 244; Allen et al 1992: 304).

Adult children

It has been noted in Chapter 4 that unlike spouse carers, younger carers face a different situation when they take on the care of a parent with a dementing illness. Adult children were more likely to feel that a 'chunk' was taken out of their lives, at a time when they were concentrating on their own families and their careers.

> I kind of feel as if I've got a piece chunked out of my life when really I should be settled and have time for me and ... feel right about things. And I'm actually feeling very not right because it's a lot of insecurities and uncertainties there.

The following section highlights several issues that were of importance to adult children in the study. I will look at the past relationship to the parent, the relationship to siblings, the carer's own marital relationship, and the carer's employment.

Past relationship to parent

To begin with, the past relationship to the parent can positively or negatively influence the carer's experience. Most notable is what has been referred to as a distortion of the 'previously existing balance of relationships' (Wenger 1990a: 199). A daughter in the study put her view into the following words:

> I've always thought that mothers should be very sort of warm and kind and nurturing and do the best for you... and it doesn't work that way.

It has been suggested that caring can have a negative impact on intergenerational relationships (Fischer 1985: 106), in the sense that roles have to be re-negotiated and that this can bring conflict into the caring situation. One daughter in the study spoke at length about the difficulties with her mother who tried to control her despite the fact that she, the mother, was the one who needed to be cared for:

> So she wants the control she had over me when I was small...[...]... It's like being a puppet on a string being pulled, you know, I mean I recognise what's happening but I still dance to that tune.

The carer found that this mother-daughter relationship affected her ability to cope, in the sense that she felt she had no choice but to care for her mother:

> ...even though I've been cast as the ogre I'm the one that gives her the most sympathy and understanding because I've actually worked through where she's coming from and although I accept and I'm told that it, that at the end of the day I am still giving up my life and it's still important that I do have a life and I know they're right but I still... because I can see where she's coming from and because I can see how it's evolved I still feel that she does need the sympathy and support and whatever... and that's the thing that keeps dragging me back, you know. And that's the thing why I can't really... er, fight back in a way that somebody less close would be able to because I'm still being the parent to my mother... I'm still trying to nurture the child that's within her, you know, and give her the love and support that I can see it needs.

In two cases, that of a separated daughter and of a divorced son, carers felt that the parent interfered to an unacceptable degree in the little social life they had managed to retain. The son who cared reported that his mother had gotten into the habit of throwing his socks and underpants away, and accused him of having affairs with his female friends. Similarly, the daughter was urged by her mother not to meet men:

> And every time and she comes back and she's gone to my sister's and she'll say 'Have you had anybody in?' and before she'll go she'll say, er... 'Don't have any men in while I'm gone'... And you think is this how she really functions, is this how she really feels... Obviously she's just very suspicious all the time but it's a negative... it's these things that you wouldn't dream of doing but she thinks that you might, you know... As I usually say to her 'Oh, mother, I'm gonna have fifty thousand men in', you know... Well, what can you say?... [Laughter - Pause]... So there are a few problems!

Relationship to siblings

As the previous chapter has shown, there is rarely a choice about who takes on the caring role (Lewis & Meredith 1988: 5) and usually one adult child takes full responsibility for the care of the parent. This could potentially cause resentment as the following quotations show:

> My sister is now noticing it and accepts that there is a problem. But prior to that I had a lot of flak because she thought I was being bossy, over-controlling... my sister thought, and my mother backed it up all the way along the line. 'Cause they only saw her for the few hours when she was a little-goody-two-shoes. And quite a nice little old lady.
>
> Nobody else in the family has sort of gone... they simply said 'Oh, you know, mother's out of it... but she was always odd anyway, wasn't she'; and then they walked away from it and that's it you see.

The daughter expressed he irritation about the fact that her siblings did not contribute to the care but still felt they could pass judgement on their mother's condition as well as the level and quality of care given.

Marital satisfaction

It has been noted that 'whether becoming a caregiver has a detrimental or beneficial effect on marital satisfaction is likely to depend on whether caregiving is viewed by the spouse as interfering with or complementing traditional family role performance' (Suitor & Pillemer 1994: 682). In my study, admittedly only giving a very small sample, there was no evidence of a negative effect of the caregiving on the carer's marital relationship. On the contrary, those sons and daughters who were married felt that their husbands and wives had been invaluable in providing emotional support. A daughter recalled that her husband was very supportive throughout the caregiving but that after her father had been taken into care he remarked 'In about a month's time I will have my wife back'. She explained that she was immensely grateful for his emotional support and felt that she would not have coped without him.

Previous research has shown that there are three factors which can influence a carer's marital satisfaction. These factors are a partner's emotional support, a partner's practical support, and a partner's hindrance in the caregiving. In a study focusing on daughters who care, Suitor and Pillemer (1994: 688) found that 'caregiving does not uniformly produce a decrease in marital satisfaction; when such decrease occurred, they were the result of the absence of husbands' emotional support and/or the presence of husbands' interference with the caregiving effort'. Moreover, it has been observed that when a carer is a son, his wife contributes significantly to the care of the parent. When however, the carer is a daughter, she is usually alone with the care of the parent (Gilhooly 1984a: 118-9). My study confirmed that married daughters who cared did not appear to receive active help from their partners. As for sons who cared, one of the sons was divorced, but the other son was indeed supported by his wife.

Employment

Interestingly, five of the seven adult children in the sample were in full-time work and reported that this was not solely due to the need to earn money (Chapter 4). Instead they saw work as their social life because it got them away from the caring situation:

> Coming to work was my social life really, for years.
>
> Work is the only thing where I can totally forget about him [father] 'cause I'm so busy.

This psychological dimension of employment has been acknowledged elsewhere (Gilhooly 1986: 170; Baldwin 1995: 127; Twigg & Atkin 1994: 43-4). In all these cases the carers tried to manage the care of their demented parent without having to give up their job because they felt they would not be able to cope without this form of 'social life'.

However, remaining in full-time employment meant that carers were faced with very complex care situations in terms of organising care for their parent. It also involved using their holidays or sick leave for their care needs rather than for themselves. A daughter noted that her employer had been very understanding and supportive when she had to take time off because of her mother:

> And I was lucky that they were very obliging in that as well.

Others were not so lucky and lived with the threat of redundancy. A son indicated that it was getting more and more difficult for him to combine his work with the increasing dependency of his mother and that this put him under pressure.

Additionally, it has been noted that full-time employment did not necessarily guarantee that the carer had sufficient funds. On the contrary, full-time employment usually necessitated outside help, such as private sitters, for which carers often had to pay (Baldwin 1995: 127). In other words, the greater the needs of the parent with dementia, the more likely it was for a working child to have to pay for the care needed in his or her absence.

The two daughters who had given up their jobs to care for their parent felt bitter about the lack of choice they had had in the matter. They also voiced concern about their future financial situation, in particular in terms of their employment prospects after care (Hancock & Jarvis 1994: 77; Twigg & Atkin 1994: 44) and their pension entitlements (Chapter 4).

MAKING SENSE OF DEMENTIA

What all carers had in common was their desire to make sense of their caring experience. This final section deals with the stages the carers went through, the need for appreciation, the rewards of caring, and the carers' thoughts about the death of the person they cared for and their own life after care.

Stages

It has become apparent in the study that carers went through stages in their attempt to come to terms with the situation in which they found themselves, and, in most cases, managed to accept that there was nothing they could do to change the inevitable deterioration of their relative. A useful stage model is the five stage model by Kübler-Ross (Kübler-Ross 1969). Originally devised to analyse the stages cancer patients go through in their acceptance of the disease, this model has been developed further to account for the emotional adjustment of carers of dementia patients (Gubrium 1987: 8). The five stages are those of denial, anger, bargaining, depression, and acceptance. One of the clearest accounts of the presence of these stages was given by a wife in the study. The first quotation indicates the presence of stages one and three - Denial and Bargaining:

> So of course they sort of said the blackouts and all the changes in him were all the diabetic hypes, you see, which I accepted and thought, thank God, it's only that and nothing worse... I was thinking Alzheimer's in the background and so I was glad, God, it's only diabetes, it's not Alzheimer's, you see.

This second quotation shows stages Two - Anger, Four - Depression, and finally the carer's current stage, Five - Acceptance:

> I mean sometimes you are frustrated and you think, 'Why us?', you know, and then you get really angry, you know, and you think well, uhh!, you know. And then you feel so sad, you know, so sad for him and the state he's in, you know, ahm, yeah, angry, frustrated. I mean when he first started with it there were a lot more emotions as well then I think because, you know, you really are in turmoil inside, really in turmoil, or at least I was. I mean I used to go out and when I saw a couple outside, maybe our age or older, I just used to cry in the middle of the street, I mean, you know, I used to think, stupid woman, pull yourself together, folks will be looking you up, you know, but I just couldn't stop. If anybody spoke to me I just flooded, you know. I've gotten over most of that now. Now I just sort of, you know, I suppose I have to accept the situation really, but it doesn't stop me from sometimes getting very angry still and blowing me top, which I do, ah, I blow me top with my grandson

> sometimes, he's the one that cops it, which is very unfortunate and he shouldn't really, but he does. Other times I just go in the bathroom and sob me heart out which I find is sort of... to get the release out... it's the only way out 'cause you gotta let go, you can't cope with it all the time. But I don't cry too much now, I seem to have settled a bit now.

Other carers reported similar feelings of anger, depression and acceptance, so that there appears to be evidence that carers go through similar stages in the course of their caregiving. However, it should also be noted that these stages were not rigid but that carers moved back and forth between the stages. The quotation above shows clearly that the carer had accepted the situation but still occasionally felt angry and depressed. The evidence of these stages could be used in providing appropriate emotional support for carers. For instance, the current forms of carer support groups are not suitable for carers in the first stage, but could be beneficial for stages two, three and four. Carers in the final stage are likely to stop attending meetings because they have moved beyond the initial need of talking about their situation (Twigg & Atkin 1994: 94). This group of carers may be more interested in advocacy, and could be used to educate carers as well as professionals, as will be discussed in more detail in Chapter 8.

Need for appreciation

It has been noted that there is a great need among carers for appreciation and for reassurance, or what has been referred to as 'positive reinforcement' (Lewis & Meredith 1988: 16). Indeed, the carers in the study appeared to have a strong need for some form of appreciation of their caring and the effort they made to give good care. What was striking was that in about a third of all interviews the carers used the phrase 'Without blowing my own trumpet...' or 'I don't wish to blow me own trumpet...' adding that they believed they were doing the best they could under the circumstances:

> I must admit though, blowing me own trumpet a wee bit, last year I was getting very very uptight and really cross, shouting a bit at her sometimes, but I'm getting more laid back now, so maybe she does something to me .... I won't let it get to me. So I'm more relaxed in that respect and perhaps since she's been going to the day centre I'm even more relaxed in that respect but I've taught meself to sort of calm down, you know, say nothing, let her get on with it sort of thing, you know, I'll sort it out eventually.

One carer repeatedly mentioned that when his wife had to be admitted to hospital for a physical complaint, one of the nurses praised him, saying 'You must be a saint', meaning that he had tried very hard to cope with his wife's difficult behaviour. Another carer proudly reported that when his wife was first assessed as suffering from dementia, the specialist gave him ‘less than a week’ but he managed to look after his wife at home for another year.

Unfortunately, there was very little evidence in the study that this need for reassurance and recognition was met. Glasser et al (1990: 330) have suggested that it should be the GP’s task to provide assurance and comfort to caregivers, and acknowledge that they are doing their best for the person with dementia. However, that GPs are rarely involved to this extent will be revealed in Chapter 6 and discussed further in Chapter 8.

Rewards of caring

Although many carers felt trapped in the caring situation most of them had retained a sense of humour and felt that there were rewards of caring (Chapter 2). For instance being successful in keeping the person with dementia calm and content were one of the priorities of carers, as the following quotation of a daughter demonstrates:

> There's some good times, I mean, I take her out to the park quite often at [Part of Sheffield] there's one called [Name] Park, I don't know if you know it, it's a wonderful place... real magic... trees... oh, it's a lovely place to be, if you haven't been you won't know, but it's one of the nicest places in Sheffield, it's my favourite place in Sheffield, you know, within the city boundaries. We go there and have a little stroll up and sit on a bench, have a little stroll back... does me no good at all except I see these wonderful trees... but to her, you know, it's good and she likes doing that and it's enough and she can sit and have a look and she can watch what people are doing, kids on the grass, and she can have a moan about people and all that kind of thing... and we have a cup of tea and she likes that because she likes food and drink and then we go back and she gets in the vehicle and then I bring her home and it's been no effort to her... she loves it.

Often these rewards were seemingly unimportant and consisted of small things which in the individual situation were a source of pride and satisfaction, a finding consistend with Nolan et al (1996). One husband 'remembered all the old songs and never forgot how to dance'. Another husband still hummed along to the hymns in church, while yet another was able to play the piano from memory until very late in the illness. One carer was proud of the remaining mental ability of her husband:

> I mean, you see, his long-term memory is so phenomenal. Marvellous. They have quizes over there [day care centre] and they have to stop Alan answering! Especially when it comes about films or things that have happened in the war. You know, I mean they are all... they have to stop him answering questions, or so I was told, he’s coming home so pleased, he’s been head of the quiz, you know.

Several carers took great pride in the way they coped well and provided the best possible care. This included trying to keep the person with dementia as healthy as possible. One daughter described at some length how she tried to ensure that her mother got healthy meals. This included 15 prunes in the morning to avoid constipation:

> I mean this sounds crazy... She has 15 prunes in a morning with a sachet of this bran stuff which I always take and these particular cereals which are oat bran, wheat and barley. 'Cause it's all... I'm a bit of a nutritionalist and it's all geared to be spot on for her. I mean this is why she's gonna live forever, you know [Laughter]. I've done it wrong, I've been too good [Laughter]... But you see, I know that 15 prunes plus two or three pieces of fruit a day will not give [me] problems with her over constipation.

Another carer, a wife, found that she enjoyed 'feeding and watering' her husband:

> There isn't anything I have coped with well, ahm, and thought, well, so I just put down on the paper 'Feeding and Watering' [Laughter]. Ahm, and then I went on to say that making meals for him is very satisfying because he enjoys whatever... he can't ask for anything, he can't choose what he has but obviously he enjoys what is put in front of him and so I feel that that's something I'm coping with.

In many cases the rewards of caring related back to the need for appreciation, in particular from the person they cared for:

> I can make her laugh.
>
> She never complains to me.

A husband reported that his wife would frequently look out of the window and remark 'You've got a lovely garden' and that he would then answer 'Yes, it's your garden as well'. The carer felt pleased that not only did he find the time to look after the garden (something she had done in the past), but that his wife actually noticed his efforts.

Another husband recalled that on several occasions he, his children and his grandchildren had laughed *with* his demented wife about something she said and did:

> I tell you something very funny. About a month ago we were at our daughter's and we were watching a video of a Western and during night time you know, a chap was approaching this shack. Chap comes out and shouts 'Who's there, who is it?' Nora [wife] said 'Father Christmas!' [Laughter] And apparently as far as we knew she were asleep, you see. So occasionally something comes out, like, you know... it made us laugh like.

At other times he would point something out to his wife, 'Look, that's funny', and laugh out loud, upon which she would frequently join in. The carer doubted his wife understood the joke but enjoyed hearing her chuckle.

Several carers were pleased that the person with dementia did not lose his or her manners:

> He treats most of us the same, he treats... ahm, he's pleasant, he's not... he's not violent in any way, which is one of the worst parts of Alzheimer's, isn't it. It can be very aggressive.

One carer reported that his wife told him 'Thank you for being so good to me' and that now despite being unable to communicate still said 'please' and 'thank you'.

> When she tries to talk or anything like that, I mean, it's gobbledegook. But occasionally something really sensible comes out, like, you know. I mean, we were sat here one day like... I sit here holding her hand, and then one night she said to me 'Thank you for being so good to me'. You know, I mean, normally she can't, she can't put two words together.
>
> She still says 'Please' and 'Thank you', you know. I mean, if I say 'Do you want some of this?', she'll say 'Yes, please', if you give her something 'Thank you'. You know, that's still there even though, you know... She's still retained her manners.

Similarly, a wife was proud to report that her husband was a 'perfect gentleman - it never left him'.

Life after care

Among those carers who were still caring at the time of the interview there were many fears and worries about the future. It appeared that the carers in the study had mixed feelings about the demented person's death. In particular spouse carers wished for a sudden and painless death for their partner. The following quotation is from a wife whose husband suffered from multi-infarct dementia:

> Strokes are just something that happens to certain people and not to others, don't know why or anything. So I mean these little strokes just keep happening and he could have a massive one and it could take him today. Ahm, it could carry on with these little strokes and it gradually makes him a total cabbage. I mean, I just wish he had a big one if that is the case. I wish he could have a big one and it did take him. I mean, no way would he want to live like that, live a life like that, he would hate it.

On the one hand they felt relieved that they would then be able to rebuilt their own lives, but on the other hand they expressed concern about how to cope with the experience of seeing their relative deteriorate and die:

> And I'm waiting in one respect for mother to go, for then I can sort meself out... mourn for my parents, and get it all over and done with. But it's... it's not gonna be able to be done while I am in this trap with my mother.
>
> I may be a bit gloomy on this but I can see he will gradually slip further and further until he gets to this stage where I know some patients are, when they don't recognise anybody anymore, yeah, I mean I could see that coming, but it may be years in the future, but that I think can be the progression of the illness and then you get this incontinence with it as well, and that is the time when I think euthanasia would be best. I do, because I don't think... I mean, you wouldn't let an animal suffer.

For themselves, the carers found there were many concerns about their life after care. The following statement by a daughter identifies some of the these concerns, namely financial worries, emotional healing, and future prospects in terms of personal relationships:

> Because my concerns when I think about it are what do I do in the future, how do I support myself, how do I heal this big hole in my middle, which is always there... [Pause]... what chance have I got of forming relationships if I continue to care...

Another major aspect mentioned by respondents was the uncertainty about the possible length of care they had yet to master. A daughter and a wife expressed the following concerns about the future:

> You rather feel as if you're just emptying out and there's nothing to replace it and you wonder how long you can go on and how drained you can get before you crack up really...[...]...It's three and a half years now... she could be here in six years time and I don't know that I will be...[...]...she's never had anything wrong with her, so yes, she could definitely go on and be 90 but I wouldn't be here... I couldn't ... I daren't even think about it because it's too horrific... the fact is I would... if she got to be ninety something I would then be sixty something and I mean... I would be a dead person, I'd be walking about but I'd be dead, know what I mean?... Couldn't cope with that. I've got to think maybe two or three years perhaps and we'll just see but I daren't think past that point because I might as well close down now. If I was to think I was to have another ten years of this or another sixteen years I wouldn't want to go on, I'd get so depressed, you know, I'd just have to close down.

> If I look to the future Alan has two sisters alive, one is now [early nineties] next month, the other one is [nearly ninety]. Alan is 75, I'm 75. Now, I can see me for the next twenty years, now that's when I get depressed, that is my future. Twenty years, if I live that long. Well, my mother lived to the age of [mid-nineties], her mother lived to [mid-nineties] and my mother's father lived to [mid-nineties]. Alan always used to say you are from a long line of battle axes, you will outlive me. He always used to say that, you know, in the old days, you know, talking about living and dying, 'Ah, she comes from a long line of battle axes' [Laughter] But you see, that was part of this depression earlier this year.

As mentioned previously most carers tried to live for each day but some issues could not be ignored. For younger carers the financial aspect of caring seemed the greatest, in particular if they had given up their job to look after a parent. For husbands and wives who cared the fear of illness and their own health deteriorating seemed more of a concern.

CONCLUSION

This chapter has shown that although most carers of older people with dementia face similar problems at some point in their caregiving, there are important differences which have to be considered in understanding why some carers appear to cope well while others struggle and need help. To begin with, I have looked at the personal resources, both on the social and psychological level, which can influence a person's ability to cope. Secondly, an overview of practical coping strategies has been given, highlighting specific coping responses identified in the study. Thirdly, the differences in coping behaviour between adult children and spouse carers have been discussed. It has become apparent that, due to their intimate relationship, and resulting lack of emotional distance, spouse carers are more likely to continue caring until their own health breaks down. This group of carers could therefore be regarded as more vulnerable than the group of adult children. The implications of these findings will be discussed in more detail in Chapter 8.

Finally, I have looked at the way carers in the study attempted to make sense of their caring experience. Specific stages were identified which carers went through on their way to accept the situation they found themselves in. Also, it was noted that the carers had a great need for reassurance, but that this need was not met. Again, the implications of these findings for developing adequate support for carers will be discussed further in Chapter 8.

To conclude, it has become apparent that, generally speaking, 'the greater the scope and variety of the individual's coping repertoire, the more protection coping affords'

(Pearlin 1978: 18). Further, one of the main problems in the care of a person with dementia seems to be that carers need to constantly reassess the coping strategies they employ because the condition of the person cared for changes over time (Hooker 1994: 391). Finally, it is vital to remember that carers trying to cope with the care of a person with dementia do not exist in a vacuum. Pearlin and Schooler (1978: 18) comment that

> ...much of our coping functions only to help us endure that which we cannot avoid. Such coping at best provides but a thin cushion to absorb the impact of imperfect social organization. Coping failures, therefore, do not necessarily reflect the shortcomings of individuals; in a real sense they may represent the failure of social systems in which the individuals are enmeshed.

This view will be discussed in more detail in the next two chapters which focus on the interface between formal and informal care.

CHAPTER 6: THE DIAGNOSIS OF DEMENTIA

INTRODUCTION

As the previous two chapters have shown, carers of older people with dementia face many different problems, and not all carers find they can cope with the demands of everyday care. All carers have different social, psychological, and material resources, so that every carer faces a unique set of circumstances. Nevertheless, one of the things that carers have in common is their desire to make sense of their caring experience.

With this background of complex relationships, values and beliefs, and individual efforts to cope with the care of the person with dementia, the majority of carers come into contact with health and social services. This chapter looks at the process of diagnosing the dementia. It has been found in previous research that the point of diagnosis is critical for the subsequent caring experience (Fortinsky & Hathaway 1990: 606). The more information a carer obtains at this point, the more likely it is for a carer to adapt to the caregiving situation and experience less psychological, social, physical, and possibly even financial burden. Unfortuately, the process of diagnosing dementia is neither uniform nor smooth. Although there are genuine clinical difficulties in recognising dementia, as already discussed in Chapter 2, it has nevertheless been criticised that medical professionals do not seem to understand the need for open communication with carers. Failure to prepare carers for what they may have to expect in the later stages of the disease has been linked to the inablity of carers to cope with the caring situation (Taraborrelli 1993: 185). It is therefore essential to examine the process of diagnosing dementia in more detail. This chapter illustrates the experiences of carers in the study and reflects on the role different professionals played in obtaining a diagnosis of dementia. Secondly, this chapter will look at the way information about the disease is given to the carer and how this process may have influenced the caregiving experience.

DIAGNOSING DEMENTIA

It has been noted in Chapter 2 that diagnosing dementia is rather difficult due to the number of different possible causes. The study has shown that in addition to the difficulty of diagnosing dementia with accuracy there seemed to be problems with the management of a diagnosis and of an appropriate response. The following section analyses the experience of those carers in the study who had obtained a formal diagnosis. Two daughters caring for their mothers had not gone through the formal channels and had self-diagnosed the dementia, based on their own knowledge and previous experience.

Crisis

All carers in the sample had cared for a period of up to several years before the dementia was recognised and appropriate action was taken.

> I had four years, battling alone.

This long period of time between the perceived onset of the first symptoms and the carer's first request for help has been commented upon in previous research (Haley et al 1992: 222; Hagberg 1997: 19). It has also become apparent that many carers only sought help when a crisis took place which forced the carer to approach their GP, or relatives, for support. In other words, in the majority of cases formal care was arranged as the very last resort (Qureshi & Walker 1989: 5). Indeed, the study showed that for all interviewees some form of crisis, or several crises, took place before an assessment was made and before any form of help was given. This applied to formal care provision as much as to informal help and this pattern was followed even in those cases where the carer had previously actively asked for help. Crises included physical or mental breakdown of either carer or the person being cared for (Twigg & Atkin 1994: 22). On the informal side, carers reported that some relatives finally accepted that there was a problem when they had to care for the demented person for a short period of time due to the hospitalisation of the carer. A wife caring for her husband was pleased to report that such a crisis had brought one of her sons closer: he had not previously wanted to either talk about the disease or visit his father. However, this acceptance did not necessarily lead to more practical help for the carer beyond the acute crisis situation (Chapter 4).

Regarding formal care the situation was little better. A wife recalled her mental anguish which, after a year and a half, led her to ask for help for herself rather than for the demented person:

> I don't know, I think I was told the braincells were dying off, you see, and it would make him gradually worse. Ahm, and then I complained actually after 18 months I think, two years, 18 months, I went to the doctor, that was it, because I was getting a bit distraught and overawed so I went down and said, 'Look, I need a tranquilliser or something'. So the doctor I saw ahm, said to me, 'You need a lot more help...' and so he said 'I think we better get you some more help'.

The carers reported heart attacks, strokes, pneumonia, severe asthma attacks, and injuries following falls or accidents which hospitalised either carer or the person being cared for. However, even in the latter situations the dementia was not always recognised, as the following quotation illustrates:

> She got a very bad attack of asthma which went on to pneumonia which put her into hospital. And I said to the... ahm, surgeon there, 'Be very very careful what she tells you because she will probably tell you just the reverse from what she... what she means', you see. And I said, ahm, 'I am sure there's something wrong because she can't... she can't knit now, she's stopped baking, she's stopped sewing and er, she doesn't seem to be able to concentrate on anything like that now'. So he said, 'Well, we will do an examination while she's in'. So they did a brain scan and then they said, 'Well, we can't find anything'. And I thought, oh, this is not right at all.

Two wives had the unfortunate experience of seeing their husbands turn aggressive before the dementia was diagnosed and any help was given. Both case were upsetting for the carer, with the more serious incident putting the carer into hospital with broken ribs:

> And all these things were happening, you know, ever so strange, and ahm, then he had a hold of me one day and I thought he was going to hit me but he didn't as it happens but I really thought he was going to and it really frightened me. And, ahm, and then two years [ago]... he did hit me. He broke me ribs, really set about me and went absolutely berserk and as I say he broke my ribs...[...]... we had a court case against him and everything because the police was called and all that.

In both cases the wives had repeatedly asked their doctors for advice because they noticed a change in personality, but they were not taken seriously. Without a doubt the experience of these two carers got them off to a bad start in their caregiving and both expressed their disappointment with the medical profession. It is conceivable that the delay in having a dementia recognised may influence the caring experience of carers, as will be seen in this and the following chapter. A daughter who had worked as a nurse commented that in her experience 'social services is crisis management' and she believed that with better management crises could and should be prevented. It has indeed been recognised that crisis intervention appears to be the main aim of social service departments, along with 'short-term support and, in cases of severe breakdown, long-term residential care' (Qureshi & Walker 1989: 25). The implications of this system for carers and the person with dementia will be discussed further in Chapters 7 and 8.

Assessment and diagnosis

The study showed a problem with the initial diagnosis of dementia and the carers reported a huge difference in efficiency between different hospitals, and different professionals in these hospitals. One of the initial problems had to do with a lack of knowledge about dementia among General Practitioners, a finding which has already been well documented in the literature (see for example Lewis & Meredith 1988: 13-14; Fortinsky & Hathaway 1990: 607-8; Buller & Buller 1987: 379; Sturges 1997: 124). Other problems encountered by carers concerned a lack of communication among professionals and between professionals and carers, leading to mis-diagnoses and misunderstandings. The most common misunderstanding was based on wrong expectations on both sides. Carers needed assurance and advice, whereas professionals often did not regard this as their task, and concentrated on the medical problem instead (Twigg & Atkin 1994: 65-71). This difference between the social and medical model of care will be discussed further in Chapter 8.

General Practitioners

The majority of the carers declared that their GP either 'didn't know' or 'didn't care' about dementia:

> He doesn't know nothing.
>
> All GPs are the same. They don't know.
>
> But as I say, the doctors are reluctant to say or do anything.

In some cases the GP had been treating the person with dementia for years for physical complaints without picking up on the problem of confusion, despite the repeated questions of the carer who clearly felt that something was wrong.

Those carers who did not share the same GP as the person with dementia encountered most problems. Carers were generally aware of issues of confidentiality and accepted that GPs could not give detailed information on the person with dementia. However, what was criticised was that the demented person's GP was often unwilling to listen to the carer's concerns. The following quotation shows how a husband alerted his wife's doctor to the confusion he observed, but felt he was not only not taken seriously but that the doctor had lied to him:

> And actually I told her [wife's] doctor but he didn't seem to be doing anything with her and said give her these tablets and she's alright and away you go, which is a lie. You get that from a lot of doctors these days, thank Goodness he isn't mine.

However, even in those situations where the carer and the person with dementia shared the same GP conflicts arose due to the changing relationship between doctor and patient. Glasser et al (1990: 331-3) have noted that dementia necessitates a shift from a dyadic to a triadic relationship. In effect, a doctor-patient relationship now becomes a doctor-patient-carer relationship and there is a real danger of ignoring the demented person's views and ideas. Examples from the study included consultations with the GP where the carer's concerns were dismissed or, at the other extreme, the person with dementia was on purpose excluded from a consultation. The latter, in itself, could be seen as an ethical dilemma.

Previous research has suggested that GPs were more likely to give detailed information to patients they had known for longer periods of time (Buller & Buller 1987: 379). However, it appeared that this study was not specific to dementia and my research found that familiarity with the GP may not aid the process of diagnosis. On the contrary, the findings seemed to suggest that a person's dementia was more likely to be noticed by a GP whom the carer had not previously consulted, rather than a GP who had treated the person with dementia for years. The following quotation illustrates how a wife found that her husband's GP would not accept that there was a problem:

> I mean, he said, 'When I first saw your husband', which like is two years ago now really, he said, 'reasonably fit bloke for a chap of that age', I mean then he was 63 coming up 64, he said 'reasonably fit chap for a man of that age actually'. Didn't know what all the fuss was about. Really had no idea what all the fuss was about!

It may therefore show that dementia does indeed present a unique situation in the primary care setting (Glasser et al 1990: 322). As a result of this and similar scenarios several carers had changed GPs, often more than once, to find a more approachable one. This process of gravitating towards a more sympathetic doctor has been observed in previous studies (Haley et al 1992: 224-5).

A number of carers claimed that their old GP was no help at all but that the latter had now retired and the new, young, GP was 'ever so good'.

> Now, her [wife] doctor was already retired so 'cause she had to go about three miles to the surgery I was always on to her. Anyway, she changed her mind and is now here with [same surgery]... 'cause mine is a darling.

Again, the study by Buller and Buller (1987: 378) contradicted this and found that whereas the age of a GP seemed to be a problem, it was in fact younger GPs who were less trusted by patients while older GPs were respected due to their experience and status. However, Buller and Buller granted that age 'does not guarantee greater understanding of medical information'. Indeed, my study has shown that as far as information on dementia is concerned younger GPs were much more aware of the symptoms of dementia, the available diagnostic tools, and the possible formal care provisions. In fact, in particular among older GPs, a lack of knowledge was identified, which led to delays in diagnosis, mis-diagnosis or no diagnosis, and in most cases to a late referral to a specialist.

> And so of course the next thing was to see our doctor and ahm, he thought like I had that it was stress and probably, you know, on the verge of a nervous breakdown, ahm, and so we went to see him and told him what had happened, and he just said...[...]... He said come and see me again in a month's time.

Milne (1998: 13) notes several reasons for the reluctance of doctors to diagnose dementia, including 'a fear of negative outcomes such as misdiagnosis, user and carer distress and a lack of treatment options'.

It has been shown that, in several cases where a GP diagnosed the presence of dementia, no further action was taken in the belief that 'little or nothing [could] be done'(Cohen & Eisdorfer 1986: 59). A wife in the study reported that her GP suspected dementia but refused to refer her on to a specialist for a more detailed diagnosis. The reason for this, it appeared, was the GP's conviction that a specialist would not be able to tell her more than he could. This assumption was not only wrong but potentially harmful to the carer and her demented husband. Firstly, there was the possibility of a treatable medical condition, such as diabetes, being present. Secondly, the carer was also not put in touch with any services a specialist may have found appropriate to this particular case. This failure of GPs to refer carers on to secondary services, and the possible consequences for carers, will be discussed in more detail in Chapter 8.

Similarly serious was the lack of sympathy many carers experienced. Previous research on communication styles identified that many GPs did not handle the situation very well and appeared unable to give the carer and the person being cared for any meaningful information (McAuley et al 1990: 208). Accordingly, several carers in my study recalled how upset they were by their GPs' attitude to them and their situation.

It has been suggested that doctors are by no means objective in their medical assessment. For instance, Hill (1996: 121) noted that 'doctors mix their expertise with judgements which may be influenced by their gender, their race and their social class'. Another factors is age. It has been observed in previous research that GPs were less likely to talk at length to older patients (Cook et al 1990: 302). Furthermore, in cases of suspected dementia, an additional factor that may influence a GP's attitude has been found to be the diagnosis itself. Iliffe (1997a: 21; 1997b: 68) has noted that such a diagnosis, and the knowledge that little can be done, may have an emotional impact on the GP and lead to a denial of the condition.

In one such instance where the above-mentioned value judgements may have been relevant, a wife turned to her doctor for help when her husband became aggressive and was told 'It's your marriage! Go and sort it out'. Yet another carer felt that his doctor overestimated his ability to cope, leaving the carer feeling misunderstood and unhappy:

> I can't.... I just can't... er, I cope but... I mean my doctor and er, other people, say I'm coping well.

It is conceivable that these problems were accentuated because the carer and the person with dementia did not share the same doctor. Both examples suggest that the carer's doctor was not aware of the full extent of the situation and dismissed any emerging problems as unfounded or non-existent.

It was interesting, though, that most carers' current assessment of their GP was very good. In other words, once the dementia was diagnosed, the GP appeared to have 'caught on' and often made sure that the *carer* received regular check-ups and was kept in relatively good health.

> ...'cause mine is a darling, she listens to me, she lets me ramble on and always gives me things...
>
> She [GP] rang up, she said, a little while ago she said, when we were leaving, I want to see you on your own in the next fortnight, that was before we got the results back from [hospital] and I thought, oh dear, she's got some bad news back, you see, and ahm, she said, it wasn't that actually, she said, all the results are good that are back so far, and she said I want to talk to you, she said it's time we started thinking about respite care and she questioned me on how I was coping.

A rather striking finding was that all those GPs who were considered by the carers as very good were female. It seemed that female GPs seemed to be better informed, more understanding, and more helpful:

> So as I said, Dr [Name], she's been really wonderful but the men doctors like, who were normally quite good like, you know, it seemed as if they weren't really interested like, you know. Whether it's because there's no cure or because they don't understand it a lot, I don't know.

Unfortunately, this issue has not been examined in previous research studies and the sample in this study was too small to say whether this was coincidence or of statistical significance.

The findings of the study have suggested that, overall, those carers whose GP was helpful from the start and acted on the first minor crisis seemed to have adjusted quicker and better to the caring situation than those who experienced one or more major crises before help and a recognition of the dementia was given. Those whose GP was helpful had a greater understanding of the disease and of what to expect. Others who were less fortunate with their GPs found that they had to fight all the way for an assessment of the dementia and for help:

> You have to fight them [doctors] as well in the early stages.

One carer put it very vividly:

> You're desperate, you're in need, you're in a hole...[...]... You're so far down in the trench that to claw your way out is very difficult.

In defence of GPs, however, a retired GP pointed out recently (Alzheimer's Disease Society; Annual General Meeting and Symposium 'Caring for the other Dementias'; 12 - 14 September 1997; University of Warwick) that the training received by GPs, in particular older GPs, was inadequate to cope with the many different forms of dementia. He suggested that it was much easier for a GP to get his or her diagnosis wrong, as specialists only saw patients where a suspected diagnosis was already given.

As valid as this defence may be, the research has shown that it was not so much the obvious lack of knowledge but the GP's attitude that created most problems. It has been noted in previous research that what patients expect from their GP is a high level of information, answers to their questions, being allowed to participate in decision-making, and generally being listened to (Cook et al 1990: 302). Carers also found that it was vital for their situation as caregivers for a GP to respond quickly to a possible diagnosis of dementia. There was a consensus among carers in the three feedback sessions that GPs were divided into four groups. The first group consisted of those GPs who had the knowledge, the right communication skills to inform the carer, and were willing to do their best to help the carer. Only one carer in the study was fortunate enough to encounter such a GP. The second group of GPs was perceived to be helpful. A husband pointed out that his GP did not have much knowledge about dementia but attempted to obtain more information for himself and subsequently for the carer. Similarly, a son explained that his GP was 'not clued up on the illness' but was nevertheless very good. It was agreed in the session that it was not important for the

GP to know everything but that it was very much appreciated if a GP was honest enough to acknowledge his or her lack of expertise in relation to dementia and offered to get more information. The third group consisted of those GPs who appeared to have the knowledge but felt unable to communicate effectively with the carer. One carer in the study voiced his anger about a GP who had been patronising, in that he remained vague until confronted by the carer. The reason, it emerged, was due to the GP's reluctance to give the carer such a depressing diagnosis. The fourth group of GPs was aptly termed a 'stumbling block' by one carer. These GPs were described as not interested, unaware of dementia, and unwilling to be of any assistance to the carer. Furthermore, previous research has shown that some doctors would rather give inaccurate information than confess their ignorance of the issues involved (Cohen & Eisdorfer 1986: 66). This phenomenon has been linked to GP training which promotes self-confidence (Twigg & Atkin 1994: 66). This sometimes leads to dangerous value judgements, as mentioned above. In dementia care, too much confidence was potentially damaging to the carer as well as the person with dementia because urgent help was not given. This point is further discussed in Chapter 8 in relation to the GP's role as gatekeeper to secondary services.

It seems, then, that in many cases there was a problem with the initial diagnosis by GPs and their subsequent referral, which was frustrating for the carer, because it led to delays in obtaining much needed help. There was strong evidence, therefore, that a lack of knowledge about dementia and appropriate services existed among professionals and potentially had serious consequences both for the carer and the person being cared for. However, it has also been shown that a lack of knowledge was less of a problem to carers than a GP's lack of interest and understanding, inability to communicate, and unwillingness to obtain information for the carer.

Specialists

Unlike GPs, the majority of the specialists whom the carers encountered were very helpful and tried to explain very briefly what the problem was. They also attempted to put the carer in touch with the right service providers if they felt there was an urgent need for support:

> But it wasn't until we saw the people at [hospital] earlier this year and they said we will send the CPN to visit you. Ahm, the one that was allocated to us actually was away on a course that particular week so the manageress [hospital] came to see us and she was very good albeit a bit forceful. She said 'Are you getting attendance allowance?', we said 'No', so she said 'You should be, I'll come back tomorrow and bring you the forms, you fill them in and I'll send them off for you'. You know, she pushed me into that. And she

> gave me a lot of other information as well. You know, all sorts of things, 'Do you want any help around the house?', and I said 'No', because as I explained, I have got the time.

Unfortunately the specialists' attempts were not always successful. One carer remarked that the consultant dealing with his case wrote a letter to his GP detailing the type of help required for the carer to cope at home. Unfortunately this advice was not followed up by the GP because the latter deemed some forms of help, for instance help with bathing, unnecessary.

Several carers found it very difficult to deal with the lack of continuity in who they saw. One carer reflected on having seen several psychiatrists about her husband's personality changes and depression:

> You know, we had a very good chappy [psychiatrist] and then his job was axed, and it's happened twice, then we had another one and then his job was axed and he had to go somewhere else, so next time we're going in November we're going to see another one. It doesn't help Alan, I mean okay, as far as I'm concerned he doesn't see the point between this now and the other two.

Although she imagined her husband would not notice the constant change of professionals she herself was nevertheless not very happy since she had found the initial psychiatrist to be very friendly and sympathetic. Two issues are important in this case. To begin with, it has been shown that dementia patients do in fact react badly to change, so that there is a possibility that the carer's husband may have been disturbed. Secondly, the carer had developed good rapport with the first professional she saw. It was suggested in a feedback session that a carer's needs may be better understood if the same professional is seen over a longer period of time and is familiar with the case history.

There was some criticism of specialists and their handling of the actual assessment. One carer experienced what he referred to as 'a specialist playing his waiting game':

> Well, she [General Practitioner] booked us down to see the specialist at the [Name of hospital], she says he's the best man to go to. And we got a letter back saying that they hadn't any ... ahm...slots in their ... ahm, not the programme, I can't remember what they called it now.. in the schedule, but they'd write to us, give us four weeks notice of when we got in. And it went on and on and on until it got to October and we still heard nothing and I said this can't go any longer because she... she's definitely getting worse, you can see this all the time gradually going down the hill and she.... I'd try and get her in to see the [Name of second hospital] specialist there. Eventually we got both appointments [one for general talk and referral, one for

> clinical assessment] within a week of each other. You know, [Name of second hospital] gave her an appointment within a month, and the other people... all they were doing... they were actually very naughty, they were doctoring the waiting list. By not putting us on the waiting list they've got a short waiting list, which is very naughty. And... I went to the doctor and complained about this and she said, 'Yes, I know', she says, 'and all the other doctors at the practice know but there's nothing we can do about this'. So... eventually it was... it turned Christmas before she managed to get on to have a proper brain scan and they said then, 'Yes, it's multi-infarct dementia', which is many... many strokes... and, ahm, so we saw the specialist psychic [Sic] and he just said, 'Well, that's what you got. Take her a quarter of an aspirin a day and off you go'... end of story, as blunt as that. I mean Helen [wife] was terribly upset about that, and I was terribly upset, but I mean I knew what was wrong.

The observed practice of having 'waiting lists for waiting lists' has been criticised elsewhere (Caldock 1995b: 3). The carer quoted above came to the conclusion that it seemed to be a matter of luck whether a person with a suspected dementia was assessed at a hospital within a reasonably short period of time. Clearly, he felt that several months was too long to wait to be told that there was nothing anyone could do. However, a number of other carers did not get as far as having an assessment at a hospital. In some cases, funding seemed to have played a part in whether the person with dementia was assessed properly. It appeared that brain scans were only done rarely because they were too expensive.

Five carers had not received any kind of diagnosis because no proper assessment had been made. One carer reported that her mother was assessed by a community nurse for 10 minutes and that, as her mother was in a very good mental state that particular morning, the dementia was underestimated. Four other carers had the same experience that there was no proper assessment and that a diagnosis was based on a short home visit. A husband recalled the short assessments his wife had had:

> Not been anything like that [brain scans]. As I say, our own doctor, she simply asked her some words and then she was asking some questions like, 'Count back from ten', you know. I mean, then this Dr [Name of consultant] when he came, he were asking her questions and he says 'Where do you live?', she says 'Here!' [Laughter]

This practice of assessing the level of confusion and resulting need for intervention at one particular point in time has been criticised in previous studies. For instance, Moriarty & Webb (1997: 20-1) commented that not only may the confusion be underestimated, it may also have an effect on the person with dementia. Indeed, the quotation given above indicates that the wife was aware of the fact that she was being tested. According to Moriarty & Webb, some individuals with dementia may become anxious and frightened.

To begin with, the carers concerned felt that an assessment based on a short home visit was not adequate to identify the severity of a person's confusion. In all these cases the carers found that the dementia was underestimated because the person with dementia showed a remarkable capacity for 'performing' in front of others:

> He [Father] performed very well when people came in.

This phenomenon has been termed 'brief visitor syndrome' (Nolan & Grant 1995: 60), describing a demented person's ability to put up a front for short periods of time, and thus managing to appear relatively normal to outsiders. For example a daughter remarked that her father had convinced a consultant, who came to see him unannounced, that he coped very well, had done his washing that morning, and was about to cook himself a meal. The daughter, living separately at the time, was surprised that the consultant was fooled, as she knew that her father was doubly incontinent, did not eat if not pressed, had repeatedly set fire to his armchair by smoking and forgetting his cigarette, and was generally unable to cope on his own.

An additional criticism related to the practice of assessing older people with dementia in the home and was brought up by three daughters and one son. All four carers found that they were either not told when the assessment took place, so that they could not take time off work, or that they were actively discouraged to be present:

> I think you are entitled to know what's going on.
>
> I'm told when carers are there they interfere. I cannot understand why they won't listen to carers.

It was felt that it was inappropriate to assess the person's level of confusion without consultation with the carer. The daughters and son in question believed that they were not only left in the dark but that their knowledge of the demented person's condition and symptoms was ignored. Indeed, it has been acknowledged elsewhere that carers' views are and should be vital in information gathering (McWalter 1997: 156).

Other carers found specialists generally helpful but again their lack of understanding was criticised, in the sense that they appeared to disregard what the carer thought. A number of carers disclosed that on more than one occasion they felt they were not taken seriously by specialists although, in their own view, they knew the person with dementia best, often having cared for years. One carer, who had kept a 'diary of care' found that the first specialist he saw was not interested. However, the carer did not give up and the second specialist listened to what he had to say, which the carer felt contributed to the diagnosis of the dementia:

> And so.. er, what did help I think was them knowing that my health wasn't too good and that the family lived away and that from about the beginning of... no, not the beginning, the middle of 1994 I had kept a sort of rough diary of how things had progressed, what I'd seen, because I thought if suddenly I went into hospital for some reason, which was a possibility, then neither the doctor nor the family would know the situation. And this did help very very much I gather when...er, when we saw the specialist at [Name of second hospital]. Now the other one at [Name of first hospital] wasn't bothered about it, didn't want it! So, the difference was absolutely fantastic between them... They just treat you as numbers there.

Not all carers were as persistent and successful, though. Two carers experienced a complete lack of understanding from a specialist. A wife reported that her husband, in his fifties, had suddenly lost his ability to read and write. Asking for advice, she was told very bluntly by the specialist 'Your husband is illiterate'. Apparently, for the specialist the case was closed but the carer felt she had to seek a second opinion, which then confirmed the dementia. The carer, however, was left feeling rather disillusioned with the medical profession as a whole:

> You have to fight everybody, you know.

She felt that this attitude among professionals did not make the care for a person with dementia any easier. Another carer, a daughter, was accused of being ‘over-protective’, received the wrong kind of help because her mother’s confusion was underestimated during a ten minute assessment in the home, and then the carer refused to accept any further help because the professional's critical approach caused distress to both herself and her demented mother.

This withdrawal of carers has been found in previous studies. For instance, Zarit and Pearlin (1993: 307) indicated that some carers were found to prefer doing everything themselves because this appeared to be easier than trying to ‘work the system’. Indeed, one carer in my study had come to the conclusion that unless she needed it urgently, it was a waste of effort to ask for help because everyone she had encountered was stretched to the limit already:

> They are so busy, like the social worker, they are so busy that unless I’m really pushed I don’t bother, you know.

This issue of a carer’s withdrawal from formal care provision will be dealt with in more detail in Chapters 7 and 8.

INFORMATION

Bearing in mind the finding that there appeared to be much uncertainty about dementia among GPs, it was not surprising to discover that carers themselves were far from clear about the nature of the disease. One carer put her frustration at the lack of knowledge into the following words:

> So really it felt sort of standing against a brick wall but we couldn't really find out much about it at all. And we still haven't, come to that, five years later I can tell you sort of how it's progressed but we're no nearer understanding it.

That this was not an isolated case can be seen in the section below which shows what carers were told, how they obtained information, and how they saw the disease on the basis of what they were told and what they themselves observed.

Explanations given by doctors

None of the carers in the study found that they were given appropriate information about the disease, about their relatives' diagnosis and prognosis, and about available services, without having to ask questions. This is a finding common to previous research studies (Ell 1996: 174). For instance, Haley et al (1992) reported that carers were given surprisingly little information on support groups and other services. Of the explanations about the condition that were given to carers in my study, some were wrong, and some were only half true in that they did not give the full picture. None of them were regarded as very helpful by the carer. Carers were told, for example, that braincells were dying, that the person had suffered brain damage, that they were simply getting a little confused because of old age, and that there was a lack of blood supply to the brain. It has been shown in other research studies that this phenomenon is not uncommon and that carers receive a wide variety of diagnoses (Haley et al 1992: 222). More 'medical' explanations included 'senility' and 'Alzheimer's disease of the multi-infarct type'; both outdated terms (Chapter 2). Indeed, Haley et al (1992: 219) quote several research studies which suggested that many doctors have an outdated understanding of dementia.

However, it was not clear in my study whether GPs were simply ignorant or whether they were unable to communicate their knowledge. It is conceivable that both scenarios were present in those cases where carers were not satisfied with the information they received. Some physicians may genuinely not have been aware of even the simplest distinction between the two commonest causes of dementia, Alzheimer's Disease and multi-infarct dementia. On the other hand, some doctors could have had the knowledge but may have tried to simplify the nature of the disease beyond recognition in an attempt to make the carer understand what was involved. What has become clear in the study, however, is that this vague language professionals used caused more uncertainty among carers whose main desire was to get as much information as possible about their spouses' or parents' condition. In one instance the carer found herself stunned when she learned about her husband's condition by accident. Not having told her what her husband was suffering from, the doctor turned to a medical student present and said 'Mrs Jones' husband is an Alzheimer's case'. Incidentally, this was not the case. Her husband had deteriorated after a stroke and kept suffering frequent little strokes as characteristic of multi-infarct dementia.

This difficulty in getting information led some carers to wrongly believe that there was no information. The following quotations are from an interview with the above mentioned carer whose husband had suffered a stroke and then continued to deteriorate:

> I mean this is a progression thing, I've seen it progress so far, it's senile dementia, the braincells are gradually dying off. [Have you actually been told that this is dementia?] Well, no, nobody tells me anything, you see. Ahm, I said to the psychiatrist, he tested him on memory, and he went from 20 to 14 within months, that's when he had the brain scan. I mean the doctors used the word dementia, they used that at....[hospital]...[...]... But otherwise we were quite alone. I didn't know what I could do, you see. I don't think there's enough information for the carers. The only thing that I was told was that his braincells are dying off...[...]... But that was more or less in relation to the stroke, you see, I read quite a few books on that. Then, ahm, with this business there is no information I think.
>
> To be candid, Monika, I do not think that there is much more information than I was given because every case is different. I'm not terribly terribly intelligent but I'm bright enough to know that Alan's got a degenerative illness which has got to take its time and I've got to learn to cope with it from day to day.

The above example illustrates what seemed to take place in the majority of cases in the study, and what has also been found in previous studies: The carers were given a diagnosis of dementia, were then sent home, and were 'left alone to live with the news' (Cohen & Eisdorfer 1986: 59).

Sources of information

Those carers who considered themselves to be more assertive found that professionals were only marginally more helpful when pressed for information. Others found that they had to rely on books on the subject, especially those books written by carers for other carers:

> I've done a lot of reading, yeah. Yeah, and I needed to... and you read something and think that's just my situation and it, it just highlights it and then you start to think it over and that's your way of working through it, you know.
>
> Most of the informations [Sic] comes through reading and observation of my mother. Nobody seems to be able to say... Well, they simply say, 'Well, everybody's different, it affects people in different ways'. Well, it's easy to say that because I mean that's the way to get away with putting your neck on the line and saying something about it.
>
> Ahm, my authority... if it sounds like authority, is simply through experience and observation and what makes common sense really in the light of what I have experienced and read, you know.

All the carers in the study had at some point been involved with the organisations dealing with dementia. (This is unlikely to be the general picture among carers of older people with dementia and largely reflects the way the sample was obtained). For instance the majority of carers had become aware of the Alzheimer's Disease Society through friends or family members who had heard that a branch existed in Sheffield. Others had previous knowledge of dementia through having cared in the past and were in some cases members already:

> Well, the first information I got on this was from the doctor, that was April last year and she said, ahm, she said, you know, life is going to get very difficult, do you realise that. I said, well, I realise that because [older relative] had this trouble.

Others had work-related knowledge by having been in the medical profession (nursing) or having run a nursing home or sheltered housing:

> We were what the council would have called wardens in sheltered housing, so we were working as house managers and we were looking after a complex...[...]... doing the job we were doing, dealing with retired people, of course we used to have people on our campus who had Alzheimer's so I mean we had dealt with Alzheimer's, you see.

It was a minority of carers who had heard about these organisations from their GP and had been encouraged to get in touch for information and services such as support groups.

Most of the carers who were involved with these organisations found them helpful and informative. Indeed, one carer went as far as suggesting that only since he was involved with organisations had he obtained enough information and help to enable him to cope. He therefore concluded the following:

> So yeah, once you get into the... the grip of these organisations it goes quite well. It's getting there first!

One carer, however, voiced her disappointment, stating that 'they just say the name (dementia) and that's it' and that they did not give her the advice she was looking for:

> Ahm, I mean I went to the ADS [Alzheimer's Disease Society] and I asked about it, you know the information... I didn't feel I was getting anywhere, you know, I was getting quite frustrated... This was in the early days, I mean, that's why I stopped asking because I wasn't getting anywhere.

Nevertheless, in general a lot of the carers benefited greatly from the fact sheets given out by organisations such as the Alzheimer's Disease Society. Particularly popular was a booklet 'Who cares?' (Health Education Authority 1995):

> And I thought this booklet was very useful...That booklet was exceedingly useful, I found that very very good indeed, and ahm, it does give you insight into how to cope with situations and having read that and having sort of lost my temper once or twice and come back and read it again I sort of realised... I gradually helped myself.
>
> I realised that a lot of the things she did, they were typical.

Problems in obtaining information

The carers' knowledge of the disease and the available support was, in most cases, good but patchy, and was obtained by asking questions or reading about the disease. This lack of knowledge among carers has been noted by other researchers (see for example Allen et al 1992: 297, Twigg & Atkin 1994: 47). Gilhooly (1984a: 117) for instance expressed surprise about how little carers knew, suggesting that this may have to do with the stigma attached to dementia. Indeed, carers in my study commented in the feedback sessions (April 1997) that they felt there was still a stigma attached to dementia and that much more awareness in the general public was needed to overcome this problem. One carer thought that people were ashamed to admit that there was someone with dementia in their family but that it had helped that more 'famous' people, such as Ronald Reagan and Iris Murdoch, had admitted to suffering from dementia.

As for the lack of information among professionals, the carers themselves were ready to excuse this on the grounds that cases varied considerably. This was what they were commonly told when they asked about what to expect later in the disease, as well as the fact that it was very difficult to predict how the person with dementia would be in the future. However, the majority of carers sounded slightly bitter about not getting enough information at a time when it mattered: that is, when the person with dementia was first diagnosed:

> You see, ideally I should have been involved from something like May last year. We ought to have been seen in [hospital] last year, that May after we'd been to the doctors, probably a month after we'd been there and er,...[...]... I don't know. I never will know, but I feel there that we lost a good part of Helen's active life in a way.... I feel very bitter about that.

Carers suggested in the feedback sessions that there should be much more information readily available to 'new' carers. Indeed, previous research has identified the point of diagnosis as a critical stage in the caregiving process (Fortinsky & Hathaway 1990: 606). It has been emphasized that it is important for carers to get as much information as possible at this stage and that the amount of information available can influence the carer's ability to cope.

Another important finding of the study was that older carers appeared less likely to ask for information and more likely to accept what their GP told them. It is important to remember that the majority of older carers were spouses. This generational difference between spouse carers and adult children caring for a parent has been commented on before (Chapter 4). The observed difference in the carer's relationship to his or her GP may be explained in terms of traditional values and social norms and the belief that doctors know best and are not to be questioned (Buller & Buller 1987: 376). There was also some evidence to suggest that older carers did not want to appear too critical of their doctors because they feared that they thereby compromised the amount of help they received. In previous research, older carers were found to be more passive, with lower expectations of their GPs, and less willing to express their dissatisfaction (Cook et al 1990: 303). Indeed, in the feedback sessions (April 1997) several older carers expressed their gratitude about the information they managed to obtain and explained that 'one mustn't grumble'.

A daughter reflected on this phenomenon, expressing the following thought:

> See, it may be just me [being assertive]... Maybe when you're older as well you don't have the same viewpoint. I mean, if you're caring for a spouse and you're in your 60s... 70s yourself maybe it doesn't come to you that you can ask for this information, you just accept what is ... perhaps.

For older carers this meant that they were more likely to get the least information of all carers and that the information was qualitatively different to that given to younger carers

(Buller & Buller 1987: 378). Younger carers, on the other hand, were much more critical and many noted that, even when they asked questions, professionals were very reluctant to give them information, either because they did not appear to have the knowledge, or because they did not know how to communicate the information relevant to the carer. Two daughters had gone to great lengths to get information:

> The only reason I got a response was that I stomped up and down and created noise.
>
> And I have... I have spoken out and told... and told people what, er... I've not told them, I've asked them what I wanted to know, er... and if you ask enough questions eventually you get bits that you can put together. And I also have been quite forward about saying, you know, what I don't think is very helpful as well, so I'd just say, you know, I do think there ought to be something better. And if you ask people to come out with something better but they don't seem to volunteer it and I think that's the problem, they don't volunteer it... And I think not everyone is as forthright as me, in fact I think very few people are. I think a lot of people just puddle through... Maybe the enormity of caring is as much as they can cope with, you know, I just happen to have a kind of mind that wants to know more, I want to know why, and questions everything. And maybe it's just my personality that questions everything. I don't accept anything.

It has been suggested that women who cared were more likely to be better informed than men because they did not hesitate to ask detailed questions (Buller & Buller 1987: 377). Although there was no conclusive evidence of this in the study, the two examples quoted above show that those carers who could almost be described as aggressive in their pursuit of information appeared to fare significantly better (Zarit & Pearlin 1993: 307). This applied not only to getting information but also invariably to services, as will be seen in Chapter 7.

Two carers in the study suggested that the reluctance of professionals to give information was related to their sense of power or rather their lack of power. Again, there was a marked difference between the way a spouse and a daughter interpreted the professional's behaviour. A daughter in the study expressed her frustration about what she felt was a deliberate act on the part of some physicians to withhold information from the carer:

> I want to know why. I wanted to know more and I have always wanted to know more. Nosy, a little bit really, but that's the only way to find out - 'cause I don't find professionals particularly helpful... it's almost as if they've got all the information and they're quite happy to keep it to themselves 'cause you are the layman... I don't accept that...[...]... Some of the professionals really think that

> they, ahm, you know, they just have to say the word and that's it and they don't have to explain themselves and in a way there's an almost fear that it's like a closed shop and they have all the information, they're in control... And a lot of people accept that.

Other studies have found a similar picture, with carers developing a cynical view (Twigg & Atkin 1994: 47). However, on the other hand, a husband caring for his wife, was less critical and felt that the lack of information he encountered was due to the doctor's helplessness, rather than a deliberate withholding of vital information:

> Er, it was very hard in beginning, er... I weren't... I weren't... I didn't seem to be getting much help from doctors. I think it's because they don't understand the disease like... er, they know there's no cure and I think it's because they don't know what to do for best but... [...] As I say, doctors don't seem to be wanting to discuss it like.

As the two examples above show, not every carer is oblivious to the relationship of power that exists between carer and professional and it can potentially lead to much bitterness among carers. There has been some evidence that adult children are more likely to challenge their doctor's behaviour, whereas older spouse carers were generally more passive. However, it has been noted that there is a more serious issue underlying the reluctance of professionals to give information. Allen et al (1992: 299) for instance note that is it common practice among professionals to deliberately withhold information on services because carers may actually ask for what they are entitled to. Rationing of information can therefore be related to rationing of services, being a sign not of power but of helplessness among professionals in the face of resource restrictions placed on them. This issue will be dealt with in more detail in Chapter 8.

Stages

From a medical point of view it is not strictly possible to distinguish between stages in dementia, although several models have been used to assess the care needs of dementia patients (Gubrium 1987). For instance, Hayter (1974: 1460-3) suggested a three stage model. The first stage was characterised by comparatively mild symptoms of memory loss, the second stage showing further deterioration, and the third stage leading to the patient's death. Another classification was put forward by Berger (1980: 235) who developed a system of six severity ratings, ranging from class I with forgetfulness to class VI for vegetative patients. Similarly, Biegel et al (1991: 148-9) distinguished between five stages which described the deterioration of the person with dementia from minor symptoms in stage one to death in stage five.

The carers in the sample had been told by their doctors that each case was unique and that therefore it was not useful to talk about different stages of the disease. However, the carers' need to make sense of their experience has already been noted (Chapter 5) and the carers themselves talked about stages in the sense of 'early', 'middle' and 'later' stage of the disease. This reference model closely resembled that of Hayter (1974) and was flexible in the sense that it mainly noted the carer's own perception of the seriousness of the demented person's condition. The following quotation is a wife's description of what she considered to be her husband's move from the 'early' stages into a more pronounced dementia stage:

> Then suddenly... well, not suddenly I suppose, I suppose it was like a creeping thing, his brain just got more and more damaged. You know, I suppose his braincells were going, and ahm, he wasn't too bad but he was still very difficult.

Those carers whose relatives were in the 'later' stages of the disease reported that caring got easier the further the person deteriorated:

> It's not as hard looking after her [wife] now as what it were in the beginning, you see... In them days it was harder because there was that resistance, see, whereas now there's no resistance, you see, she's so docile and that and, you see. I mean the hardest part now like, is toileting her and lifting her in bed and things like that kind of thing, you know... She's a lot easier to manage now... she's no problem at present, you know, she's gone through them awkward phases, you see.
>
> It actually gets much easier from the carer's point of view when they're actually in the final stages 'cause you're not fighting against them. 'Cause she [mother] was very difficult at home sometimes, she would fight, quite aggressive, ahm, verbally, but also at times she would pick up something and throw it.

This phenomenon has been commented on before (Chapter 5). For instance, Chiriboga et al (1990: 136) suggested that the finding that carers had higher morale in the later stages of the disease could be explained in terms of the demented person's deteriorating physical condition. This meant he or she was either bedridden or institutionalised, making it easier for the carer to provide, or accept help with, practical support.

Asked about stages in the interviews, the carers reported either a very rapid development after a sudden start, or a gradual worsening of the demented person's condition. Depending on the form of dementia, there was either a sudden decline followed by a 'plateau' (as characteristic of, for instance, multi-infarct dementia) or a very gradual deterioration (as characteristic in cases of Alzheimer's Disease).

> It just crept and crept... it's insidious.

It became apparent in the study that the medical profession seemed reluctant to reveal the full extent of the patient's possible future deterioration and the full extent of what the carer may have to deal with later on in the disease. Taraborrelli (1993: 185) suggested that medical practitioners seemed to be unaware that the extent of the information the carer received on possible future problems could influence the carer's ability to cope. The carers in my study felt that doctors seemed to be of the opinion that it was better for the carer not to know how the disease may or may not progress. However, several carers criticised this reluctance of professionals, and to some extent organisations, too, to give them a clear indication of what they may have to expect. A daughter voiced her frustration in the following words:

> And I have had to learn all this on my own because I have not managed to find anybody that could say to me definitely, yes, this is likely to happen and that's likely to happen. And I found that as a carer the hardest thing of all. Even at the ADS, you know the Alzheimer's Society, they couldn't really... they would seem to say, 'Well, er... well, it could be as a part of that condition or well, all sorts of things are happening...depends ...' what they mainly said is 'It depends on the person' - And that doesn't help you when you're asking for advice! You need to know what could be a symptom. You know, because I, even now, can't always tell whether it's the disease or whether it's mother's manipulative personality.

There was convincing evidence that it is important for carers to have a frame of reference in order to compare notes with other carers and give advice on the basis of their own experience. It was also expressed very strongly by the majority of carers that instead of being spared the details they would rather know what *could* happen in the course of the disease. This did not suggest that they believed all those symptoms which may be present would be experienced by their relative at any one time. What it did mean was that the carers felt that by knowing the worst possible scenario they were better prepared to deal with any emerging problems rather than having to fight against an unknown enemy.

The lack of professional guidance on the issue of stages in the progress of dementia had led some carers to develop their own ideas in an attempt to explain what was happening to their relative:

> She's still able, if you understand me, she's not like someone... I was talking to, his wife's absolutely gone...[...]... 'cause she hasn't gone... back of her mind, I think there must be a little thing still at the back of her mind, you know, what brings on all the funny things, with one little ball left what makes her see through things at times, you know, I don't know, I'm not trying to be a doctor or a

> scientist but that's how I see her think because of what she does.

Again, there was a marked difference between older carers and younger carers, with the latter being much more likely to refer to the literature in an attempt to identify possible symptoms. Older carers, as the above quotation illustrates, were more likely to rely on their observation of the person with dementia. Having often been married to the person with dementia for over 50 years (Chapter 4), this group of carers used their intimate knowledge of their spouse to develop their own theory of how advanced the dementia was.

Conclusion

This chapter has shown that, in every case in the study, there was a crisis in the carer's or demented person's mental or physical health which led to a recognition of the dementia. To what degree this delay in diagnosing the dementia may have consequences for the carer's ability to cope with the care of the demented person will be discussed in more detail in the next chapter.

The findings of the study suggested very serious and far-reaching problems with GPs. GPs were not very good at diagnosing dementia and referring carers and the person needing care for proper diagnostic tests. Schofield et al (1998: 367) have commented that doctors need to be much more aware 'of the potential benefits to the carer of having a diagnosis'. At present, very few carers obtain a diagnosis from their GP. Specialists, on the other hand, were found to be very efficient and helpful but several carers remarked that they were not personal enough, in the sense of not taking the carer's views and opinions into account. Furthermore, five carers who were not referred to a hospital for brain scans and other diagnostic tests felt that a short assessment in the carer's home had not been sufficient to make any kind of valid diagnosis. Again, in these cases, the carers felt ignored by the professionals who did not appear to take the carers' views seriously.

That there was a lack of knowledge about dementia among carers. Explanations given by professionals were often outdated, such as 'senility', and many carers found they could not get information out of doctors unless they were very assertive. Furthermore, carers felt they would rather have the true picture of how the dementia could progress in the worst possible case, rather than being spared the details and finding themselves fighting against something they did not understand. Also, it was found that it was important for carers to have a frame of reference, in the sense of talking about early and later stages of the disease, despite the insistence of professionals who told them that every case was unique.

To conclude, the carers in the study felt that they had to fight to get recognition of the condition, and that they had to fight for information on the disease and available services. These issues will be discussed in more detail in Chapter 8, where it will be argued that much more could be done to inform and empower carers. The next chapter highlights the different services used by the carers in the study and reflects on the usefulness of each.

CHAPTER 7: CARERS AND SERVICES

INTRODUCTION

The previous chapter has shown that there is a dearth of information on dementia and on services available to most carers. Because of this lack of information, and subsequent lack of support, there was a marked split between those carers who received help and those who tried to cope without much-needed services. Several of the carers who received very little or no help noted that they felt resigned in the belief that there was nothing professionals could do to help them:

> But quite frankly apart from giving him memory tests, and we go and see the bloke [psychiatrist] and I tell him what's going on and so on and so forth, but what can they do? It's someone for me to talk to and explain the difference in Alan, ahm, but I mean they really can't do much. The only thing they can do is to give me a little more time off...[...]... apart from putting him on antidepressant tablets there's been nothing done for him. I don't think they can... I don't know, I mean I've asked but there doesn't seem much they can do.

Those, on the other hand, who received support such as day care or respite breaks, often praised the usefulness of these services. Unfortunately, it has become apparent that formal care is administered as crisis intervention and short-term relief (Qureshi & Walker 1989: 25; 29) rather than a permanent and regular source of help for carers. Previous research has shown that the carer's role in the formal sector is ambiguous. For example, Twigg and Atkin (1994: 11-15) have identified four different models. Carers are seen, firstly, as resources, secondly, as co-workers, thirdly, as co-clients, or, fourthly, they are superseded (Chapter 2). My research has shown evidence that carers are often treated as resources, and at best as co-workers where their efforts are often subject to exploitation.

This chapter looks in more detail at the way the carers in the study were supported by the formal sector in caring for the person with dementia. To begin with, I will look at the process of obtaining help from the formal sector, a process which one carer termed 'working the system'. Secondly, an account is given of the actual help the carers received from the formal sector and whether this help was perceived by the carers as beneficial. A distinction has been made between two types of formal support, that of 'instrumental' and 'emotional' support (Stephens 1993: 262). Instrumental support is the form of support that aims to relieve the carer of some or all of their caring tasks for short periods of time. Examples of instrumental support are day care and respite breaks. Emotional support on the other hand is designed to enhance the carer's ability to cope with the caregiving. Examples of emotional support include counselling, psychotherapy and support groups. Both forms of support will be analysed in relation to the findings of the study.

WORKING THE SYSTEM

It has been suggested that carers have to occupy several roles if they are to cope successfully with the care of the person with dementia. Carers do not only have to provide all the care, they have to be 'care managers' as well (McAuley et al 1990: 206). The term 'care manager' will be used in this and the following chapters to denote the task of carers to manage their own care. It should not be confused with the position of care managers in the social services. Indeed, I will argue that the term care manager is mis-used in the social services, as research has shown that very few carers are in a position where a professional manages their care requirements. On the contrary, the majority of the carers in the study reported that, although a doctor eventually suggested formal support, it was, in fact, the carer who was left to organise it:

> I sort of, you know, spoke out and complained and made the inquiries and ... Like, my doctor is brilliant, she has been very supportive all along the line and she suggested, ahm, you know, when I have gone and said 'I am not happy with this', she said, 'Well, there is such and such a thing', and then I've gone and made the inquiry, yes. So she really has been very good and very very helpful and a lot of it would be down to her but she's not done the organising, I've done it for meself, you know.

This finding had important implications for a carer's ability to obtain services. It has already been noted (Chapter 6) that those carers who were more assertive in their approach managed to get significantly more information on the disease. Similarly, those carers who were more persistent got more formal help while those carers who were passive in some cases failed to get any support (Zarit & Pearlin 1993: 307). In other words, those carers who were good in their role as care manager and succeeded in negotiating care, as well as supervising it, appeared to fare better than their less demanding counterparts.

Two ideal types have been put forward by Zarit and Pearlin (1993: 304) in an attempt to describe the integration of the two systems of care, the informal and formal. A 'synergistic effect' shows a carer who is good at 'initiating the links' and who 'will get relief from well-conceived formal services, which in turn facilitate better functioning of the informal system'. The 'entropic effect' on the other hand shows a situation where 'the time and effort expended in linking and monitoring services further depletes the informal caregiver'. Furthermore, it has been shown in previous research that a carer's first failed attempts to negotiate help can negatively influence a carer's future attitude to formal care (Savishinsky 1990: 79). As previously noted (Chapter 6), some carers who do not succeed initially may withdraw and decide to try to cope on their own because they find this easier than trying to 'work the system' (Zarit & Pearlin 1993: 307).

The study has shown that there was a very fine balance between a synergistic and entropic outcome of the carer's attempts to be both care provider and care manager. Several carers indicated that they found it very difficult to integrate the different services they received into their everyday life. A son, who tried to keep his full-time job while caring for his mother, operated what he called his 'multi-agency requirements' and noted that if something did not go according to plan he would have to make around 14 'phone calls to cancel various services, including a home care team, sitters, and a day care centre. Other carers criticised the bureaucratic side of formal care provision. Firstly, carers in the feedback sessions voiced their confusion about the different services available and said that, in their opinion, the social and health services appeared to push responsibility from one to the other without effectively providing help for carers of older people with dementia. This confusion as to who is responsible for formal care provision in the health and social service sectors has been commented on in previous studies (Savishinsky 1990: 92; Cayton 1997: 56; Sturges 1997: 56) and will be discussed further in Chapter 8.

Secondly, all the carers in one feedback session complained about the amount of forms they had to fill in to get any services. This also included forms to obtain benefits, as already noted in Chapter 4. Many found it difficult to cope with these forms and tried to get help from other family members or the staff at the Alzheimer's Disease Society. Several carers criticised the system for being too complicated, in particular for older carers. A daughter pointed out that asking for any kind of help required using the telephone and filling in endless forms, which she thought was more difficult for older carers:

> 'Cause I think a lot of that generation find it hard to use a telephone, believe it or not. I think that will change as years go by, but I mean the telephone is quite a recent invention for my parents...[...]... Well, to actually sort of pick up the phone and deal with a problem, and get, you know it's like ringing hospitals, you know... it's very... the holding on, you get passed around and you get answering machines.
>
> And that's the other thing, I had quite a lot of things to do, quite a lot of forms to fill in as well for that, the attendance allowance and all that. Well, I don't find it easy, I can do it. I hate doing things like that but I can sit down and I can read

> it and I can understand and work it out. Well, a lot of people just can't. It's quite daunting to some people.

For some, this daughter felt, these problems could even mean that some carers may never ask for much needed help because they did not know how to:

> The system altogether is quite hard for some people. I wonder sometimes whether that's why people fall by the wayside. They either don't know how to get on the books, or, ahm, they are too frightened of the system and how to deal... how to make 'phone calls.

Other carers agreed that filling in forms was another burden which was hard to cope with as most carers were 'too depleted already'.

All the carers in the study had had some experience of the different types of support available. Those who took advantage of the services that were offered to them felt very grateful for the help:

> Obviously it helps 'cause... Anything helps - it's a question of if you've got a tank full of water that's going to overflow, every cup you take out stops it from overflowing that bit more, do you know what I mean, so it's got to help.

Several carers expressed that they felt very lucky since they had spoken to other carers in support groups who received less help:

> I mean I am lucky I've got three days [day care]. Because most of them have only got one or two days.
>
> I'm lucky, she goes four days a week. I'm very very lucky.
>
> So I rather fancy I've been rather fortunate in so much in when I asked for help I got it [three days in day care] I mean, I've spoke to other people... er, and they've been struggling along for years.

Ideally, each carer should have a key person, usually a social worker, they can approach and who ensures that the carer and the person being cared for get the support they require. In reality, however, most of the carers did not know whether they had a social worker allocated to them (Moriarty & Webb 1997: 20). Indeed, some carers did not appear to have a key worker at all. Very few of those who knew were happy with their key worker, reporting frequently changing social workers, unreliability in keeping appointments, and general unhelpfulness:

> We've seen him [social worker] once before, once in two years that is, and that is all; absolutely useless and he arranged to meet us actually one day and my husband and I went up and waited for nearly two hours and he never turned up. And apparently he was at the hospital and got tied up

> there with something and couldn't get out, ahm, never made an appointment to come again, and I said, well, we couldn't have been that important, could we, for crying out loud, that he never wanted to see us again...

Several other carers had only seen their key worker once in several years. Twigg & Atkin (1991: 11) have noted that this pattern was often due to normal practice in social work. Social workers were expected to assess the situation, arrange services if appropriate, and close the case. That this procedure is neither clear to carers, nor adequate in relation to dementia where long-term support is necessary, will be discussed in Chapter 8. Only one person in the study praised her key social worker as being very helpful and very good in negotiating formal support for her husband:

> I had an extremely helpful social worker who's done anything she could to help me to keep him at home.

The above carer was in the remarkable position of having a lot of help with the care of her husband, and had only lately realised how unusual her case was:

> I have sort of begun to feel a bit guilty about the amount I have because ..[...]... there are a few of them whose partners go to day centres but ahm, they don't seem to get any other help...[...]... Well, George started off with two days, and then they made it three days, and ahm, earlier this year they made it five days. It's only been five days since June - May time, before that it was just three days, so I had him home four days a week. But with the five nights a week with [Sitter] coming, that's fine, that's five nights and five mornings where I have had help, but until a couple of weeks ago I was able to cope on a Sunday morning and a Monday morning on my own with him and I can't any more. Simply I... he just needs so much more physical help. So last weekend [son and daughter] came on Sunday and Monday morning to help me get him up. So I'm hoping that, it may not be this week, but I'm hoping that from next week there will be someone either throughout the night or come in in the morning for an hour just to help me get him up, but I just can't do it on my own any more, and that's come rather suddenly. [And you said you are using respite care as well?] Yes, he's home three weeks and then in respite for two weeks. That again is from September.

In the feedback sessions several carers expressed their surprise that there were such marked differences in the level of care different carers received. A husband felt that in his experience getting the right services at the right time was due to luck alone and not his ability to negotiate:

> If you are lucky you get services.

He criticised what he called the 'hit and miss part' of caregiving. However, apart from luck, several more factors have been identified which influence a carer's success in being both care provider and care manager (Mullan 1993: 244). To begin with, carers had to be aware of the available services and needed to be able to access them (Chapter 6). Secondly, a carer's beliefs and attitudes played a part in whether formal services were accepted (Chapters 4 and 5). Thirdly, certain norms, such as marriage vows or a sense of duty, may have prevented some carers from accepting help with the care they believed to be their responsibility (Chapter 5). Finally, some carers voiced concerns about the safety and quality of formal care (see below).

INSTRUMENTAL SUPPORT

It has been noted in the previous chapter that the carers in the study used what they had observed to be clear stages in the disease as a frame of reference. This frame of reference was applied to every case of a dementing illness, regardless of the cause of the dementia. It appeared to help the carers to help themselves by discussing their experiences within this framework. That dementia is a degenerative illness is obviously well known in the medical profession (Chapter 2) but surprisingly these stages of the disease, whether they are termed 'stages' or not, did not appear to be taken into account in formal care provision (Fortinsky & Hathaway 1990: 604). It has already been noted (Chapter 6) that, in many cases, an assessment of the level of confusion was carried out on a short home visit, usually by a Community Psychiatric Nurse (CPN) who then determined whether the carer and the person being cared for needed help. Clearly, the carers in the study felt that this was inadequate. It was therefore surprising to find that whether a carer received some form of formal support was typically determined during the initial assessment. The most common intervention consisted of instrumental support such as day care and respite care (Stephens 1993: 262). Other services included sitters and home helps.

Formal services were usually only offered in response to a crisis in the caregiving and very few carers received all these forms of support. The idea behind the reported interventions appeared to be a smooth progress from no help to full-time nursing care, as and when the need arose. However, the picture emerging from the data showed a system of trial and error. Furthermore, although carers often had to investigate and negotiate possible sources of help themselves, they also found that they had very little choice in terms of quantity and quality of support. This issue will be discussed further in Chapter 8.

Over-simplifying the matter, and disregarding the evidence of crises, carers in the study usually progressed in the following way once they were 'in the system': If the initial needs assessment was carried out and revealed that the carer could not cope without support, carers effectively entered the system. To begin with, day care was suggested for the person being cared for, normally starting with one day a week. When this was no longer sufficient to relieve the strain of caring, carers received two days, then three or four day a week and, in severe cases, five days a week. When carers reached the stage where their relative attended day care for three days a week, a respite break was suggested, usually lasting one to two weeks. In some cases this was a one-off, in others the demented person went into respite several times a year. One wife alternated between having her husband at home for three weeks and in respite for two weeks, although this case was the exception rather than the norm. Finally, when all these interventions were no longer adequate, full-time nursing care was suggested to the carer.

Unfortunately, there was only one carer, quoted above, who enjoyed something resembling care management, and who was fully supported by her social worker from the initial assessment through to finding full-time nursing care for her husband. It has already been noted that the majority of carers did not have a key worker or were not aware of a key worker involved in their case. As a consequence they did not experience such a smooth succession of available services but entered the system at any stage. For example, a wife in the study had obtained no support until her husband entered respite care following an emergency when she had to be admitted to hospital. After two weeks in respite care he was then placed in a nursing home when it became clear that his wife would no longer be able to care for him at home.

Day care

On average, day care was received about two or three times a week by the carers in the study. Overall it was seen as beneficial to both carer and the person with dementia.

> It's practical and it's wonderful and I can't fault it. The main... main benefit to me is the luncheon club service because it enables me to know on a regular basis how much time I'm gonna have spare in the day to plan things like shopping expeditions and sorting out all the bills and stuff like that and doing jobs in the house I can't do when mother's there because she won't have me out of her sight.

However, some of the carers expressed feelings of guilt because they felt they were 'abandoning' the person, despite the fact that in most cases the person with dementia appeared to benefit from the experience as the following quotations illustrate:

> They arranged for him to go to a day centre for two days a week and I said to my son, 'Do you think dad will go?', and he said, 'I don't know'. And I said 'Neither do I, I'm

> dreading that ambulance coming up the road because they said they would pick him up and bring him home again'. And that ambulance came for him and I put his coat on and told him he was going to a day centre, ahm, for a day to, you know, to see what it was like, and he walked into that ambulance without saying 'What on earth are you doing, what, why on earth have I got to go in ' He didn't say a word, he just walked straight out with the carers to the ambulance. And he has done that every day ever since.

> Because she settles... as I say, she settles down there, she enters into all the activities they have and she's quite happy to go, yes, quite happy to potter off in the ambulance in the morning, yes. She will go out without a kiss or anything, yes [Laughter] ... quite aloft. So, yeah, and they say she settles down so well there.

> I mean they speak well of her at those luncheon clubs. She goes in, she jokes with them, she's got quite a sense of humour... she hasn't at home but she has when she's there... she jokes with them, she gets on well with everyone, she talks...[...]... She is the life and soul if she goes places and she joins in and laughs, ahm, you know, she talks to people and has jokes.

Examples of things that were praised included the activities in the day care facilities, the good food, the kindness of staff, and the company of others:

> I mean they are very good to him over at the unit [day care]. When he has one of his off days or he keeps on about me, they have to telephone me so he can speak to me, if he thinks I miss him. But they are very good, they'll telephone me, and keep trying until they get me 'Alan wants a word with you', so I have to assure him that I'm here and that I will get his cup of tea ready for when he comes home.

> And she has the benefit of the four meals a week that she has out there [day care]... it's very good meals they're given, they always look very well balanced to me.

One carer reported that his wife had settled down since attending a day care centre, and seemed much more content which, in turn, had made him a lot calmer and more able to cope with the care situation:

> So they said, well, er... 'We ought to think about asking you to apply to go to the day centre' and I said 'I don't really like that very much'. But eventually the doctor and the nurse persuaded me to let her go and said, 'Well, it will be far better for you. It will give you a rest... ahm, it will give Helen a change of environment 'cause they've got all sorts of activities there, so you're both going to benefit from it'. So eventually I did give in and I must admit that we both have benefited from it... ahm, I'm a lot more relaxed .. ahm, ...some old problems are settled quite a bit now. And now I said that it seems a long time between Wednesday.. ahm,

> and the next Monday, because she goes Mondays and Wednesdays, you see.

However, three main problems were reported with this type of service. To begin with it was noted in one of the feedback sessions that day care was not appropriate for all carers and that only a limited number of carers had access to this service. Explanations mentioned were, for instance, that some demented persons were too ill to attend day care or did not live in a designated catchment area. Another problem identified in the study was that some individuals with dementia were unaware of their own symptoms:

> The first day she came home, ahm, I said to her 'Have you had a nice day? What have you done?' She said 'Yes, I did enjoy it, it was company'. 'But', she said, 'there's some funny people there, funny people, well a bit strange, you know', she says, 'as if they're not all there'... It never occurs to people with Alzheimer's that they are the problem, no, they never see it like that, er, so she actually felt sorry for the other people.

As the above quotation illustrates this caused amusement for some older people with dementia. Others, however, refused to attend the day care centre on the grounds that it was full of people who were 'not quite with it' and 'funny'.

Secondly, it was pointed out that it was not the quantity that mattered but the quality of day care received. One day care centre was praised as being excellent with a high staff to patient ratio. This particular facility provided notebooks for every person attending, in which staff noted the day's events and conveyed any messages to the carers. Similarly, carers were encouraged to write short notes to the key worker about how the person with dementia had been at home. This was found to be an excellent means to keep in touch and enabled both staff and carers to understand what was happening, for instance when the person with dementia had had a particularly bad night. Moreover, several carers pointed out that they felt that attending day care had 'arrested' the demented person's decline and had prevented them from getting much worse quickly. This was thought to be due to the range of activities provided in this centre. Carers whose relative attended different day care facilities, on the other hand, reported fewer activities which they thought were attributable to a lack of funding and the fact that those people attending this particular centre were further into the dementia and therefore less responsive. Carers whose relatives attended one of these centres found that there was more scope for misunderstandings with staff. It has already been noted (Chapter 6) that some individuals with dementia show a remarkable ability to hide their confusion for short periods of time. One carer in the study described how she observed her mother in a day care centre:

> She talks... because she's developed this ability to... er, make small-talk, I mean, talk about the weather and answer... what did she say... er, one day I was watching her and she didn't know I was there and oh, did it make me laugh! And she said... somebody was talking about some old phoney they were complaining about and she said 'Well, they do things like this don't they?'... in confidence you know, she's like... I was absolutely gobsmacked! And I thought she sounded so sort of with it and understanding and... [Laughter] ... this is what they do, they go out there and they put on this front... and... and they seem quite normal and, ahm... with it. They have these little platitudes and phrases that they use, they're sort of blanket things and it's... it's....it's confusing.

Previous research has found that this could potentially be a problem for staff and carers. For example, Gilhooly (1984b: 39) reported that, in some instances, 'day hospital staff viewed the day patients as less impaired than supporters'. In the feedback session it was concluded that there should be more places in what carers termed 'centres of excellence', even if this meant a reduction in levels of provision. Among other things these centres should have a high staff to patient ratio and a lot of activies. The carers clearly felt that it was more important for them and the person they cared for to be happy with the quality of the care that was received.

The third problem and the biggest hurdle for carers in the study, was the fact that the provision of day care did not really give the carer a lot of time off. One carer remarked that although she was grateful for the break, it was not as much time to herself as she would wish:

> You know, they're taking him away in the morning and then he's coming back, you know, it's not really a lot of time out of the day if you think about it.

Related to this was the unreliability of the ambulance service, a problem which does not appear to be new but has been discussed in the literature (Lewis & Meredith 1988: 14). All carers were encouraged to take advantage of having their relative picked up by ambulance in the morning and returned in the afternoon. This was no doubt designed to give the carer more time off but caused some anxiety about the comfort of the person being cared for. Several carers claimed that the person with dementia was 'on the road' for well over an hour which not only meant little time actually spent at the day care centre but also potentially caused problems with toileting. One husband had discovered that his wife's distressed state in the late afternoon was caused by the route the ambulance took on her way back which included coming down a steep hill in the dark, which frightened her. Also, the carers reported that the ambulance was rarely on time, sometimes early and very often late. The following quotation illustrates one husband's experience of the ambulance service:

> Any time from about quarter to four onwards. They told me actually, four... four o'clock onwards and the first time I went down to town, I went to the Alzheimer's meeting in town and I thought... previously, up to then she had always come half past four, quarter to five, so I said to them I must be home for four o'clock, but then I missed me bus, I was here at 5 minutes past 4, went to open the door, the door was unlocked. I thought, hold on. Helen is sitting inside with a neighbour. The ambulance had come at 5 minutes to four. And of course they had been round the back to see whether anyone was in or whether I had collapsed around the house or something. Anyway, our neighbour fortunately spotted them, she's got the key, of course she set the alarm off with the key... Anyway, then I thought, now, I'm not gonna let that happen again, her coming home and me not being here. It really upset me...[It happened a second time]... So I'm back at half past three now. And of course it's costing me time. I like to have a walk and I rush back...[...]...So I mean, that's frustrating.

Similar problems were encountered by this carer in the mornings when his wife was repeatedly picked up late by the ambulance service:

> So, the first morning they said they were here from anywhere from half past 8. Up we got with a struggle for half past 8, and we knew that the session started at half past 10, so it got to quarter past 10 so I rang up and they said, 'Don't worry, it'll be here, it'll be here'. So it got to 20 to 11 and it still hadn't come so I rang again. They said, 'Hasn't it come yet?', and I said 'No'. So they rang through to the ambulance and apparently it had broken down there. So finally they were here at 5 to 11, and that was on the first day of all things, and I mean we were both absolutely on edge. Anyway, the next day it didn't come until quarter to 11 again. But then after it's been fairly consistent, half past 9 to quarter to 10 but more often than not nearer to 10. They've been much better recently.

In other words, although the carer got time off by sending the person with dementia to a day care centre, the time the carer could actually leave the house was limited due to the late arrival in the mornings as well as possible early return in the afternoon. It also interfered with carers' plans in terms of cooking and eating dinner:

> I mean, last night he was back at 5 o'clock. Ahm, on Tuesday it was half past 5. But from half past 4 the kettle has to be flicked on and off every five or six minutes and if I'm cooking with the oven I leave that on or if I'm baking something or got some chicken or something in there and it's, sometimes I have put it in ten or quarter past five if he's not here and then they can fool me easily because he's been

> home quarter to six before now, you know, it's any time between half past 4 and then.

Further, those carers who lived outside a certain catchment area had to provide their own transport for the person they cared for. Usually taxis were used. One carer reported problems with this as on several occasions the drivers did not accompany his wife to her front door but dropped her off at the bottom of the street and she was subsequently found wandering in the neighbourhood by the concerned carer. On one occasion the carer opened his front door to find that the taxi had brought the wrong woman:

> Anyway, one night doorbell rings, and I look ...and he says 'What's up?' and I says 'That's not my wife!' He says 'You're kidding', I says 'I'm sorry, I'm not!'. And there's this old lady stood there, so I says 'Come on in love'.

His wife, meanwhile, was still in the day care centre.

Respite care

Respite care has been defined as 'an arrangement whereby elderly or disabled people, normally cared for at home by relatives, are placed temporarily in alternative accommodation to give their usual carers a break' (DoH 1989: 73). This narrow definition implies that the break is seen as being solely for the benefit of the carer and not the person for whom they care. Also, the main idea appears to be to provide a break for the carer in order to avoid a breakdown of informal support whereas the carer's wider needs are not addressed. Three different types of respite beds have been identified. 'Crisis beds' are used in those cases where there is a crisis in the informal care set-up and the carer suffers a breakdown. 'Holiday or relief beds' are used as the name implies, whereas 'rota beds' offer the carer a more permanent arrangement where the person with dementia alternates between staying at home and in respite care. It has been suggested that 'rota beds' are the most likely arrangements offered to carers (Nolan & Grant 1995: 51-4).

The study confirmed that those carers who did take advantage of respite breaks saw it for themselves rather than for the person going into respite:

> It is important [respite] I mean everybody tells me it is and I do realise they are not talking a load of rubbish at all. It's only really when he goes in that I realise how tired... I mean the first couple of days when he goes in I feel absolutely whacked, and as I say it's only when he's not here that I realise how busy I am when he is at home.

However, the study has shown that those carers who did make use of respite care appeared to have access to occasional breaks only, usually once or twice a year. Only one wife in the study had been offered a 'rota bed', with her husband alternating between three weeks at home and two weeks in respite care.

The benefits of respite care for the carer included emotional and physical rest, the chance to see relatives or go on holiday, and to complete those tasks which were impossible while the person with dementia was at home, such as DIY. Asked how carers spent their time while their relative was in respite care, most reported enjoying some time on their own and trying to get on with tasks they had no time for when they were caring. For instance, a daughter stated that she caught up on necessary maintenance work on the house, while a wife caring for her husband reported that when he was away for a week or two she took some time to look after herself. She also enjoyed a break from those things that she found hard to cope with in everyday care:

> As I say he's been twice, I thoroughly enjoyed two weeks freedom, ahm... What did I do? I slept, I went to bed when I wanted to, I got up when I wanted to. If I woke up in the night I could read my book which I like to do. I... now, this probably will sound quite mad to you but every morning when I get up, before I can have my cup of coffee to wake me up, he has to have a cup of tea and his tablets and that irritates me beyond all measure! It gets me to a terrible pitch sometimes, I keep doing it but then sometimes I feel rebellion welling up. Well that was one of the wonderful things when he was in respite that I didn't have, I didn't have to do it. And it's a very small thing but it's like the straw, and ahm, I could watch television because sometimes he doesn't like the noise of the television.

Others went swimming, and generally had a quiet time. One carer very strongly expressed the notion of freedom (emphasis added):

> Well, what else did I do, I went swimming every day ahm, oh, [friend] came and took me shopping to the supermarket and we didn't have to rush back which was nice...[...]...There was *freedom*, that's the nice thing. I could go and visit friends which I did do, you know coffee and all that, which was very nice, which I don't always get to do in the three days [day care] because I have a lot of shopping to do, I like to go for a swim, and food preparation and all that. Well, while he was away I ate but I had all convenience food in the microwave [Laughter] and I ate when I wanted to and not just when Alan wanted to. But otherwise I don't know what I did really, not such a lot.
>
> I still could go [on holiday] I suppose when he was in respite but I wouldn't...[...]...I said [to her son] you don't realise, that bit of *freedom*, here in my own home, so I can go out and come back, I said, is worth so much. That is the

> *freedom*, I don't want to go [abroad], I'm quite happy here, you know, ahm, because there is *freedom* it's like a load being lifted, and I've got *freedom*, I can do what I like.

However, apart from a welcome break in the caregiving there was no evidence that the respite break resulted in an improvement in the carer's general situation and well-being. As for the demented person, it has been suggested that respite care appears to have more negative than positive effects (Nolan & Grant 1995: 52). Indeed, in the study there was little evidence of benefits to the person with dementia. Instead, several carers reported that their relative seemed to tolerate the experience rather than enjoyed what was happening to them. The following quotation shows how a wife was told when she collected her husband that he had not been very happy:

> Alan's been twice. He doesn't like it...[...]... he didn't like the food and they told me when I went to fetch him that he wouldn't sit down except at meal times and at bed time, he just wandered about the whole time.

Other carers felt that the demented person's condition had deteriorated while they were in respite and that their relative appeared more confused than before:

> Ahm, when she's been in the nursing home for some respite care... she seems to come away with the attitude... well, she doesn't know, er, where she's going to and she doesn't know where she's been and she doesn't know who's been to see her and it's all very... you know, she's lost it, and that's what I'm dreading. But then, you know, within a few days she's back in full force again and she's very much in control and on the ball and you think 'What's going off?', you know. It's almost like she closes down.

However, as the above quotation shows, the negative effects did not necessarily last. Nevertheless, other studies have found these effects on the person with dementia to be undesirable, and they may prevent carers from using respite care a second time (Newton 1997: 89).

Not all carers in the study wanted to use respite care for the person they cared for, a finding consistent with previous research (Cuijpers & Nies 1997: 173). Several problems with respite breaks were mentioned. To begin with, respite care seemed to be more popular with younger carers, in particular adult children. For them, respite breaks provided an opportunity to focus on their own social lives, careers and other responsibilities such as their own families (Chapter 4 and 5). There were more doubts about the benefits of a respite break among older spouse carers and the findings indicated that respite care may not be appropriate for this group of carers. It has already been discussed in previous chapters (Chapter 4 and 5) that the care older spouse carers give is very often based on love and becomes the focus of their lives (Wenger 1990a: 199). It appears, then, that the way in which the caregiving is rationalised influences the carer's attitude to formal care. Previous research has found that older carers were less likely to ask for help and more likely to continue caring for as long as they could manage (Wenger 1990a: 200). Instead of an actual physical break from the person with dementia, this group of carers was more interested in relief from responsibility and lack of sleep (Wenger 1990a: 212-3; Gilhooly 1984a: 125). My study uncovered similar concerns, although day care was generally tolerated. Respite care on the other hand was no option for some carers. A husband noted that he did not want respite because he had been married for nearly 60 years and had never been parted from his wife:

> It will kill me if I do.

This husband refused to take advantage of the respite breaks offered to him because he felt he would let his spouse down by sending her away.

Those spouse carers who had accepted respite care felt ambiguous about it. The following quotation is from a husband whose wife was going on her first respite break the following week:

> I'm still apprehensive, like, about letting her go, you know. It's hard trying to... you know what I mean, we've been married for fifty-odd year like, 53 year, and we've never gone anywhere separately... Although I know she'll be well cared for, you know, you don't doubt in that... you know, you have butterflies in your tummy, is she gonna be alright...

Another husband reflected that he felt neither he nor his wife was ready for respite yet but that he had been urged to consider it:

> You know, I really ought to be considering a longer term respite care for a week or a fortnight. That's the situation they have normally and that's the situation I don't like at all because I don't think she's bad enough and yet... there are times in the week when I think oh my goodness, I wish... I wish she could be going next week, I could do with a week's break.

To conclude, there is strong evidence to suggest that the current form of respite care is unlikely to be of benefit to older spouse carers due to their reluctance to take up the service. For this group of carers different forms of respite, such as home-based respite, may be more appropriate, as will be discussed in Chapter 8.

A second main problem with respite care concerned the lack of flexibility in its administration. It has been noted that the allocation of respite places does not necessarily take the carer's wishes and needs into account (Nolan & Grant 1995: 57). The study found that in some cases respite care was not available when it was needed, as illustrated by the following quotation from a daughter who only received an offer of such support after her father had suffered a fall and had been admitted to hospital:

> I would have wanted to be able to get respite care when I needed it. When I was desperate it wasn't there. By the time I got respite it was too late. One piece of advice: Try to get respite sorted out before you need it.

The daughter quoted above clearly felt that she had been let down by the formal sector when she most needed a break from the care of her father. As a consequence she felt disillusioned:

> You scream but they are all partially deaf!

It was further suggested in a feedback session that carers found they had little control over the use of respite care. Several had experienced a certain amount of pressure and felt they had to take those breaks that were offered to them because this was better than not getting respite care at all.

One wife was unable to find appropriate respite care for her husband due to a combination of dementia and severe mobility problems:

> I was asking initially for respite care for him, ah, but it sounds as if we might have all sorts of problems because the [homes] won't take him because of his mobility problems. Now, they do have [hospital] which would take him as a dementia patient with mobility problems but apparently the people that are currently in [hospital] are far deeper into the dementia than David is, plus they are a lot older, and they are frail, you know, they are old and frail, and that's why they, well, have the mobility problems. And it's not David's problem.

It appeared that the facilities available for demented individuals were not able to cater for his physical disabilities. On the other hand, those which provided the appropriate level of nursing care tended to admit severely confused older people which upset her husband who was only moderately confused and still aware of his surroundings. Another problem that was mentioned by this particular carer was that she believed a week away to be too long, and felt her husband was not confused enough not to worry about being abandoned:

> And I initially said, you know, just for a long weekend, just to give me that break, and they don't do weekends, they only do full weeks. I don't want him to go for a full week because he's gonna think I'm putting him away! 'Cause he is not far enough into dementia to appreciate it, or not to

> appreciate it, you know. He knows what's going on, and he's gonna think I don't want him.

The carer had no choice in this matter and had to either accept a full week or not use respite care at all.

The third problem identified in the sample related to the carers' concerns about the quality of care their relative would get. Several carers found the thought of someone else caring for their relative unbearable, particularly because they felt that not all respite homes available to them were of the quality they would wish for. One husband explained that his wife had lost her sense of smell and that probably she would not notice but that he was very sensitive to odours and found it unbearable to leave his wife in a home which smelled bad:

> My main difficulty really now is deciding whether I ought to think about this longer term respite care. I mean I went to...[Respite home]... it's a new home, very pleasant, en-suite facilities, very relaxed regime, they do what they like when they like, they've got some activities there and I thought this is great, but then you go to the lounge and you see them sitting around... I can't really see Helen sitting around like that at the moment. They are not sitting in straight rows like they are in some homes and you get an overpowering smell of urine when you walk through the door. When you walk through the door there, there was a little bit of a pong but we went there sort of mid-morning when they were only just sort of starting to get things organised, you see.

The following quotation shows how a wife had to reconsider sending her husband away for even a week after she found that, although he was not treated badly, the staff did not care for him with the consideration and respect she would have expected:

> Ahm...so then we said why not try [another home] so we sent him there for a week. Well, I don't know, he didn't like it there. The matron told me he was very uncooperative. I asked her why, knowing full well he can be, ah, so she said, er, 'Mainly dressing and undressing'. And it was she who called him a poor old man, well, I said 'I'm a poor old woman then'...[...]...I know Alan can get like that...[...]... and he fell out with one of the other patients...[...]...but anyway, we will see, I mean he's not badly treated there.

Carers' concerns about the quality and safety of care, has been mentioned in previous studies (Mullan 1993: 244; Nolan & Grant 1995: 59-60). It has been suggested that some of the carers' fears could be alleviated through increased communication between staff and carers (McAuley et al 1990: 209). For instance it has been observed that carers often felt that they knew the person with dementia best and therefore felt the need to 'educate' staff about their relative's needs (Chapter 8). Staff on the other hand sometimes misunderstood this concern and took it as criticism of their abilities. More open communication could prevent such problems and may help carers to feel more satisfied with the care their relative received. This issue was relevant for respite breaks but even more pressing if the person with dementia was admitted to full-time nursing care, as the following section illustrates.

Nursing homes

Permanent care arrangements were regarded as the very last resort by carers in the study and filled many of them with dread. Several issues were important in this context. To begin with, it appeared that the image of the workhouse frightened older carers most, although surprisingly even younger carers did not seem able to rid themselves totally of this concept. A daughter explained that she had to promise her father that she would look after her mother after his death to prevent her being admitted to full-time care:

> [He said] 'I don't want her to go in the poor house'.... which is what he meant by the state run nursing homes, you know, the old-fashioned attitude.

This 'old fashioned attitude', as this daughter put it, was still more widespread than expected. Previous studies found that many carers had an irrational fear of the 'workhouse' (Cohen & Eisdorfer 1986: 65; Nicholson & White 1993: 918; Ungerson 1987: 100; Victor 1995: 260-1). Unfortunately, these fears do not always seem to be unfounded. Kitwood (1997b: 9) has noted that

> '[a] new-style residential or nursing home, despite all its appearance of comfort and efficiency, may reproduce many of the worst features of the older institutions; and - in some cases at least- with the additional dehumanizing tendencies that accompany the relentless pursuit of profit'.

Secondly, there was a marked difference in the carer's attitude to nursing care between adult children and older spouse carers. Younger carers appeared less reluctant to actively organise full-time care for their parent when they felt they could no longer cope (Gilhooly 1986: 166). Older carers, on the other hand, did not resort to full-time care until they were forced to do so because they could no longer cope physically with the demands of care.

> It's hard, I mean, if ever it comes that I've got to make a decision for her to go into full-time care, I don't know what I shall do then, whether I will be able to cope with that all. I'll see that when time comes, if ever it comes.

It has been suggested that to have a spouse admitted into permanent care constituted an end to the marriage for many older spouse carers and was regarded as damaging to the relationship and sometimes even seen as equivalent to getting divorced (Oliver 1988: 75; Ungerson 1987: 99).

Thirdly, several carers felt horrified at the thought of having their relative admitted to full-time nursing care because they had experienced problems when the demented person was temporarily admitted to hospital for physical complaints, such as pneumonia. Staff in 'normal' wards in several hospitals in Sheffield had been found to be unable to deal with a patient with dementia. More serious incidents included food not being cut up and no help being provided with feeding despite the fact that the person with dementia had suffered a mild stroke and could not use one arm. This kind of problem was more widespread than previously estimated and a recent report published by the Alzheimer's Disease Society (National Newsletter; June 1997) found that problems have been uncovered in the provision of good nursing care. Patients with dementia seemed to be affected most by staff shortages which led to patients not being fed. In some cases, the person with dementia had gone without food until relatives noticed what was happening and provided nursing care. It is not surprising, in the light of these findings that carers in the study had mixed feelings about full-time nursing care for their demented relative.

Finally, those carers whose relative was or had been in full-time nursing care reported that there were a number of very well run establishments in Sheffield, alongside a number of unpopular sites. A problem that was encountered by one carer was that a nursing home would not take a person with dementia due to security reasons. One carer's father finally died in a mental hospital. However, this was several years ago and the data suggests that the situation has since changed for the better. Instead, very efficient nursing homes were mentioned which allowed the carer to chose the decoration and furniture of the room the person with dementia was going to occupy.

On the other hand several carers found the care their relative received to be inadequate (Walker 1997: 202). One carer in particular recalled that the staff did not appear to recognise the seriousness of her husband's physical condition (among other things severe dehydration and pneumonia) and that a doctor was not called until the demented person was nearly dead. The carer's husband died shortly after and the carer felt that even if her husband may not have been saved he could at least have been made more comfortable. Another problem was brought up by one carer whose wife had to be admitted to full-time nursing care following pneumonia. The carer felt very bitter about the indifferent treatment his wife received and noted that he thought the staff did not pay enough attention to the fact that, as a carer, he knew the sufferer best. This issue of the carer's belief that his opinions were not taken into account has been noted previously in relation to respite care (Mullan 1993: 244; Nolan & Grant 1995: 59-60; McAuley et al 1990: 209). One incident which greatly upset the carer mentioned above was that a framed picture of the family pet was 'lost' when his wife was moved from one room to another. Though a small matter in itself the carer felt that the framed photograph was his wife's only link to home.

The small sample of this research does not allow much to be said about the level of good nursing care generally available to carers of older persons with dementia. However, disregarding the generalisability of the sample it was nevertheless compelling that all seven carers whose relatives were institutionalised or had been institutionalised prior to the person's death had had harrowing experiences similar to the ones mentioned above. It would appear therefore that the problem of unsatisfactory nursing care of people with dementia may be more widespread than previously thought. This issue clearly needs to be addressed in more detail in future research.

Other services

Several other services were used by carers in the study, some of which were voluntary. The following briefly discusses sitting service, home helps, and other help carers received.

Sitting service

Another fairly popular service was the sitting service. There were several organisations which provided sitters, some of whom were unpaid volunteers, while others were paid up to £6 an hour (usually the carer had to fund this):

> Well, I did have a sitting service and I had a young man come twice a week, about six hours actually, and when [social worker] had to leave and then another came to see me and she said, 'Are you paying for it?', and I said 'No', and she said, 'Well, you should do'. And I said 'I don't know anything about that'. Apparently I slipped through the net, so I had to cancel that because they wanted six pounds an hour.

Some carers reported good experiences, having built up a friendship with the sitter. Others were not entirely convinced of the usefulness of sitters, in particular if they had to pay for one:

> But if you want the sitting service you can have it but you see they employ these agencies... [...]... and I think it's terrible. I mean, okay, some people need it, I mean some people need someone to come in and wash and dress them but they pay for that. Six pound an hour because the young

> lad came in to sit with him or take him out, ahm, ... he had this time-sheet and he was going through people and I asked him how much do you get paid for this and he said, 'I'm getting three pounds twenty-five for it but the firm charges six pounds'. And I think that's terrible, I really do, I think that's scandalous, when people are living alone or you've got a wife who's disabled and can't manage it that you've got to pay six pounds every morning of the week to be got up and washed and changed and get out of bed. And I mean, my age group, honestly, we've paid our stamps since we were teenagers.

Several carers found that the sitter did not come on time and was generally unreliable. For instance, one sitter was found reading a carer's personal letters, forcing the carer to cancel the service:

> Then we had a young man come. He were awful. He were very very naughty. Caught him reading one of me letters one day, so I said I'm not having this.

Another carer had problems with unreliability and expressed doubts about the sitter's suitability:

> I was told about this [Volunteer sitting service], the doctor told me and said get in touch and they came to see me and it was arranged that I would have a sitter once a week, and Martin, a chap called Martin.... and he came, and he was meant to come at twelve and he came at twenty past nine in the morning and I said to him, 'Look Martin, I don't...' and he said, 'Well, you go and do your shopping and I'll be with Alan for a couple of hours'. And he's got Parkinson's Disease himself, you see, but he's a volunteer, and well that happened a couple of time and I booked him for twelve o'clock and he did used to come when he took his wife to work in the morning which was twenty past nine, which was a bit difficult!

The carer also expressed the view that many female sitters did not want to sit with a person of the opposite sex and that there were not many male sitters available:

> But they have very few males who do the sitting and ahm, I think a lot of the ladies are not very keen on coming to sit with Alan. [Really, why?] I get that impression.

Contrary to this view was the observation that it appeared to be common to place men with women and women with men because learned social norms often meant that this arrangement worked best for both sitter and the person they sat with. Indeed, one daughter reported that her father would only get on with female sitters because he respected them and did what they asked him to do (in particular at meal times) whereas male sitters had been 'a disaster'.

Home helps

A number of carers were supported by home helps but it did not become clear in these cases whether this service was provided by the social services, voluntary services, or privately. This finding, that the majority of carers were largely unaware of who was involved in their formal care arrangements, will be discussed in Chapter 8. Similarly, some carers seemed confused about the differences between sitters and home helps. Generally speaking sitters did what the name implies; they sat with a person to give the carer a break. Home helps on the other hand were trained to assist with washing, dressing and feeding and some provided nursing care.

Very few of the carers in the sample reported that their demented relative was assisted by home helps. It has been observed in previous studies that older spouse carers are more likely to receive this service (Twigg & Atkin 1991: 11). This finding appeared to be confirmed in my research, although the small sample did not allow generalisation. Those carers who were supported by home helps were very satisfied with the service they received. One carer recalled that he was pleasantly surprised when his home helps, in addition to the tasks they already did, offered to give his wife breakfast, too, so that he could have his breakfast in peace:

> I mean, now I have... now these ladies they come in in the morning, they get her out of bed, they completely wash her down from head to foot, you know, dress her and ... and then a few weeks ago they even started giving her her breakfast for me. I mean, it were their suggestion that, not mine... but that's made it easier because... because I mean, before I were trying to eat my breakfast and feed her at same time like, and I'll finish up with cold coffee, you know, and all that.... but...so they do that for me and now they even come in in't evening about half past six and undress her for me... undress her for me and sit her in a chair and then I take her to bed.

The carer found this a great help for himself and thought his home helps were very kind and understanding and went out of their way to support him. On one occasion they had even accompanied him to his GP practice when his wife needed to have tests for a urinary infection.

However, two problems with home helps were mentioned by other carers. Firstly, a daughter reported her bad experience with one particular home help who was unreliable and appeared to have very little time allocated to getting her father up, washed and dressed. She felt that her father's exposure to being rushed by someone who was to him a stranger upset him and made him aggressive. Secondly, in some cases where the use of home helps was not required on a daily basis, but for instance only for bathing, it was found that a different person was sent every time. The carers in the study felt that this confused the person with dementia more than necessary and caused anxiety. Indeed, previous research has found that having no continuity could be detrimental to the demented person's condition (Zarit & Pearlin 1993: 307).

Other (private) help

Four carers privately employed a cleaner, two others a gardener. All other carers rejected the offer of help, saying that they did not feel they needed help with the practical tasks of keeping the house clean. One carer remarked that the latter was the least of his problems:

> I can't leave her... alone in the house, so I may... I may as well do the housework. I've got to do the housework anyway, since the middle of last year I've been doing all... all the main... and lots of the other work... so, er...that's not a problem.

He maintained that being retired, he had enough time to do the cleaning and cooking, especially as there was very little to do with only two people in the house.

EMOTIONAL SUPPORT

Emotional support has been defined as the help given to carers that aims to enhance the carers' ability to cope (Stephens 1993: 262). These services include counselling, psychotherapy and support groups. Both day care and respite breaks, the two main interventions, go some way towards having benefits for the carer, as the previous section has illustrated. However, although the carers in the study generally welcomed every bit of help they could get, previous research has shown that the benefits of this purely instrumental support have not become clear. It has been suggested that, although carers do seek help for problems that are unrelated to their own psychological well-being, the majority are motivated by psychological stress rather than the physical strain of caring (Stephens 1993: 269; Bibbings 1998: 173). As the previous chapters have shown, emotional support was often what carers needed most, but this appeared to be the least focused on by service providers. There was little help designed specifically to address the emotional needs of the carer. Indeed, it has been suggested that carers are not usually seen by the medical profession as prospective patients but are treated as resources and co-workers (Nolan & Grant 1995: 51; Bibbings 1998: 179; Twigg & Atkin 1991: 9; 1994: 11-15).

Several services for carers have attempted to fill this gap by providing an environment in which carers could share their experiences. Only two carers in the study had had access to psychotherapy which was only offered in cases of severe mental breakdown.

However, all carers attended, or had attended, support groups (The latter was a characteristic of the sample and does therefore not necessarily reflect the general picture). Research has shown that for the majority of carers, attending a support group was a positive experience (Savishinsky 1990: 92).

Role of support groups

Support groups have been mentioned as useful in coping with isolation, and they provided the carer with a certain appreciation of the work they did:

> To hear other's problems doesn't solve yours but helps to know you are not alone.

Support groups seemed to offer those carers who attended some form of acknowledgement of their efforts and gave a certain amount of encouragement (Chapter 5). Several carers noted that it was important to talk to people and that it helped to hear that there were others 'worse off':

> But it does do you good because there's always somebody worse off, always somebody with a problem that's much worse than yours, ahm, also you do have this feeling like comradeship almost.

Support group meetings for carers were very different in their nature and content (Murphy 1986: 64). Some meetings served mainly as an informal discussion, letting carers introduce themselves and talk about their problems. Other meetings were more structured with an agenda of topics to be discussed, such as how to get formal services. In the third type of meeting, an outside speaker was asked to present a topic, such as information on a certain type of service or organisation. (More information on the dynamics of the three different groups observed in the study can be found in Chapter 3).

In groups which were mainly attended by younger carers there was more discussion on practical topics such as the legal arrangements, for instance how to arrange for a power of attorney, and financial problems. In groups attended by spouses, on the other hand, the talk centred around the carer's mental and physical health and carers tended to give each other advice on coping strategies. In response to this difference in focus several different groups existed, catering either for spouse carers or for adult children who cared for a parent. A frequent topic of discussion in all support groups was the lack of information and the unsympathetic behaviour of some doctors (Chapter 6). It was acknowledged that it was very difficult to ascertain whether dementia was present, and which dementia it might be. In many cases there was a mixture of multi-infarct dementia and Alzheimer's disease, or other conditions such as Parkinson's Disease.

From the carer's point of view, however, putting a name on the condition, whether the diagnosis was correct or had to be revised after further observation of the person with dementia, seemed to help them accept the problem. It has already been noted (Chapter 6) that carers found it important to have a frame of reference within which to exchange their views and experiences. It was interesting to observe in this context that the term 'Alzheimer's disease' was often used as an umbrella term.

However, a number of problems were reported in relation to carer support groups. One problem was the fact that such groups only seemed to attract a certain type of carer and that many others cared without having this emotional support. One reason for not attending support groups was that some carers did not know they existed. Others did not receive help such as day care and could therefore not leave the person with dementia alone to attend a group meeting. For some carers, however, it appeared to be a general anxiety that prevented them from leaving the person with dementia alone, even if they had someone to sit with their relative. This feeling, that something might happen in their absence, has been noted elsewhere (Twigg & Atkin 1994: 37).

Secondly, it was suggested in the feedback sessions that support groups were not useful for every carer. In particular in the early stages of the disease some carers reported that they did not feel ready to confront other people who were in the same situation. One carer also suggested that, although he attended a group, he did not feel he benefited a lot because he frequently felt annoyed about people who 'moan all the time' while others, like him, had cared for much longer and coped with much more, such as incontinence. Thirdly, there was no consensus among carers about what the main aim of a support group should be. The majority of carers felt that it was good to 'have a moan' among people who understood what they were going through. Although every situation was different there was a common theme in the support group and a lot of similarities in the carers' experiences. A daughter caring for her father reported what she felt was a good sign, namely that she had seen several people 'break down' at some stage, and that she had 'let off steam' once herself. However, a number of carers suggested that support groups should not be there to 'have a moan' but that there should be some structure, in the sense of providing information on the disease and on the services available in the Sheffield area. Indeed, other commentators have suggested that support groups should include an educational element to enable carers to not only be supported emotionally but to help themselves (Morris & Morris 1993: 262-3). It could also be speculated that, given the right environment in support groups, carers could potentially move beyond the need for emotional support within a group and give feedback to service providers. This function of support groups as a means to prepare carers to speak out about their needs and experiences will be discussed in detail in

Chapter 8. Finally, another unexpected problem with the support groups encountered in the study was that one group actively discouraged former carers, including those who were recently bereaved, from attending. It was feared by the group leaders that these carers frightened new carers with stories of what may happen in the later stages of the disease. What it meant for bereaved carers, however, was that they lost their source of emotional support by abruptly being cut off from current carers as soon as the person with dementia had died.

Bereavement

In those instances where the person with dementia was deceased, death had often occurred unexpectedly and suddenly, giving the carer very little time to adjust to this new situation after caring for several years. Many carers felt that there was suddenly a gap in their lives and that, in their grief, they lost all sense of purpose immediately after the death of the person with dementia (Lewis & Meredith 1988: 15-6; Brown 1996: 5).

There was some indication in the research findings of the way the five bereaved carers attempted to cope with the loss of the person they had cared for. Three of the adult children in the sample who cared for a parent reported that their own supportive marital relationship had played a big part in helping them come to terms with the death or institutionalisation of the parent. Others resorted to different ways of coping with bereavement. It was interesting to note that carers appeared to fill the gap in their lives with what they knew best, caring for people with dementia. Of the five carers whose relative had died, three, all women, had already found another such caring role. Several possible reasons were mentioned in the interviews. The first reason was guilt. All these previous carers felt they had failed the person they cared for in some way, in particular as the death of the person with dementia had been sudden and traumatic. Several carers said that they thought they should or could have done more. One carer felt directly responsible for the person's death: An accidental fall in the home led to hospitalisation, and the person with dementia died of pneumonia. It is conceivable that this feeling of guilt may have driven some carers into voluntary work, in the sense of trying to make good what they felt they neglected with their own relative. The second possible reason was that carers may have tried to cope with their bereavement by going out and being among people who knew and cared about dementia, for instance those people involved in organisations and support groups. It has been reported that carers have a great desire to get as much information as possible about the disease and new developments even after their own caring has ended (Fortinsky & Hathaway 1990: 608). Being involved on a voluntary basis enabled carers to get the information they required. Another factor, as discussed above, could have been that some support groups discouraged former carers from attending meetings but that voluntary workers were always welcome.

Finally, a possible reason was that the carers enjoyed their caring role and found it rewarding. However, this possibility was not suggested in the interviews. All but one bereaved carer felt relieved, but at the same time guilty about this feeling, when the person they had cared for was admitted to full time care and then died.

To summarise, there were no facilities to help bereaved carers to cope with their loss and some support groups appeared to cut off their support. Two issues are of importance here for future research. Firstly, a daughter who lost her mother, reflected on this lack of support and suggested that professionals should talk to families about the death of the demented person and prepare them for a possible sudden loss. Secondly, some carers found they could deal with their loss by getting involved in voluntary work. The fact that these carers were all female may support the finding of previous research studies that it seems to be harder for men to re-establish a social life after the death of their spouse (Scott & Wenger 1995: 160). Unfortunately, the sample was too small to elaborate further on this potential gender difference in coping with bereavement. However, on the basis of the finding that for some, most notably women, voluntary work provides an enjoyable activity in dealing with their bereavement, it has been suggested (Chapter 8) that former carers could use their knowledge of the disease and their practical experience of caregiving to play an active part in educating current carers (Fortinsky and Hathaway 1990: 609) and professionals (Soliman & Butterworth 1998: 26-7).

CONCLUSION

It has been shown in this chapter that carers had to be both care providers and care managers and that they needed to play an active part in negotiating and supervising services provided by the formal sector. Numerous problems were brought up in the study, with the main concern being that those carers who were more passive effectively lost out on much needed help. The formal help that was received by carers was on the whole regarded as very good and the carers who received help were grateful for what they had. However, several problems were uncovered in the study in relation to the different forms of care provided. The majority of carers either did not know whether a social worker had been assigned to them, or had only seen their social worker once in several years. Furthermore, while day care was much appreciated by those carers who had access to this service, there appeared to be a transport problem. In some cases the unreliability of the ambulance service limited the carer's free time. As for respite care, it was expressed that respite breaks were not appropriate for all carers. In particular older spouse carers were reluctant to take advantage of this service. Finally, there was much uncertainty about the safety and quality of permanent nursing care.

To conclude, whereas carers of older people with dementia appreciated some aspects of the formal support that was available to them, there are several areas which clearly need to be addressed in more detail in an attempt to improve the carers' experience of formal support and thus the carers' ability to provide care at home. Some of these areas were shown to be an over-emphasis on instrumental care, a lack of flexibility in the administration of services, and a failure to provide bereavement services to former carers. These issues will be discussed in the following chapter.

CHAPTER 8: CONCLUSION

This thesis has provided an analysis of the situation of informal carers of older people with dementia. Dementia has been found to have unique consequences for carers in terms of the length of care that is required, the nature of the care that is needed, and the unpredictable course of the disease. It has been confirmed that the majority of older people with dementia are cared for by relatives or, more typically, one relative, at home. This care set-up has been shown to have considerable effects on informal carers and there has been evidence of physical, psychological, financial and social strains. The response of the state to the situation of carers has been inadequate and is based on practical support such as day care and respite care. Only few carers had access to these services and for the majority of carers this form of support was inappropriate.

The study has brought together within a single account the literature in the field and the research. Qualitative interviews were conducted with spouse carers as well as adult children caring for a parent. Firstly, by focusing on the carers' views and interpretations of their situation it was possible to gain a clear and comprehensive picture of the real situation of carers. To date, there appears to have been a mis-match between the assumptions which have informed community care policies and the carers' actual views and needs. Secondly, the study breaks new ground in that it provides an analysis of the way different groups of carers, adult children and spouse carers, attempt to make sense of their experiences. Previous studies, mostly quantitative, have found no consensus on the processes at work in enabling some carers to cope better than others. Finally, the study has highlighted the carers' relationship to the formal sector and has demonstrated that the current level of formal intervention is inadequate and largely inappropriate for older people with dementia and their carers. Services are mainly based on practical support, such as day care and respite care, and are usually only provided following a crisis in the caring relationship. There is very little emotional support available to carers.

The analysis of the findings has identified important flaws in the understanding of caring relationships, the ability of carers to cope, and their need for support. I have suggested that government policy in relation to carers of older people with dementia is characterised by contradictory principles and that there is a lack of coordination between the different players involved in providing services. This failure of government policy has had an impact on older people with dementia and their carers. This study has aimed to redress the balance in favour of carers. Three issues are of importance if the situation is to improve: the recognition of the dementia and the status of the carer, the management of care, and the empowerment of carers. These issues will be discussed further in this chapter, which also summarises the study and its main findings, and then comments on the policy implications of the research.

THE STUDY

My research was an exploratory study of the situation of carers of older people with dementia who are cared for in their own home or the home of the carer. The main aims of the study were, firstly, to obtain a comprehensive picture, from the carer's perspective, of the care currently given to older people with dementia. Secondly, the level of support provided by the informal and formal sector was analysed. Thirdly, on the basis of this evidence I attempted to identify ways in which the situation could be improved to make care at home more effective, providing good care for the person with dementia while ensuring better health outcomes for the carer.

Eighteen unstructured interviews were conducted with a sample of carers taken from three carer support groups in Sheffield. The interviews were on average just over an hour and a half long and were tape-recorded. The method of 'grounded theory' (Glaser & Strauss 1969) was used to identify provisional coding categories by constant comparison and the evolving themes were then tested in subsequent interviews. After the initial analysis of the data, feedback sessions took place to allow carers to comment further on the findings as well as, in effect, verifying the latter. This approach provided the respondents with a high degree of involvement in the research process beyond the stage of data collection (Chapter 3).

Three major limitations have been identified in the approach taken to study the carers' experience of home care. To begin with, the study focused exclusively on how carers *felt* about caring. In other words, there was no reliable information on actual service provision (whether statutory, private or voluntary) and the precise nature of the carer's relationship with formal services. However, the majority of carers appeared uncertain about who provided which service and who was involved in arranging their care provision; an important finding in itself. The only way to get around this problem and to get an accurate picture would have been to change the interview format to a more structured one and to access case notes to verify information. As this was not the objective of the study, the potentially limited nature of detailed information concerning formal service provision has been taken into account in the analysis of the findings.

Secondly, the nature of the interviews meant that carers only reported those issues which were of particular importance to them. One consequence of this was that I did not obtain a lot of information on the financial aspects of caring apart from some hints about the costs of caring. Other research has shown that there are long-term financial effects, in particular for adult children. However, I did not see a way to include detailed questions on finance without compromising the good rapport by asking for what may have been seen as too personal information. As a result I obtained a wealth of information on the physical, emotional and social effects of caring with less information being proffered about carers' financial affairs.

Thirdly, the way the sample was obtained meant that the study, like many others in the field, may have helped to perpetuate the stereotype of 'the carer' (Fisher 1997: 137; Graham 1997: 127), that is, white, middle class, middle-aged, mainly female, and married with an established family network. To overcome this problem effectively a larger sample of carers could have been used to achieve a greater mix of different carers. However, this was beyond the scope of this small-scale qualitative study. Alternatively, it would have been necessary to narrow down the research objectives and focus on one group of carers, for instance men who care, instead of allowing variety in the sample studied. However, this would have made a comparison between different carers impossible.

Moreover, for this study it should be noted that all but one carer of each of the three support groups was interviewed, so that the sample reflected the *actual* distribution of carers in such groups. In Sheffield, there is an equal proportion of support groups run by the voluntary sector and those linked to formal services such as day care. Although the evidence on the composition of such groups may fit the picture of 'the carer', it also serves to highlight the problems in current service provision which appear to target certain carers (Chapter 7). It has also already been acknowledged elsewhere (Chapter 3) that carers of ethnic minorities do not at present attend these support groups in Sheffield and that this issue needs to be addressed in future research and practice.

SUMMARY OF FINDINGS

Qualitative interviews took place with spouse carers as well as sons and daughters who cared for a parent. It emerged that all respondents had provided assistance to their relative for a considerable period of time before a diagnosis of dementia was made. The carers had taken on full and sole responsibility for the person with dementia and there was no evidence of a significant amount of emotional or practical support from other family members, neighbours, or friends. The finding that there was typically only one carer appears to be specific to dementia where long-term intensive care is needed.

There was a marked difference between older spouse carers, younger spouse carers and adult children, in the nature of care given, the attitude to care, and the ability to cope. For instance, spouse carers experienced the loss of the partnership as most distressing. Adult children, on the other hand, encountered what they saw as a 'chunk' taken out of their lives. Often they had other commitments, such as employment or the demands of their own families, and found it difficult or impossible to strike a balance between these and their caring role. The group of younger spouse carers shared attributes of both of these other groups and found themselves in a particularly difficult situation.

Common to all carers, however, was the fact that the emotional strain of caring appeared to be experienced as harder to bear than the physical demands of caring for a person with dementia. The majority reported feeling insecure in their role as carer, unsure of whether they were doing the right thing. Although none of the carers questioned their role as main carer, the need for appreciation of their efforts and reassurance that they were doing their best, was emphasised.

A number of problems were found in relation to the carers' contact with formal care. All carers had experienced one or more crises before the dementia was formally recognised. The main 'stumbling block' in this process was the carer's or the demented person's GP. The interviews indicated that only very few GPs had the knowledge, and the ability to communicate this effectively to the carer, so that a diagnosis and referral for assessment and services was delayed.

Generally, the processes of diagnosis and assessment were regarded as inadequate. For instance, the practice of assessing the demented person's condition and need for services on a short home visit led to an underestimation of the person's confusion because demented individuals are capable of putting up a front for short periods of time. Frequently the carer's own judgement was also ignored and the carer's presence discouraged.

It was felt by carers that there was a lack of information on the disease and on available services. Participants in the study claimed that they had encountered great difficulty in obtaining information, particularly at the crucial time of diagnosis. Adult children were better informed than the group of spouse carers about symptoms of dementia and support services. All carers maintained that they would prefer to know what could happen in the course of the illness, instead of having to fight an 'unknown enemy'.

The range of social and health services obtained were believed to be good but a patchy provision was revealed, ranging from carers with a lot of help to those with no support at the time of the interview. It was suggested that obtaining formal care was partly down to 'luck' in a 'hit-and-miss' system, and partly down to the carer's abilities to negotiate services and 'work the system' effectively.

The services that were available to this sample of carers were mainly day care and respite breaks. Those facilities with which the carers had become familiar were considered good but it was pointed out that these services were not suitable for all carers and all demented persons. For those carers where this type of support was seen as adequate, a desire was voiced to have more centres of excellence where quality care was given, even if this restricted the availability and amount of support each carer was likely to receive.

Finally, the help the carers themselves received was examined and very little emotional support for the carers was recorded. Although support groups for carers have aimed to address this gap, they were not regarded as helpful by all carers. Bereaved carers in particular found that once their caregiving role had ended there was no support for them available to help them cope with their loss. The latter was often exacerbated by the demented person's sudden and dramatic death following a fall, a stroke, or some form of infection.

POLICY IMPLICATIONS

The previous section has summarised the main findings of the study in relation to the carer's situation, coping strategies that are employed, and the relationship between the formal and informal sector. It has become clear that dementia creates a very unique caring situation. To begin with, both the length of the disease and the range of symptoms experienced by the person with dementia distinguish the caring experience from that of other diseases. In particular, the intellectual deterioration of the person with dementia is thought to place the greatest emotional strain on carers. Secondly, in the majority of cases there is only one carer, rather than a network of care as can be found in other caring relationships. This main carer is usually a close relative, often a spouse or adult child, who provides intimate care. Thirdly, there is a stigma surrounding dementia which means that very little information is available to carers about the disease and the channels of support. Fourthly, the response of doctors is often inappropriate because they are either ill-informed, or feel helpless because there is no cure or effective treatment. Furthermore, there are no services specifically for older people with dementia, and the existing service provision may be inappropriate. Finally, it has become clear that there are serious flaws in service providers' understanding of the carers' real situation which influence the provision of support. Also, the current system of supporting carers has been found to be inadequate in almost all aspects of care provision: diagnosis, assessment and management of dementia, and practical and emotional needs of carers. The section below focuses on each of the main findings of the study and identifies which areas will have to be addressed in order to improve the situation of carers. There are three main areas where reform is needed: The recognition of the dementia and the situation of carers, the management of care, and the empowerment of carers.

Recognition

The study has uncovered a mis-match between the views of carers and the views of service providers. In policy debates, the definition of the term 'carer' has been vague and as a consequence there has been no real recognition of the role of carers in the system. For this reason, attention has to be given to the different social and psychological resources of carers. Furthermore, it is vital to improve the practice of diagnosing and assessing the dementia. In this way, information on dementia and services could be given to carers before a crisis necessitates intervention.

Caring for dementia

Previous research studies have placed great emphasis on the gendered nature of caregiving and the plight of the large number of women who provide care (Chapter 2). This thesis has argued that the picture may be more complex in the case of dementia care, with gender being just one factor among many in the choice of carer as well as the experience of caring. Dementia is different to other diseases because the intimate care that is required in the long term is almost always provided by a close relative. With only close relatives involved in the choice of carer there is less room for negotiations and a strict hierarchy is present (Chapter 4). Spouses are always expected to be the first choice of carer, whether male or female. It has been found that for this group of carers, gender is less relevant and the older couple is more concerned about managing to keep going (Wilson 1995: 111). If no spouse is available, an adult child takes on the role of carer. Here, gender does play a part, in that daughters are more likely to be expected to care than sons (Chapter 4). If there are no close relatives, the person with dementia is in danger of being institutionalised. There has been very little evidence in this and previous research that neighbours and friends provide more than temporary care or support in a crisis for a person with dementia (Chapters 2 and 4). In the light of this evidence, it has been proposed to analyse the needs of carers in relation to their stage in the life course rather than their gender alone (Chapter 2). Three distinct groups were identified in the research: older spouse carers, younger spouse carers, and adult children.

The study has shown that there is usually one carer who takes on full responsibility for the care of the person with dementia (Chapter 4). The significance of this finding should not be underestimated. For instance the White Paper (DoH 1989: 4) assumes that 'the great bulk of community care is provided by friends, family and neighbours', giving the impression that there are a plethora of informal helpers at hand. This suggested form of community care places a heavy reliance on the family, in particular marriage (Askham 1995: 92). Carers are often talked about in the plural and there is no recognition that more often than not there is one individual who cares. The research has confirmed that the majority of care is provided by one family member, usually a spouse or adult child. More importantly, there was no evidence of anything that might be called a social support network (Chapter 2 and 4). The reason for this lack of informal support may relate back to the very different nature of care required in dementia care, as compared to other diseases, such as cancer, where patients usually retain their cognitive abilities (Chapter 2).

Thus, the debate on how to help carers of older people with dementia needs to be much more aware of the fact that there may be no network of potential carers but normally only one carer who takes on the caring role with little or no help from other relatives. In other words, the concept of a 'natural' support networks may be too simplistic for the care of individuals with dementia. The implications of this finding for the policy debate are clear: it should not be assumed that a social support network exists. Rather than relying heavily on the family it should be recognised that formal support has to be provided much sooner. The aim should be to arrange other support (paid and unpaid) to back up family carers. Furthermore, it has to be recognised that carers are not a homogenous group (Allen et al 1992: 305) but individuals with very different needs. The study has identified the different attitudes to care and the resulting differences in the needs of spouse carers and adult children who care (Chapter 4). For example spouses have a different approach to care than adult children, due to the intimate relationship to their partner. However, these needs are not being addressed in current service provision, an issue which will be discussed below.

Coping with caring

Chapter 4 has presented the physical, psychological, social and financial effects of caring on the carers in the study. It has become clear that, although the physical side of caring was difficult for many carers, it seemed to be the 'subjective burden', the emotional involvement, which was hardest to bear. Again, differences in coping abilities between carers were reported (Chapter 5). For older carers the loss of the partnership was often felt most acutely. However, not every partnership is a loving one and the caring situation can be destructive as well as supportive. Therefore, it should not be assumed that a spouse is the best person to provide care but that there are also destructive relationships which can cause long-lasting damage (Qureshi & Walker 1989: 22, 244; Allen et al 1992: 304).

Adult children caring for a parent, on the other hand, reported a lot of anxiety about their own future, in terms of financial security as well as the prospect of having personal relationships. Several carers in the study regarded going to work as their only form of social life, without which they would not have been able to cope with the care of their parent (Chapter 5). The importance of this psychological dimension of employment has not been given enough attention (Gilhooly 1986: 170; Baldwin 1995: 127). For those who gave up work to care it was found that having to give up employment could have far reaching consequences. To begin with, carers may sacrifice more than just a current income. Although the study did not cover the financial consequences of caring in any detail (Chapters 4 and 5) there was some evidence to suggest that carers feared the prospect of not finding employment in the future and thus compromising their own financial security, in terms of pensions, in their own old age (see also Baldwin 1995: 125; Bibbings 1998: 175-6; Ungerson 1998: 173; Hancock & Jarvis 1994: 5-7). Several factors are thought to influence the financial circumstances of carers (Chapter 4). For example, gender plays a role, in that women are thought to suffer most financially because they are more likely to give up work, or work part-time, resulting in low pay and inadequate pension entitlements (Hancock & Jarvis 1994: 6). More research needs to be conducted to assess the financial as well as the psychological dimension of working carers.

Generally speaking, for all groups of carers, there has been much research into the effects of caring on carers but little attention has been given to the *long-term* effects of caring (Hancock & Jarvis 1994: 73). The possible detrimental effects caring can have on the future life and well-being of the carer have not been analysed sufficiently and this issue is therefore not addressed in enough detail in the debate on coping with caring. At present, then, there is no recognition of the psychological, physical, social and financial consequences carers may have to face in the long-term. It is important to investigate whether an emphasis on more preventative services would help to prevent physical and psychological long-term effects. It also has to be recognised that practical help is not what all carers need or not the only thing they need. The study has shown that the majority of carers found the emotional dimension of caring hard to cope with and would therefore like to see more support in dealing with the psychological stress they experience. Furthermore, it has been stressed that carers have different needs which require different responses from the formal sector. There clearly have to be services tailored to individual carers because each carer copes differently. The emphasis on 'packages of care', as suggested in the White Paper (DoH 1989), appears to be a step in the right direction in this context. However, as will be seen below, only very few carers receive intensive packages of care, with the majority having to go without much needed support. Secondly, it is clear that more should be done to address the financial consequences of caring. In addition to losing out on income, pension entitlements, promotion, and savings, carers may also face costs directly related to their caregiving, such as heating, laundry and transport costs (Baldwin 1995: 129). At present there is little help for carers and current benefits, such as attendance allowance, are hardly adequate to even begin to compensate carers for these extra costs.

Information

The study has identified a lack of information on dementia as well as on services (Chapter 6). Carers reported that they were not given adequate information when they needed it most, that is, at the beginning of their caregiving and at the point of diagnosis, if a diagnosis was made. Also, those carers who actively tried to get more information encountered numerous problems in their attempts and were either not taken seriously or were 'fobbed off' with vague or inaccurate explanations of their relatives' condition.

Several issues have to be addressed to improve the situation. To begin with, the assumption that professionals have enough information themselves and the ability to communicate this to the carer needs to be challenged. It should be noted that the majority of carers prefer to know the truth about dementia and the full picture of the possible deterioration of their relative. Several carers reported feeling patronised by professionals who seemed to think they had to spare the carer the details. Similarly, carers need to be able to access information on services (Bibbings 1998: 174). In relation to this information it has been questioned whether there is a genuine lack of knowledge among professionals (Chapter 6). In some instances it appears that a rationing of information takes place which is associated with rationing of services (Allen et al 1992: 299). In other words, carers are not informed on services because by doing so, professionals create a demand they cannot meet due to a lack of resources. As a consequence it has been noted that many carers are not aware of which services are being offered in their area of residence and can therefore not make an informed choice (see below).

Secondly, the study has found that carers need a frame of reference to relate to their experiences (Chapter 6). A great need to communicate about the perceived different stages has been uncovered which is used in carer support groups. It seems to help carers to understand what is happening to the person with dementia and it serves to put their own and others' experiences into perspective. However, a word of caution is necessary. Although the Alzheimer's Disease Society has done invaluable work in shedding light on the plight of carers and raising awareness of dementia, it has unfortunately also caused a considerable amount of confusion among carers due to its name. It has been noted in Chapter 7 that 'Alzheimer's ' is used as an umbrella term in support groups. Whereas this finding reflects the way carers themselves have attempted to put their situation into perspective, it also highlights the real need for an adequate and accurate reference model. Unfortunately this need seems to be ignored by the medical profession which dismisses the idea of stages because, clinically, it is said that there are no stages of dementia and every individual is affected differently by the disease. Therefore, steps should be taken to have a simple reference model to ensure that carers and professionals literally 'talk the same language'.

Thirdly, the feedback sessions suggested that much needs to be done to raise awareness of dementia among the general public. It was suggested by carers that only by educating people about the condition can something be done about the stigma attached to dementia. It was pointed out that classifying dementia as a mental illness, as the Department of Health has done (DoH 1989: 55), does not help its image. To get away from this image one carer suggested a programme of talking to primary school children about dementia. The carer hoped that this approach of bringing about greater tolerance and more knowledge among the younger generation might pay off in the future. Another suggestion has been to produce a list of warning signs of the possible first symptoms of dementia, similar to the lists published for meningitis.

What needs to be done, then, is to make more information on dementia and on services readily available to carers, professionals, and to the general public. To achieve this, there needs to be a 'single accessible source of comprehensive advice' (Twigg & Atkin 1991: 9). Carers have to be able to access information at the beginning and throughout their caregiving, and there has been evidence that this need for information does not cease when the person with dementia dies. On the contrary, for some carers, the desire to keep informed appears to be part of their grieving process and a useful way to cope with their loss. At present, voluntary organisations, such as the Alzheimer's Disease Society, distribute leaflets and booklets which are designed to give carers information on the disease as well as services. In addition, Community Health Sheffield has developed a training package for their 'Caring and Coping with Dementia Project' which was first put into operation in July 1996. The emphasis of this project has been to educate carers about the disease as well as making them more aware of their own needs.

Furthermore, it is important to train professionals, in particular GPs, so that they are better equipped to diagnose dementia and inform carers about the disease and prospects. The problems identified in the primary care setting are well documented (Chapter 6 and below) and there have already been attempts to address the shortcomings. For instance the 'Action on Alzheimer's' training programme (Iliffe 1997: 21) which ran in May and July 1997 received a positive response and provided GPs, as well as other professionals such as community nurses, with a chance to learn more about dementia and how to manage it. It is hoped that similar projects will be set up in the future to reach more GPs. The training of GPs is more urgent than ever, in particular since the recent White Paper (DoH 1997) has given primary care an even greater role in the NHS.

Diagnosing dementia

Chapter 6 has shown that there was a crisis in every case before the condition of the demented person was recognised. However, even this recognition did not necessarily involve a full assessment and diagnosis. This policy of crisis management has been criticised elsewhere (Chapter 6). There is also research evidence to show that early intervention, before a crisis takes place, and 'intensive care management' can and does improve carer's lives (Killeen 1998: 13-14). The initial problem lies in the early and correct diagnosis of dementia. In Britain, GPs are seen as gatekeepers to more expensive secondary services (Hill 1996: 119). In other words, for most carers their GP is the first person they approach for help, and it is the GP who decides whether action has to be taken. Bibbings (1998: 174) notes that 'a good GP can transform a carer's life simply by putting him or her in touch with services'. Unfortunately this first step may not be taken.

The study has shown that GPs may not be the right person in the role of gatekeeper when dementia is involved. Carers experienced very different GPs, ranging from the unwilling and unhelpful to the knowledgeable and helpful. However, the majority of carers found their GP to be a 'stumbling block'. Two issues were discussed in the feedback sessions. Firstly, carers noted that there was a lack of knowledge among GPs about dementia and about possible services. In particular older GPs appeared to find it difficult to recognise dementia in a patient. Secondly, many carers criticised their GP's attitude and their inability to communicate with the carer. A further problem was added when the carer and the person with dementia had different GPs. Some GPs refused to talk to the carer about the person with dementia due to patient confidentiality. However, although the ethical problems were understood and accepted by most carers it was nevertheless criticised in the feedback sessions that GPs would not *listen* to the carers' concerns, when listening did not in itself present a breach of confidentiality on the part of the GP. Other carers found their GPs positively patronising and felt that they did not get the information they wanted because the doctor wanted to spare them the truth. Iliffe

(1997a: 21) has referred to what he terms the 'heartsink effect', meaning effectively that the emotional impact of a diagnosis of dementia on the GP may lead him or her to deny the diagnosis:

> Since no rapid treatment response is possible and the disease itself has a heartsinking effect on all around it, avoidance of the diagnosis may influence professional thinking. This may explain the discrepancy between the ability of general practitioners to identify dementia when given case histories, and our much poorer actual practice.

However, this study should have demonstrated sufficiently that the potential emotional trauma of GPs is nothing compared to the situation carers of a person with dementia face if they do not receive a diagnosis. Therefore, there is a great need for GPs to be able to communicate more effectively with carers and to listen to what they have to say. Carers do not expect GPs to know everything, as long as doctors admit to their lack of expertise, and maybe even to their feelings of helplessness, and offer to get more information.

However, the GP's role as gatekeeper can have more serious consequences in the long run for the carer and the person with dementia. In an ideal, though very rare, situation the GP would suspect a diagnosis of dementia, refer the patient on to secondary services, and then maintain effective cooperation between him or herself, and the social and health services. The study has shown that the reality looks very different. Some carers got no help from their GP and no diagnosis was made. For some, this meant approaching a different GP for a second opinion. Others carried on caring until a crisis took place which precipitated support. A third group, referred to as the 'hidden carers', may never be in touch with services (Moriarty & Webb 1997: 20).

Another group of carers encountered GPs who suspected dementia but deemed it unnecessary for the person to be referred for an assessment. Partly this seemed to stem from the belief that nothing could be done for the person with dementia because there was no cure, and partly it seemed to have to do with a lack of resources. Indeed, a specialist at the Alzheimer's Disease Society conference (Warwick University, September 1997) urged GPs to refrain from referring 'normal' dementia patients and reserve expensive brain scans for those cases where the symptoms were 'abnormal' (That GPs may not be able to tell normal from abnormal has already been established above). Instead, the GP referred the carer and person being cared for directly to social services to arrange practical support such as day care. Whereas in some cases this may have been justified, it is important to stress that this approach could lead to serious problems. To begin with, as already noted, few GPs have the expertise and knowledge to diagnose dementia accurately. Examples of worst-case scenarios include a person suffering from depression being labelled as a dementia patient, although the depression could be treated effectively (That this is not just a hypothetical case was confirmed by Simon Burrow, Carers Support Manager, Alzheimer's Disease Society, Sheffield). Secondly, although carers who are referred directly to social services often do receive good and efficient services they lack the back-up of the health service. One of the consequences of this is that they do not receive medical attention specific to the dementia and that no key worker is involved in the case. It is not uncommon, at least in Sheffield, to find that needs assessments were made by home care organisers alone when there were no 'medical' problems, such as difficult behaviour, present. Finally, if carers are directly referred to social services and are not in the 'medical system' they will also inevitably be excluded from new developments in the treatment of dementia. For instance the recently launched drug Aricept has to be prescribed and monitored by a consultant.

To sum up, there is an urgent need to recognise that crisis intervention is not the right approach to dementia care and that most crises could be avoided. A more flexible approach is needed in diagnosing dementia and it may have to be taken into consideration that the primary care setting may not be the best way to do this, a finding which goes against the recommendations of the recent White Paper (DoH 1997). The evidence suggests that GPs occupy a crucial role but that in order to play the role of gatekeeper to secondary services they need to be trained better in recognising dementia and responding to it appropriately. Furthermore, the role of GPs in health and social care needs to be clarified. At present, there is evidence of a profound misunderstanding between the expectations of carers and what GPs see as the boundaries of their role (Chapter 6). For many carers their GP is the only link to information and services (Bibbings 1998: 174). It has already been reported that some carers are now side-stepping their GP to obtain help directly from social services, a phenomenon which is relatively recent (Moriarty & Webb 1997: 20). Although these carers will receive some form of help with the care of the person with dementia they are potentially losing out on information and support.

Assessment procedures

The study has shown that if an assessment is carried out the actual assessment procedure is not always appropriate to dementia (Chapter 6). What carers criticised particularly was the practice of assessing the person with dementia in the home. Often these assessments did not last longer than 10 minutes which the carers felt was not enough to establish the level of confusion in the person with dementia due to the observed 'brief visitor syndrome', the ability of the person with dementia to put up a front for short periods of time. It has also been found that current procedures do not take into account that the condition of the person can change. This is particularly important in a degenerative disease such as dementia. When no reassessments are made (Caldock 1995a: 106) it is almost inevitable that a crisis will take place sooner or later because the level of support is no longer adequate.

Secondly, some of these assessment procedures actively excluded carers because allegedly they interfered. Again, this picture is contrary to the guidelines contained in the White Paper (DoH 1989: 19) which states clearly that 'assessments should take account of the wishes of the individual and his or her carer'. It should not be underestimated that carers can be important sources of information on the person with dementia, in particular where the confused person is no longer able to communicate (Chapter 6). What also appears to be neglected in current assessment procedures is the fact that carers themselves have the right to have their needs assessed. The Carers (Recognition and Services) Act 1995 states that carers can request to have their needs assessed alongside, but separate from, the needs of the person they care for (Ungerson 1997: 149). However, there has been criticism of the practice of assessing need separately from the provision of services. In other words, having their needs assessed does not guarantee that carers will receive support (McWalter 1997: 154). Furthermore, the findings of the study suggest that carers are usually unaware of this right and, by being excluded from the assessment of the person with dementia, do not have the opportunity to exercise their rights.

It is clear that there is a need for a review of the current assessment procedures. To begin with, it is important to move away from crisis management to more preventative services. Secondly, guidelines should be developed on the use of scans and other diagnostic techniques in an attempt to diagnose dementia and exclude other conditions. Thirdly, there is a need for a 'one door' approach and a clear pathway to obtaining formal support (Cox S. 1997: 196). This need for a centralised service was expressed by a carer in the study who explained the following:

> I think it would have been more helpful if they.. if there were some special clinic or special department where you could be sent and properly assessed to make sure what it is. Then you'd feel, perhaps not happier in your mind but more contented in your own mind that it'd been diagnosed properly...[...]...I think it would be more advantageous if there were some kind of clinic or somewhere where you'd... where there were proper specialists, you know.

Finally, to be able to decide who should be referred for a medical assessment and who should be referred to social services, new assessment procedures need to be introduced. The latter should be specific to dementia and take into account the observed 'brief visitor syndrome' as well as the carer's views and the changes in the patient's condition over time.

Management

The second area where reform is required concerns the adequate management of dementia. It has been observed that the provision of services relies on crisis management and that the support that is given is mainly of a practical nature, such as day care and respite breaks. Furthermore, carers in the study often had to negotiate and monitor their own care requirements, thus being the real 'care managers' (Chapter 7). The Department of Health (1989) has issued guidelines to promote effective care management and the implementation of packages of care. However, this system has been found to be either absent or flawed. What is needed is a reassessment of the requirements of older people with dementia and their carers, in an attempt to provide the right level of the right forms of support at the right time.

Working the system?

It has been noted in Chapter 7 that the majority of carers are expected to occupy two roles, those of 'care provider' and 'care manager'. For many carers it was increasingly difficult to negotiate services for the person they cared for, not least because of the lack of clear information. Carers in one of the feedback sessions commented that they felt social and health services tended to push responsibility from one to the other, leaving the carer baffled and insecure (Chapter 7). Indeed, it appears that some of the problems experienced by carers are due to the arbitrary distinction between the social and health service. This distinction has been criticised extensively in the literature on caring (See for example Cayton 1997a; Sturges 1997; Savishinsky 1990; Walker 1997; Killeen 1998; Bibbings 1998). For example, Cayton (1997a: 56) notes that:

> The health and social care divide is one of the most destructive and unhelpful aspects of our present system made even more so by the internal market.

This 'false boundary' has been held responsible for the lack of a comprehensive service (Killeen 1998: 12) and the confusion about who is responsible for which service. Bibbings (1998: 177) quotes a DoH official who commented:

> If you are not confused about community care policies you are not thinking clearly!

It is only too obvious that no carer of a person with dementia should be expected to negotiate their own care arrangements but the evidence has shown that many carers have little choice if they want to receive services and benefits. Others either do not know their entitlements or simply lack the energy to understand who is responsible for what (Bibbings 1998: 180-1). Chapter 5 has shown that many carers are themselves old and frail, or otherwise vulnerable due to exhaustion or depression. In other words, often carers are in no state to 'shop around' for services and therefore have little choice (Walker 1997: 215).

As far as benefits, such as the Invalid Care Allowance, are concerned some carers were not aware that they had entitlements (Chapter 4). Other carers criticised the fact that there were too many forms to fill in and too much confusion about possible help (Chapter 7). The majority of carers in the study had sought help in filling in forms, for instance asking staff at the Alzheimer's Disease Society to assist them. It appears that no clear guidelines exist which tell carers to what they are entitled. Combined with rules and regulations, such as overlapping benefits (Invalid Care Allowance is tied to Attendance allowance) it is not surprising that only few carers claimed the benefits to which they were entitled (Bibbings 1998: 172; Baldwin 1995: 134).

What is needed, then, is much more clarity in the 'kaleidoscope' of services (Baldwin 1995: 138), whether they are statutory, voluntary or private. Similarly, the social security system needs to be made easier for carers to understand and use. Carers need to be able to get clear and accurate information on the different services and benefits available to them. Although this does not mean that carers of older people with dementia should be expected to manage their own care arrangements, it would introduce some degree of choice. At present, as Allen et al (1992: 315) point out, 'there must be a questionmark over whether real choice can be exercised when someone else is assessing your needs and then 'managing' your care'. A further step towards more choice for carers would be to introduce a complaints procedure to enable carers to ensure the quality of services they receive. There has been evidence that carers feel they cannot complain for fear that much needed services may simply be taken away (Chapter 6). In other words, the current system gives carers no control over the quality and quantity of care, with the only real choice being to refuse care altogether (Allen et al 1992: 313-14; 325).

Care management

The study has identified a wide-ranging level of service provision among carers, with some carers getting a lot of help whereas others got no help at all. It has been suggested (see above) that two possible reasons for this could be the involvement of the GP and the carer's ability to negotiate. Other factors that have been investigated in this context are the carer's age, sex, class, race and area of residence (Bibbings 1998: 177; Gunaratnam 1997: 116).

However, there is some evidence that one of the main reasons for the surprising differences in service provision is the system itself. The 1989 White Paper called for a needs-led service, individually tailored 'packages of care' and intensive 'case management' (DoH 1989: 5). These high ambitions have been criticised as being based on management strategies in an attempt to cut costs, rather than an acknowledgement of the real situation of carers (Walker 1997: 211). It has also been noted that 'community care policies may be inappropriately based on middle class life styles and resource assumptions' (Caldock 1995a: 106), such as access to cars and telephones. Therefore, the reality with which carers were faced revealed a number of inappropriate services in a fragmented, poorly co-ordinated system of care (Caldock 1995a: 98). Furthermore, carers in the study were restricted in obtaining services by what was available in their area of residence. In other words they experienced a service-led system with very little flexibility in its administration. Also, there was only one example of what could be seen as an adequate package of care (Chapter 7). Admittedly, this particular package of care worked very efficiently, bringing great relief to the carer. However, this was an isolated case and the carer herself realised how unusual her level of support was. What this example does show, however, is that the idea of a package of care *can* be realised but that at present it appears that only very few carers enjoy the benefits of such an intensive approach to professional care management. The question remains how this level of support can be made available to more carers, without expecting them to be their own 'care managers'.

One of the problems identified is the confusion as to who should be responsible for the proposed packages of care. The White Paper (1989: 21-2) lays down guidelines about the tasks of the person or persons who should be responsible. These include 'identification of people in need, including systems for referral', 'assessment of care needs', 'planning and securing the delivery of care', 'monitoring the quality of care provided', and 'review of client needs'. It is further suggested that social workers, home care organisers or community nurses would be the most appropriate professionals for these tasks. As a consequence, social workers have increasingly been seen as the creators and managers of packages of care (Twigg & Atkin 1994: 49). However, Chapter 7 has shown that the present system of this form of professional care management is not working. The majority of carers did not know who was involved in their care and very few could identify their key worker. It was reported that those carers who had a key social worker were not necessarily in contact with him or her, or felt they could not approach the social worker for help. The picture that emerges is that social workers were completely at a loss and were asked to do more than they could cope with. Indeed, previous research has illustrated that many social workers face prohibitively large case loads which make it impossible for them to concentrate on special cases, such as dementia patients (Allen et al 1992: 298-9, 303). It has also been noted that dementia care is not popular and that social work with older people has been regarded as routine and low priority (Walker 1997: 193). Social workers usually only come into contact with carers briefly due to the current practice of assessment, arrangement of services if appropriate, and case closure (Twigg & Atkin 1991: 11; 1994: 54-5). This good practice in social work (Chapter 7) has been found to be totally inappropriate for dementia, where careful monitoring is needed over a longer period of time. It appears, therefore, that social workers are not the right professionals to fulfil this role of managing packages of care in supporting older people with dementia and their carers.

In order to solve these problems a realistic assessment of what is practical is needed because the current system has been shown to be inadequate in all but a few cases. In the one case where a social worker did actively manage the care of a person with dementia, from assessment through to admission to full-time care, this arrangement seemed to work well. At the heart of the problem, then, is firstly, the lack of key workers responsible for older people with dementia and their carers, and secondly, a lack of understanding of the fact that long-term support is necessary.

Three options have been identified to improve the situation of carers and ease the responsibilities they face as care providers and care managers. Firstly, as mentioned above, it has been acknowledged that social workers would be one of the best group of professionals to deal with dementia care because they work closest to carers and demented people in the community. However, the current case loads and misunderstandings of the role of social workers have meant that the system is not working well. However, although the system has flaws, there is the potential for improvements and for it to be developed further. To improve the effectiveness of social workers it would be vital to give more training to those social workers specialising in the care of older people with dementia and their carers, as there has been evidence that skills and knowledge can significantly improve the effectiveness of a social worker's involvement (Moriarty & Webb 1997: 21). Furthermore, the concept of good practice in social work needs to be re-examined in the light of the long-term needs of older people with dementia and their carers.

Secondly, in recognition of the social rather than health care needs of carers and older people with dementia, the Admiral Nurse Scheme was developed in London. The first pilot project was introduced in North East Westminster in 1989-1992 with further schemes covering other areas in London. Working alongside other health care professionals, this service uses registered mental health nurses with training in dementia care. Burningham (1996: 4) notes that the scheme has been extremely successful:

> Carers particularly appreciated that Admiral nurses came specially to see them to ask about their needs and feelings. They also liked the fact that Admiral nurses could provide them with helpful information, could liaise with other services on their behalf and could easily be reached by phone if there were any problems.

Unfortunately, this 'admirable scheme' appears to be restricted to London. Potentially, and with the right funding, this service could be the answer to effective care management, and this issue should receive more attention.

A third option has been the attempt to involve social workers as well as other professionals to form dementia management teams. Sturges (1996: 126-7) notes the success of such team efforts in Wales and concludes that:

> Britain needs to heal the lack of coordination between services, stop splitting off functions, and start targeting. Dementia care management doesn't need assessors, care managers, counsellors, reviewers and outside advocates. These roles can be successfully combined in the same care management team if members are skilled and specialised.

The emphasis of these teams has been to ensure open communication between the different professionals involved in individual cases and to ensure a seamless service. Tuppen (1998: 10-11) reports on a successful approach in Kent which was based on 'co-operation, collaboration, information sharing and joint working'.

Day care and respite care

Both day care and respite care have been welcomed by the majority of carers. However, several problems were identified (Chapter 7). It appears that neither service is flexible enough to accommodate the different needs of carers (Chapter 4). As far as day care is concerned, this service is not appropriate for many carers and indeed only available to some. In some instances the person with dementia did not live in the right catchment area, was too ill to attend day care, or refused to attend day care because, unaware of their own symptoms, they could not tolerate the 'funny' behaviour of others (Chapter 7). Furthermore, the provision of day care was patchy and rarely based on the assessed needs of people in a particular area (Tester 1989: 48, 50). The carers in the study received between one and five days a week, not necessarily in the same centre. The latter caused problems for some carers who refused offers of more days at a day care centre because they had observed that the constant change had negative effects on the well-being of the person with dementia.

The study found that the provision of respite care was even less predictable. In Sheffield, the health service only provides respite care for dementia patients who display challenging behaviour, and one ward offering such care was recently closed. In other words, only few carers have access to this service. Moreover, many carers felt ambiguous about this service, with some older spouse carers refusing to use respite care because they did not want to be parted from their spouse.

To make the system more useful and acceptable to carers there needs to be greater flexibility in the administration of both day care and respite care. The current form of respite care in particular requires thorough scrutiny. To begin with, there is a need to make respite breaks available to more carers for short and regular breaks as well as longer respite breaks (Bibbings 1998: 175). Secondly, problems with the organisation of respite care were reported by carers in the study. For example, it was criticised that carers faced the time-consuming task of having to label every item of clothing the demented person was taking on respite. Even the labelling did not prevent damage or loss to clothing. Several carers were angry about the loss of expensive coats and gloves, and damage to dresses and trousers which appeared to have been washed with the wrong colours or at high temperatures. Thirdly, the idea of giving respite should encompass older spouse carers who find the current system unacceptable. Respite care in this country is defined very narrowly (Chapter 7), whereas in other countries, for example the United States, a much broader definition of respite care is used (Scharlach 1986: 78). By understanding respite care in a broader sense of relieving the carer, some thought should be given to ways of helping older spouse carers. This could be achieved by home-based respite care, which does not necessitate the physical separation of carer and demented person (Newton 1997: 89; Cuijpers & Nies 1997: 173). Finally, it has been criticised in Chapter 7 that day care and respite breaks are regarded as beneficial for carers, rather than the person with dementia. It is therefore necessary to find an approach that makes the experience a happier one for the person with dementia, which would in turn positively influence the carer. This view was confirmed by the finding that for many carers the quality of care was more important than the quantity (Chapter 7). A positive experience is particularly relevant for spouse carers who reported a lot of uneasiness about the use of day care and respite care.

Thus, it is particularly interesting to look at the practice in Scotland as well as in other European countries for ideas of how to organise these services more effectively. In Scotland, for example, there are schemes which provide day care in a family home, effectively providing a 'home from home by the fireside', where older people with dementia can join ordinary family life (Mitchell 1998: 16-17, emphasis in original):

> It *is* somebody's home: it's the difference between going out to day care and going to a friend's house for lunch.

Day care in a family's home may also be more acceptable to those spouse carers who feel ambiguous about institutional day care.

A similar approach, which incorporates young children, has been used in Finland and in the Netherlands. Seppänen (1998: 18-19) reports on a project in Finland which provides day care both for older people with dementia as well as children between the ages of two and four. Benefits for both the demented persons and the children were observed:

> the children had given the old people stimulus, cheerful company and a sense of being needed, while the presence of the old people made the children feel more secure, taught them to respect difference and how to behave well.

In the Netherlands, toddlers were used in a project covering twenty-eight institutions where permanent nursing care was given. These 'toddler programmes' are 'programmes in which children aged two to four visit nursing or old people's homes and participate in activities with elderly who suffer from dementia' (Mercken 1997: 2-3). Mercken has noted the similarities between children of this age and older people with dementia which appear to make their relationship so successful:

> Both elderly with dementia and toddlers have a fragmentary experience of the world around them and react spontaneously to what is said without confronting it with laws of time and logic. They have difficulty in understanding abstractions and in connecting cause and effect. They have a limited concentration span and communicate through short sentences that refer mainly to what is present at the time. And finally they tend to communicate non-verbally.

These toddler programmes could potentially be used not only in full-time nursing care but also in institutional respite breaks. It has already been noted in Chapter 5 that grandchildren were popular with both carers and some older people with dementia. The Finnish and Dutch projects have shown that this could be utilised in providing enjoyable day care and respite care. However, it is important to be cautious. For these schemes to be successful, older people with dementia and children have to be chosen with care. Not every older person with dementia can tolerate small children, as Chapter 5 has shown. Mercken (1997: 7) has also noted that women tend to react more openly to children than men. As an alternative, pets, in particular dogs, have been used with similar therapeutic effects (Burningham 1997: 5). Secondly, there may be a danger of infantilising older people with dementia (Hockey & James 1993) by placing them on the same level as toddlers and addressing them as such. However, the mentioned projects did not seem to encounter this problem. The evidence appears to show that it is possible to avoid such a problem by organising and approaching combined day care for older people and toddlers in a sensitive manner. Finally, it is not clear whether these schemes are only useful for older people in the early stages of dementia or for all demented individuals. The Finnish study is restricted to early dementia, whereas the Dutch model includes older people in the later stages of the disease. However, generally speaking, these examples show that day care as well as respite care could be created much more imaginatively and could do more to address the different needs of carers as well as their demented relatives.

Institutional care

The study has revealed that, as in the case of the general population, long-term formal care is usually seen as the very last resort (Chapter 7) when there is no other alternative (Qureshi & Walker 1989: 29; Allen et al 1992: 307). Again, there are important differences between different groups of carers, with adult children more likely to recognise their limitations, in terms of other commitments, and plan ahead. But, even then, carers may face problems in finding a suitable place for their relative because some homes exclude older people with dementia. Generally, however, carers are rarely able to exercise any choice, in particular when institutionalisation follows a crisis (Walker 1997: 200-1).

Those carers whose relative was or had been in permanent care all reported bad experiences (Chapter 7). The association with former workhouses caused anxiety in particular in older carers. Other fears were reported in relation to formal care for the person with dementia and seemed to stem from problems encountered in 'normal', that is general, hospital wards where staff appeared to be unable to cope with a patient with dementia. Similarly, in formal care placements, the problems reported usually had to do with unsympathetic staff who did not take the carer's opinions into account. Also, the quality of the care given in some establishments has been questioned (Walker 1997: 202). There has been evidence of malignant social psychology, including among others the practice of infantilisation (Kitwood 1997b: 7).

While the current care arrangements have been identified as often inappropriate for older people with dementia, it is not clear what kind of service would meet the needs of this group of patients. There have been attempts to adapt other approaches to care, such as the hospice model, to the care of dementia patients. Hospice care is normally associated with terminal cancer but the approach to care is based on holistic care, elements of which are applicable to other diseases. Central to the concept of hospice care is, for instance, an emphasis on the social and emotional needs of the patient as well as the family, and the provision of bereavement services (see for example Saunders 1981 and 1990; Manning 1984; Lewis 1989; Seale 1991; Twycross 1980; and Taylor 1983). There has been relatively little research on the usefulness of the hospice *concept* of care for the care of older people with dementia. A small pilot programme in America attempted to run a specialised hospice for dementia patients and their families (Brechling & Kuhn 1989: 28-9). It was found that 'hospice' as an *institution* is a problematic option due to the difficulties of making a terminal prognosis, the length of care needed, and more practical issues such as the intensity of care required and the inability of dementia patients to communicate with staff.

To improve the current situation regarding full-time nursing care for older people with dementia steps need to be taken to avoid carer breakdown and subsequent enforced institutionalisation. Carers, in particular older spouse carers, need to be better informed on the available choices, if any, to help dispel the fears relating to the workhouse association. The latter still appears to cause a lot of anxiety and stress among carers as well as older people with dementia. Also, it should be made more acceptable for carers to plan permanent care in advance so that decisions based on informed choice can be made. To achieve this, two issues need to be addressed. Firstly, the majority of older people with dementia will require institutional care at some point, if only for brief periods of time. Advance planning therefore makes sense in particular as only very few of the current arrangements for permanent care were found to be appropriate for patients with dementia. It would be desirable to develop good quality care, bearing in mind the specific needs that dementia creates. Furthermore, much can be done to improve the existing places which provide permanent care. For example, a simple cost-effective intervention would be to use one page case studies, written by carers, to be included in the case notes of the person with dementia (LeNavenec 1997: 224-5). This simple form of using life histories has been shown to have benefits for both the demented person's relatives as well as staff, in promoting better understanding.

Secondly, it needs to be considered that 'community care' can only justifiably be expected to work up to a certain point in cases of dementia, in particular given that 'packages of care' are non-existent or do not work. Community care, if adequate and successful, is no cheap option (O'Shea & Blackwell 1993) and it has been questioned whether community care may have gone too far in keeping people out of institutional care at all costs and beyond what could be considered realistic (Allen et al 1992: 308). The study has shown that, in relation to dementia, the carer tends to be the person to bear these costs, as the available support has been found to be inadequate. Clearly, something needs to be done to remedy this situation. Research evidence from abroad, for example the Netherlands, has shown that for dementia patients, care in small groups in home-style environments has worked best in terms of quality of care and satisfaction of patients and staff, while being no more expensive or cheaper than traditional institutional care (Fahrenfort 1997: 287-9; 295-301).

Empowerment

The third area where reform is needed concerns the empowerment of carers. It was reported in Chapters 5 and 7 that carers have a great need for reassurance and appreciation of their efforts, but that there is very little in terms of emotional support for them because the existing services are based on practical support alone (Allen et al 1992: 316). Indeed, the White Paper (DoH 1989) has been criticised for giving little priority to the needs of carers compared to those who receive care (Laczko & Victor 1995: xiii). It has been found that the available services, such as support groups, do not always meet carers' emotional needs sufficiently. The study has also demonstrated that the views of carers are very often not taken seriously (Chapter 6) and that they have little choice in terms of quality and quantity of services. The following section discusses the role of support groups and the two dimensions that have been identified: Firstly, support groups provide much-needed emotional support to carers. Secondly, it will be suggested how support groups could move beyond this basic level of support to incorporate the empowerment of carers.

Role of support groups

To begin with, it has to be determined in how far carer support groups can alleviate the stress of caring. There has been evidence in this and other studies that carers benefit from support groups by meeting others in the same situation to exchange experiences and ideas. Carer support groups have also played a crucial role in passing on information on those services locally available, as well as convincing carers of the usefulness of these services (Bibbings 1998: 174). However, not all carers have access to such groups. It appears, for instance, that the majority of groups provided by social services are linked to day care. In other words, only those carers who receive day care have the option of attending these groups. Furthermore, support groups are not useful for all carers who attend or have attended. For some, this form of social interaction is regarded as a nuisance, as one carer stressed when he noted that he felt some members of the group complained too much (Chapter 7). For others it may be impossible to attend meetings on a regular basis due to the commitments of caring, or the general anxiety of leaving the person with dementia alone. It was also pointed out by Coates (1995: 43) that support groups are only useful for carers who experience a certain level of stress. In other words, those carers experiencing extreme stress are unlikely to attend support groups, and if they do they may not benefit. For this group of carers individual attention may be warranted, in the form of counselling (Cuijpers & Nies 1997: 174).

Particular attention also has to be paid to the differences between carers. The research has identified the different needs of spouse carers, adult children, and younger spouse carers. To give carers the best possible information relevant to their situation, separate groups have to be created with the specific needs of different carers in mind. In Sheffield, this had already taken place to a certain extent at the time of the study. One such group was attended by adult children only, who, as mentioned in Chapter 4, were more interested in the financial consequences of caring and the possibilities of full-time care. However, another group of carers, that of younger spouse carers in their late 50s and early 60s, was found to be left out of the discussion because the needs and expectations of people this age were not the same as those of either older spouse carers or children caring for a parent (Askham 1995: 90). As this group of carers is in the minority, albeit a significant and increasing minority, it may not be practical to run a support group specifically for these carers. However, since the interviews for this study were conducted, the Alzheimer's Disease Society in Sheffield has started several new groups due to the high demand for this form of support. There are now several groups for those caring for a spouse or a parent, for someone with 'early onset dementia', as well as 'open' support groups for all types of carers, adding up to a total of six groups (Newsletter, Alzheimer's Disease Society, Sheffield Branch, No 28, February 1998).

It was pointed out in one of the feedback sessions that no members of ethnic minorities attended support groups. The carers were of the opinion (and the leaders of the group supported this view) that there were important cultural differences which meant that older people with dementia in the group of ethnic communities in Sheffield were looked after in a network of extended families who preferred to be self-sufficient instead of asking for help (Richards 1996: 6; Nolan et al 1996: 18). This familiar stereotype has been commented on by several researchers. For example, Gunaratnam (1997: 116) notes that more research needs to be done into why the present services are not used. One factor Gunaratnam identified is the inability of some older people to speak English, coupled with illiteracy in the first language (1997: 118). In other words, information on services are passed on by 'word of mouth' alone because even translated information is of little use to these carers. However, there has also been evidence that the poor uptake of services has less to do with cultural differences than with the system itself. It may stem from a long history of poor service provision and inaccessibility of the system (Cox C. 1997: 39). Although few or no carers of ethnic minorities attend the existing support groups, there are other groups in Sheffield within the local communities which provide support to carers. A recent study by the Sheffield Joint Consultative Committee (Knights & Midgley 1998: 42) found that members of these groups had a 'great deal of experience of not being able to access mainstream community care services' and 'did not receive information about services. However, they 'were able to relate well to community care services provided by projects that were run and managed by people from the same community background as themselves'. This evidence suggests that carers from ethnic minorities have the same need for support as the rest of the caring population, but that at present the system is not flexible enough to respond to the situation of this group of carers within the existing support groups.

Also, there should be clearer guidelines about the nature and purpose of the support group, if the latter is to benefit the majority of carers. Within the scope of this study three different groups were observed (Chapter 3 and 7) and a rather subjective assessment suggested that the group run by social workers was best organised and gave the carers valuable information as well as the chance to talk about their personal experiences. That this balance is important was illustrated by a daughter who felt that support groups should provide more than just a chance to 'have a moan'. Indeed, Coates (1995: 44) touches on two levels of support groups. Firstly, support groups *should provide an environment for carers to learn* more about dementia, about services, and about ways of coping with caring for a demented person. Secondly, there is the 'socio-emotional' dimension of the support group which provides carers with emotional support and encouragement and the opportunity to share their experiences (Glasser et al 1990: 330). It is the responsibility of the 'facilitator', or group leader, to achieve the right balance between these two levels.

However, there is some confusion about who should provide this type of service, emotional support, for carers. At present about half the number of support groups in Sheffield are run by voluntary organisations such as the Alzheimer's Disease Society. However, it should be noted that the provision in Sheffield has been recognised as exceptionally good, so that it needs to be considered that the picture may be very different in other parts of the country. In Chapter 6 it was noted that some carers felt that as soon as they got 'into the grip' of these organisations they were coping better. The implications of this are that in areas where there is a lack of voluntary organisations, such as some rural areas, carers potentially lose out on emotional support altogether (Caldock 1995a: 108). Although the presence of voluntary organisations which offer support groups is clearly desirable from the perspective of the carers, this situation prompted a speaker at the Alzheimer's Disease Society *Conference* (University of Warwick, September 1997) to question whether voluntary organisations should take on so much responsibility. It was commented that, for instance, the Alzheimer's Disease Society increasingly serves to pick up the pieces after social services fail carers. Clearly, the role of the voluntary services in providing support to carers needs to be re-assessed.

Bereaved carers were reported to be discouraged from attending some support groups because the leaders of the group felt they would unnecessarily upset 'new' carers by relating their caring experiences. This practice went against one of the main ideas behind support groups, that of exchanging experiences. It further highlights the problems of bereaved carers who do not receive support in coping with their loss (Cohen & Eisdorfer 1986: 259, 267). Although dementia has been referred to as 'the long bereavement' (Forsythe 1990), it is necessary to consider the effect which the actual death of the person with dementia has on the carer (Brown 1996: 5). Chapter 7 reflected on the observation that some carers found ways around being excluded from support groups by becoming voluntary workers and thus again gaining access to these groups. Undoubtedly, this arrangement is far from ideal and some form of support should be developed, either in combination with current support groups or in the form of a group for bereaved carers only.

There is, then, an urgent need for two types of services in particular, one to address the needs of current carers, and one to follow up those carers who are bereaved. In the case of ethnic minorities more research is needed into how carers could best be supported and whether their needs could be accommodated in the existing support groups. Although support groups have been found to be useful, they need to be tailored to the carers' needs and structured in a way which gives carers a chance to learn more about their situation and how to cope as well as providing an environment in which carers can talk about their experiences. One such attempt to provide carers with emotional support as well as education has been the 'Caring and Coping with Dementia Project', a support and training package for informal carers run by Community Health Sheffield. The pilot project ran from July 1996 to July 1998, and has reportedly been a great success. However, two concerns were voiced by carers in my study, who were also involved in the project, about the usefulness of this project. For instance, the project focused on carers *aged 60 or over* who looked after someone who had been *diagnosed* with dementia, thus excluding a significant proportion of carers. Secondly, one carer reported feeling uncomfortable with the intensive approach that was taken in the project, referring to what she described as 'opening a can of worms'. In her opinion, the project could cause damage to carers who were not ready to confront certain issues relating to the care of the person with dementia but were forced to do so.

Advocacy

To sum up, there has been evidence to suggest that a multi-disciplinary approach such as the 'Caring and Coping' project is a positive step towards more emotional support and education for carers. However, such projects may not be feasible, or indeed fundable, in the long-term and on a large scale. Instead, there should be clearer guidelines to improve the existing support groups. The study has shown that, rather than being run by volunteers, support groups should be led by health care professionals who have the right amount of knowledge combined with a certain detachment. However, it has been discussed previously (Chapter 6) that, for instance social workers, lack the knowledge and skills, and more importantly the time, to pay special attention to dementia patients. There is then a need for a group of professionals who focus exclusively on the needs of older people, in particular those with dementia.

More importantly, there is a second dimension, that of advocacy, to support groups. Advocacy 'means making the case for someone, or a group of people, or helping them to represent their own views, usually to defend their rights or to promote their interests' (Quoted in Dunning 1997: 95). There are three forms of advocacy that are important in relation to carers of older people with dementia: public advocacy, self advocacy, and group advocacy. Voluntary organisations, such as the Alzheimer's Disease Society, use public advocacy. For instance, newsletters, both on the local and the national level, serve to promote the views of carers. The Alzheimer's Disease Society also organises numerous events throughout the year, such as awareness weeks.

Furthermore, carers have the option of self-advocacy. Self-advocacy means 'speaking up for yourself and involves a person expressing their own needs and concerns, making their own choices and decisions, and representing their own interests' (Dunning 1997: 97). Unfortunately, this study has shown that for many carers this form of advocacy is not practical because they are too depleted by the demands of caring to be able to speak out. Support groups could potentially fill this gap and provide the option of group advocacy in the sense of allowing carers to develop the confidence and strength to have a voice. Chapter 5 has commented on the different stages carers go through on their way to acceptance of the disease. It has been noted that support groups are beneficial for carers in stages two to four (anger, bargaining, depression) because it provides an environment for carers to work through these feelings. It has been mentioned above that support groups should be structured in a way that allows carers to understand their situation and be reaffirmed in their rights to information and services. With the right amount of emotional support given in these groups carers can successfully reach their full potential in stage five, the stage of acceptance. Although not all carers in this stage are articulate enough to speak out for themselves, this group of carers is potentially able to practice self advocacy. Having accepted the condition of their relative, these carers are a valuable source of knowledge based on experience. To date there has been little recognition of the fact that this group of carers, as well as bereaved carers (Fortinsky & Hathaway 1990: 609), could provide education and support for other carers as well as professionals. Soliman and Butterworth (1998: 26-7) report on the first moves in this direction which involved carers as public speakers during training days in London:

> It began to be recognised that lay people speaking the unvarnished truth about caring for their own relative could bring home to their listeners, as nothing else could, the reality of dementia, its effects upon the person and the consequences for relationships and the rest of one's life.

It appears, then, that the first steps have been made towards the recognition that carers do have something to offer. It has also become clear that carer support groups should be more than a 'place to moan' and that they can play a great part in enabling carers to find a voice. However, this move towards the empowerment of carers should not be misunderstood as providing an alternative to adequate resourcing of services (Barnes & Walker 1996: 385). Carers need to be enabled, but empowerment has to be achieved in a complementary way to the recognition and management of dementia.

Summary of implications

On the basis of the findings of this study certain recommendations have been made regarding the possible implications for policy and practice. Three areas where reform is needed have been discussed: recognition, management, and empowerment.

To begin with, it is important to recognise that the majority of carers of older people with dementia are alone with their caring task and do not receive significant amounts of help from family, friends, or neighbours. What this means is that while there may be an extensive social network, this is rarely a social *support* network in cases of dementia (Nolan et al 1996: 11). Rather than placing heavy reliance on the existence of a family network, it is therefore necessary to give much more thought to the question of how these carers can be supported. Moreover, although there is more awareness of dementia among the general public as well as professionals, much needs to be done to improve the way information is transmitted. More information on both the disease as well as available services needs to be made readily available to carers of older people with dementia. The research has shown that, for some carers, the knowledge that support exists may be enough to provide relief (Schofield 1998: 366). There is also a great need to provide more training for those professionals dealing with these issues. The study has revealed that GPs in particular may be ill-informed and ill-equipped to make important and far-reaching decisions about the diagnosis and care of the person with dementia and support for the carer. It has been found that speed is of the essence in diagnosing dementia and responding appropriately before a crisis takes place. There are two options to address this problem: It should either be considered whether the process of diagnosing dementia could be made more effective by moving away from the primary care setting. The other option would be to create a centralised 'diagnostic service' and to provide better training for GPs as well as those professionals coming into contact with older people with dementia and their carers. To achieve a seamless service, the assessment procedures will have to be reviewed to accommodate the specific needs of older people with dementia and their carers. Particular attention has to be given to the degenerative nature of dementia and the resulting changes in the person's condition. The latter should be monitored more carefully to facilitate the adaptation of support services as and when the need arises.

Secondly, regarding the management of care, it is vital to clarify the responsibilities and roles of the Departments of Health and Social Security. It has been noted that current policy fails carers because the arbitrary distinction between the health and social service creates an environment where neither the health nor the social needs of carers and their relatives are addressed adequately. The study has shown that intensive care management can improve carers' lives but that the existing services, such as day care and respite breaks, are not appropriate for the majority of carers. Ideally, services which are different in both quantity and quality should be developed to address the needs of both carers and the person they care for. Alternatively, current care provisions could be modified to be more flexible and more imaginative. Also, the issue of appropriate permanent care for older people with dementia needs to be addressed further.

Finally, the issue of empowerment has to be addressed. There is a need to further develop services which are not exclusively based on practical support. Carer support groups have contributed greatly to providing emotional support for carers. Moreover, support groups can put some carers into the right psychological frame of mind to be able to practice self-advocacy. However, in order to maximise these benefits for carers there have to be clearer guidelines about the aims and contents of support groups. It is important to recognise that carers have a great deal to offer in terms of knowledge and experience and that this knowledge could and should be used to educate new carers as well as professionals. Attention should also be paid to supporting bereaved carers as, to date, there are no bereavement services for carers.

* * *

The research has shown that many informal carers of older people with dementia show remarkable dedication and commitment in an attempt to provide the best possible care at home. This thesis has provided the first step on the way to achieve recognition of dementia and of the role of carers, management of dementia, and empowerment of carers. The discrepancies between the needs of carers and the views of practitioners and policy makers have been highlighted. The study has pointed out areas of mis-match and misunderstanding and has suggested what could be done to improve the situation of current and future carers. Tom Kitwood (1997a: 143) has concluded about the current situation that

> In Britain the recognition is slowly dawning that there is a vast training and educational deficit, and that none of the existing forms of professional preparation properly address the issues arising in dementia care.

It is hoped that this trend to understand the problems surrounding dementia care continues. However, there is still a long way to go. There has to be much more awareness of the fact that dementia does present a unique situation and that the problems will not go away. The numbers of older people with dementia are steadily increasing and, as yet, there is no cure.

For these reasons, more research is needed. For example, to understand both the similarities and the differences between carers it would be useful to have a comprehensive account based on each of the identified groups of carers. The study has analysed older spouse carers and adult children who care, and has briefly touched on a third group, that of younger spouse carers. It has already been noted that more needs to be done to understand the needs of carers from ethnic minorities. In addition, research is needed into the situation of carers of *younger* people with dementia who are thought to face a different set of problems not least due to the fact that current services for dementia tend to target only older people.

Focusing on the person with dementia rather than the carer, much more attention needs to be paid to the growing number of people with dementia who live alone. Given that community care policies rely very heavily on the existence of at least one informal carer, urgent research is needed into ways in which this group of sufferers can be supported. It is particularly relevant in this context to be able to identify signs of crisis and to respond early.

Another area which needs to be researched more is the long-term detrimental effect caring has on different carers in terms of their physical and psychological well-being, as well as carers' financial situations. The long-term effects on older spouse carers in particular have been neglected to date. Furthermore, detailed study is needed on how former carers cope with their life after the caregiving has ended and whether it would be possible to ease the transition back into 'normal' life. In relation to younger carers it has for instance been pointed out that benefit payments stop as soon as the person with dementia dies or is institutionalised, leaving the carer theoretically 'available for work'. Realistically, however, few carers are in a physical and mental state to find employment soon after their caregiving ends.

The level of awareness of dementing illnesses and the plight of carers has risen in recent years and major work has been done to identify the causes of dementia as well as to develop effective treatments. However, it is important to remember that much more can be done to support those people who *currently* provide care, not least by making more resources available to improve the provision of services and to fund further research. It is hoped that this study will contribute to the ongoing debate on how to help carers and their relatives with dementia.

APPENDIX 1: SYMPTOMS OF DEMENTIA

The following shows the various symptoms in two broad categories: medical and physical problems and problems with activities of daily life, and psychological and behavioural problems. The mentioned problems and behaviours are not necessarily found in every older person with dementia and some problems occur temporarily at a certain point in the disease process.

Medical conditions and problems in daily life

Some aspects of daily life which are normally taken for granted become a struggle for carers of people with dementia. In this section I will refer to activities of daily living, covering personal hygiene, dressing, eating, using the toilet and safety issues. Further, there are a number of treatable medical conditions which, if left untreated, can cause distress in a patient with dementia and often makes the confusion worse. It is therefore necessary to distinguish between these problems of physical origin and other symptoms which are caused by the disease itself. Some of these treatable physical conditions are mentioned below.

Personal hygiene

Some individuals with dementia not only forget to wash but seem to develop an irrational fear of water, washing (especially their hair) and bathing (Murphy 1986: 35). This phenomenon has partly been explained in terms of the changes to the brain and the fact that activities of personal hygiene are in essence personal activities. In this sense the person may find it difficult to accept help from a carer, whom he or she might not recognise. In the later stages of the disease the person may then altogether refuse to bathe (Edwards 1994: 197). One reason for this might be that the person cannot understand the necessary tasks, and their order, involved in taking a bath (Mace 1992: 80). Getting undressed alone is a procedure which involves many different steps and the mental effort of this may overwhelm the person.

Dressing and personal appearance

Similar to hygiene, dressing is an activity which the person which dementia may want to keep personal. The refusal to change clothes may also be the result of the lacking sense of time and the conviction that clothes have been changed already (Mace 1992: 79). With the progressing disease the person's refusal to dress or change can be due to the difficulty of putting clothes on in the right order, manage buttons, shoelaces and zips, and dressing may take much longer (Wilcock 1990: 132; Mace 1992: 82; Edwards 1994: 198). Further, older people with dementia may no longer be able to distinguish what is socially acceptable in terms of dress and may, for instance, leave the house in their night clothes or without clothes. In terms of general personal appearance, hair and hair-style, finger- and toenails may be neglected and, particularly the latter, can cause discomfort (Wilcock 1990: 133; Mace 1992: 83).

Sight, hearing and dental problems

Although seemingly obvious areas, sight, hearing and dental problems can be neglected when a diagnosis of dementia is made. Partly, the impaired person may not be able to communicate problems with sight, hearing or dentures, and partly, carers may expect problems with sight, hearing and communication in later life and might therefore not suspect some underlying cause (Murphy 1986: 25). It is therefore necessary to ensure that the confusion of a person with dementia is due to the disease and not to some other factor which could be remedied if discovered.

Food and eating problems

Two major problems are observed in relation to eating. Either the person refuses to eat in the belief that he or she has eaten already, or the person demands food constantly, having forgotten that he or she just had a meal. In both cases ensuring adequate nutrition can become a problem. Further, many older persons with dementia develop certain preferences and only want to eat certain foods, very often sweets or biscuits (Edwards 1994: 200; Murphy 1986: 32; Mace 1992: 66). Eating habits usually also deteriorate, the person takes longer to eat less food and will eventually be unable to use utensils (Edwards 1994: 200). It has to be noted that refusal or failure to eat in the later stages may be due to the person's inability to remember how to eat, that is, how to chew and swallow (Wilcock 1990: 139; Mace 1992: 70-1). Further associated with nutritional problems is dehydration which can cause further confusion and a range of physical symptoms (Mace 1992: 104). Another, very different, problem some carers have reported is that of eating any type of food if left lying around such as a whole loaf of bread (Micklewood 1991: 7, 17), eating 'inappropriate' food such as bananas in their skin (Gilhooly 1984a: 115), vinegar or Worcester sauce, or attempt to eat non-food items such as soap (Mace 1992: 69).

Using the toilet

With increasing confusion some persons with dementia will forget to use the toilet, or not get there in time. However, there may be an underlying physical cause. Incontinence (of urine) can be due to a range of factors including infections of the urinary tract, prostate gland problems in men, constipation, diseases such as diabetes, or medication such as diuretic drugs or tranquillisers (Murphy 1986: 39). If these causes of incontinence are ruled out and incontinence occurs relatively early on in the disease and only at certain times, such as at night, the confusion of the person and the inability to find the bathroom in time might be to blame. Some men have been found to urinate into items such as waste paper baskets in the mistaken belief to have located the toilet. Addressing this problem by adequate lighting and signs or pictures can often achieve continence in the short term. However, virtually all patient become doubly incontinent as the disease progresses.

Communication and coordination

The impairment of speech and communication ability develops gradually as the disease progresses. However, there is a possibility that these problems are brought about or worsened by side effects of medication or by a combination of drugs. In any case the process of 'getting in touch' with a person with dementia should be taken literally to a certain extent, as facial expressions and gestures can convey more meaning than words which the person cannot comprehend any longer (Murphy 1986: 28). Moreover, the changes in the brain of a person with dementia can significantly influence a person's sense of balance and coordination. The effects of this can be simple things such as not finding one's way even in familiar surroundings. It can, however, result in people getting lost, or result in actual falls and injuries. In the later stages of the disease a shuffling, slow walk is common and some persons are either unable to walk unaided or unable to walk at all (Mace 1992: 92).

The combination of the above-mentioned communication problems and problems with coordination may make the presence of infections or pain difficult to detect, in particular because infections or pain can lead to more confusion. Dementia in itself is not thought to cause pain, but other causes of pain, such as undetected sprains or fractures, or constipation, can be present. Mace (1992) stresses the importance of checking a person with dementia periodically for cuts and bruises and be aware of sudden changes in behaviour. The latter might be the only indication of pain because the person might not be able to communicate discomfort, or may continue to use a broken limb and forget about a fall (Mace 1992: 103; Wilcock 1990: 143).

Safety issues

The confusion and impaired judgement of a person with dementia means that such persons can be a danger to themselves and to others due to irresponsible behaviour. These persons may be more accident prone than 'normal' people because they fail to avoid situations or behaviours that can lead to accidents (Wilcock 1990: 115). One such behaviour which is fairly common is putting the kettle on and forgetting (Gilhooly 1984a: 115). The use of other kitchen equipment may be incorrect and lead to dangerous situations and injuries, for example by putting things into the toaster and causing fires. Further there is the problem of falls (Murphy 1986: 49) especially in the dark, and not finding light switches which might bring about fear and panic and increase the likelihood of accidents. Open doors and loose keys can cause problems because people with dementia might wander off and get lost, or lock themselves in or out by accident and lose the keys (Micklewood 1991: 14).

Psychological and behavioural problems

The changes in the brain of a person with dementia can cause a range of psychological and behavioural problems. Not all these occur in every patient and the occurrence of some may be a temporary phase in the process of the disease. Jorm (1987: 16) differentiates between two forms of problem behaviour, either passive and withdrawn, or showing an unstable mood. The former can be just as difficult to deal with as the latter, in the sense that the patient refuses to do things rather than does unwanted things. Some of the observed problem behaviours of both forms are listed below.

Catastrophic reactions

It is common for older people with dementia to over-react in seemingly harmless situations. This is termed 'catastrophic reaction' and is thought to be triggered by a person's fears in situations which are out of their control and which they cannot comprehend. Contributing to the occurrence of catastrophic reactions are unfamiliar and confusing surroundings, groups of people, unfamiliar noises, and being asked several questions at once or being expected to do more than one difficult task at a time (Mace 1992: 28-9). It has been stressed that these outbursts are not 'stubbornness' or deliberate actions but most probably a sign that a person is overwhelmed by a situation (Murphy 1986: 31).

Losing track of time: Sleep disturbance and restlessness

The loss of the sense of time in a demented person shows itself in particular in sleep disturbances and restlessness generally. Some of these problems can be due to lack of activity, or frequent naps during the day (Mace 1992: 131; Murphy 1986: 42). Other problems of this sort are caused by the person's confusion and the conviction that it is time to get up (Wilcock 1990: 106), the inability to distinguish between dream and reality, and the problem of finding one's way, for instance to the bathroom and back, in the dark.

Wandering

Many older people with dementia show a tendency to wander to some extent. In some this may be caused by a lack of exercise and may be counter-acted by adequate activity during the day. Others are more persistent wanderers and tend to wander off whenever given the opportunity. If this is confined to the house it may not be too difficult to control, but if the person repeatedly 'escapes' and is found wandering miles away from home, wandering becomes more of a problem (Wilcock 1990: 104; Murphy 1986: 40). The wandering may not in itself be the problem. If wandering happens at night, in winter when the person is inadequtely dressed, for instance in a bathrobe, or if the person is no longer able to 'understand' traffic (Edwards 1994: 187) the occurrence of wandering can become a cause for concern. The person may get frightened by being lost and this might result in a catastrophic reaction. In such a situation the public might not be much help in the belief that the person is either drunk or insane (Mace 1992: 124).

Anxiety and Depression

Fears, anxiety and actual depression have all been found in persons with dementia (Wilcock 1990: 113). Often depression features in the early stages of the disease as a direct reaction to the diagnosis (Micklewood 1991: 13; Biegel 1991: 149-50). However, it has to be noted that, firstly, not every person with dementia becomes depressed, and that, secondly, if depression occurs this has to be investigated properly (Mace 1992: 149). Some patients with clinical depression show all the signs of confusion common in dementia, but those signs can disappear if the actual cause, the depression, is treated (Wilcock 1990: 113). Other patients may have dementia *and* a depressive illness and a compromise will have to be found whether or not to treat the depression, as medication can in some cases make the confusion worse. However, general fear and anxiety is common in older persons with dementia in any stage of the illness and most of this has been explained in terms of the mental impairment of the person and the inability to make sense of one's surroundings.

Clinging and attention seeking

Because of the above-mentioned anxiety, the person with dementia may become insecure and attempt to be as close to the carer as possible. This behaviour can take the form of clinging to the carer, following the carer around and not leaving him or her out of sight (Mace 1992: 140; Gilhooly 1984a: 115). Further, some individuals with the disease may seek constant attention or become very demanding (Mace 1992: 145) and react with aggressiveness if this attention is not given.

Aggressiveness and abusiveness

For most people with dementia, aggressiveness and abuse, either verbal or physical, is only a temporary phase if it occurs at all. Some bouts of aggressive behaviour have also been reported as a result of a catastrophic reaction. This aggressiveness is often directed at the primary caregiver, although it is not thought to be a deliberate act but rather a general 'cry for help' in the face of confusion and the individual's helplessness in particular early in the disease (Edwards 1994: 194).

Suspiciousness and accusations

People with dementia often become obsessed by the idea that someone has taken away their belongings, stolen or sold them, and they tend to accuse their main caregiver of lying. (Mace 1992: 158-9) adds a note of caution to this phenomenon, remarking that not all forms of suspiciousness should be blamed on the progressing disease but that these suspicions may be founded on fact. In the extreme form individuals show paranoia, thinking someone is trying to harm them (for instance poison them), is plotting against them, or is out to get them (Wilcock 1990: 110; Mace 1992: 142). In the belief that things have to be kept safe from strangers some people with dementia begin to hoard and hide objects.

Hoarding and hiding

The hoarding and hiding some individuals with dementia display is closely related to the suspiciousness mentioned above. Thus, objects considered of value, or food, might be hoarded or 'hidden' away to keep them safe. As the person with dementia subsequently forgets where those objects have been hidden they may again accuse someone of stealing.

Hallucinations and delusions

It has been reported that some persons with dementia hear, feel, smell or see things (Mace 1992: 156). The latter can be due to poor sight, but generally the cause of these hallucinations is thought to be connected to the brain damage. There are two different categories of visions: actual hallucinations, and real objects which might be misinterpreted. In some cases of the first category no harm is done if the person with dementia has 'invisible friends' (Wilcock 1990: 112). However, if these hallucinations frighten the person and are too distressing they may have to be controlled with drugs. The misinterpretation of reality may be easier to correct by simple adjustments to the home. It has been reported that persons with dementia have been found to perceive their own mirror image as a stranger, or believe people in pictures or on TV are real and threatening (Murphy 1986: 49).

Verbal noises and repetitions

In the early stages of the disease the person with dementia may repeat questions over and over again despite an answer being given and accepted. This can be regarded as a sign of memory impairment and the person cannot retain the information given. The only solution is to answer fully once or twice and then distract the person and possibly bring him or her away from the object or situation that triggered the initial question. Similarly, repetitive actions can be stopped by distraction (Mace 1992: 139). In the later stages of the disease when the older person has lost the ability to communicate he or she might repeat verbal noises, shout out or moan as if in pain or distress.

Inappropriate sexual behaviour

Older people with dementia lose the sense of what is thought socially acceptable. This applies to any interaction with other people, and in particular to sexual behaviour. Persons with dementia may take off their clothes and wander around naked or approach strangers and expose themselves (Mace 1992: 135). Some of these behaviour patterns may not have sexual connotations at all, for instance a person taking off his or her clothing might need the toilet but has simply forgotten to go there first and not undress in public (Wilcock 1990: 110). In other words, these actions are not normally deliberate, even if severely confused individuals appear to lose all inhibitions and touch themselves in ways which are, or are by others perceived to be, sexual.

APPENDIX 2: CARER PROFILE

INTERVIEW NUMBER	DATE	PLACE	PSEUDONYM	AGES	RELATIONSHIP	LENGTH OF CARE	CURRENT CARE
I.1	22 September 1996	My house	Caroline	Carer: 49 Cared for: 80	Daughter cares for mother	3 1/2 years	Care at home
I.2	24 September 1996	Carer's Home	James	Carer: 81 Cared for: 85	Husband cared for wife	1976-1995	Wife deceased
I.3	25 September 1996	Carer's Home	Richard	Carer: 71 Cared for: 71	Husband cares for wife	2 1/2 years	Care at home
I.4	4 October 1996	Carer's Home	Sue	Carer: 75 Cared for: 75	Wife cares for husband	4 years	Care at home
I.5	4 October 1996	Carer's Home	Jane	Carer: 60 Cared for: 94	Daughter cared for mother	3 1/2 years	Mother deceased
I.6	9 October 1996	Carer's Home	John	Carer: 73 Cared for: 72	Husband cared for wife	6 years	Full time nursing care
I.7	6 November 1996	Carer's Home	Stephen	Carer: 80 Cared for: 84	Husband cares for wife	8 years	Care at home

I.8	7 November 1996	Carer's Home	Bill	Carer: 73 Cared for: 74	Husband cares for wife	5 years	Care at home
I.9	8 November 1996	Carer's Home	Kate	Carer: 57 Cared for: 58	Wife cares for husband	2 years	Care at home
I.10	8 November 1996	Carer's Home	Marian	Carer: 66 Cared for: 67	Wife cared for husband	6 years	Husband deceased
I.11	12 November 1996	Carer's Home	Anne	Carer: 60 Cared for: 65	Wife cares for husband	5 years	Care at home
I.12	13 November 1996	Alzheimer's Disease Society	Robert	Carer: 76 Cared for: 74	Husband cares for wife	15 months	Care at home
1.13	14 November 1996	Carer's workplace	Deborah	Carer: 44 Cared for: 80	Daughter cared for mother	?	Mother deceased
I.14	15 November 1996	Carer's Home	Alice	Carer: 70 Cared for: 70	Wife cares for husband	5 1/2 years	Care at home
I.15	18 November	My house	Kath	Carer: 45 Cared for: 74	Daughter cares for mother	2 years	Mother living alone
I.16	18 November 1996	My house	Jim	Carer: 48 Cared for: 72	Son cared for father	4 years	Father deceased

I.17	25 November 1996	Carer's home	Liz	Carer: 52 Cared for: 82	Daughter cared for father	2 1/2 years	Full time nursing care
I.18	2 December 1996	Carer's workplace	Paul	Carer: 43 Cared for: 76	Son cares for mother	3 years	Care at home

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