

## **Male caregiving of a spouse with Alzheimer's Disease: A narrative of care**

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### **Abstract**

*The objectives of this paper are to document the case study of a male caregiver's experiences while caring for his female spouse with Alzheimer's Disease (AD) and to examine this narrative against key themes within contemporary Australian literature. It employs a qualitative single case study approach, with one male caregiver providing two in-depth interviews regarding his experiences. Key themes are identified and compared with current literature. The themes within the narrative related to: early signs and diagnosis of AD; carer and spouse relationship; becoming a carer; engaging with health care professionals; seeking and receiving support; caregiver health; financial considerations; social attitudes towards AD and perceptions about the future. The paper concludes that documenting the unique and contextualized narrative of male caregivers regarding spouses affected by AD gives voice to their experiences. Such narratives can affirm other caregivers and also raise awareness of practitioners, service providers and the general community about the experiences of care giving.*

**Key words:** *Alzheimer's disease, male caregiving, narrative research*

### **Introduction**

Contemporary Australian society is ageing as a result of factors such as high living standards, lifestyle choices, improved health care services and access to medical technologies and this trend is expected to continue (Australian Institute of Health & Welfare 2008:5; Taylor, Foster and Fleming, 2008:xiii). More people than ever before in Australia will live to experience ageing-related diseases like dementia and Alzheimer's disease (AD) and to require care in their later years (Foster 2008: 85). By 2050, the total number of Australians with dementia is expected to be over 730,000, a fourfold increase since 2000 (Access Economics 2005a:i).

In Australia, the ageing of the population has been accompanied in recent times by policy shifts towards community-based health care (Hancock & Moore, 1999:266). This trend is expected to increasingly impact on individuals, couples and families who have family members affected by a disability or chronic disease as well as on community-based health care services. While women as traditional caregivers within families are likely to be significantly affected by these demographic and policy changes (Hancock & Moore, 1999:265), so too are male caregiving spouses of women who develop dementia or Alzheimer's disease (Access Economics 2005b:3). How males approach and experience caregiving is an area that has been relatively under-researched in Australia however (Cahill 2000:53).

This paper describes a small research study undertaken in South East Queensland which aimed to document the narrative case study of a single male caregiver whose

spouse was affected by Alzheimer's Disease. This project was undertaken by the first author as a component of an honours degree in social work and as a result of a special interest in this area. The intention of the student researcher was to engage in collaborative and reflexive research and to authenticate the carer's voice and elucidate his experiences. In so doing, it was hoped that other carers, patients, community members and professionals would also benefit.

### **Alzheimer's Disease (AD)**

Alzheimer's disease is the most common form of dementia among older people. AD is estimated to constitute 70% of all cases of dementia (Australian Institute of Health and Welfare 2004:2) which altogether constitute the second highest disease burden for women and fourth highest for men (Access Economics 2003: 54). AD is a neurological illness and causes a progressive decline in a person's ability to remember, learn, think and reason; it is characterised by the gradual deterioration of intellectual abilities and changes in personality over time (Australian Institute of Health and Welfare 2004:2; Mace & Rabins 1991:284-5). The loss of short-term memory is the most striking early sign of AD and as the disease progresses, sufferers become increasingly less aware of their condition (Mace & Rabins 1991:284-5). During the course of their illness, affected individuals can also exhibit anger, aggression and behavioural disturbances although drug and non-drug therapies are available to help manage behavioral changes (Alzheimer's Australia 2005:2).

There are currently no treatments that are able to halt the progression of AD, the cause of which remains unknown. As with all diseases, the rate of progression and symptom severity associated with AD varies across individuals; people with AD can be expected to live an average of 10 years after diagnosis and this can extend to up to 20 years or more (Alzheimer's Australia 2005:2; Mace & Rabins 1991:285). In the final stage of the illness, the affected person is typically unable to recognise family members and is fully dependent on others for all aspects of their care (Alzheimer's Australia 2005:2; Mace & Rabins 1991:285).

### **Caregiving in the Australian Context**

Recently in Australia, there has been an increasing policy shift regarding the care of people affected by chronic illnesses like AD from institutional to community-based or 'informal' care (Access Economics 2005b:i; Hancock & Moore, 1999:276). This shift has resulted in family members like spouses or adult children providing personal care to a family member affected by AD, as well as assistance with mobility, communication, meals, financial management and transportation. From the policy perspective, this shift is based on the assumption that caring for a person in the community is a less costly care option. The implications of this policy shift are highly significant not only for individual patients, their carers and families but also for community-based medical practitioners, allied health professionals and community based services (Hancock & Moore, 1999:276).

## Caregiving and Caregiver Health

The experiences of caregiving for a loved one with a degenerative illness like AD are complex and multi-faceted. Although community-based support services are funded to provide supportive services for aged people and their carers (Hancock & Moore, 1999:266-7), caregiving within the family context is mostly carried out within the family home. For carers such as spouses, caregiving can be a very solitary activity and can have many inherent challenges, especially if it continues for an extended period of time (Russell, 2004:124; Mace & Rabins, 1991:218).

The health status of people who provide ongoing and constant care to family members affected by chronic or degenerative disorders has been identified as an important issue within the health care context (Access Economics 2005b:ii) and has been the subject of a range of Australian and international studies (for example, Cahill, 2000; Russell, 2004; Hoffman & Mitchell 1998; Gallant & Connell, 1998; Toseland & Rossiter, 1989). Overall, research indicates that providing caregiving for a sustained period of time is likely to impact negatively on the caregiver's health status because such caregiving can be associated with high stress and increased susceptibility to depression (Mace & Rabins, 1991:200-21; Hoffman & Mitchell, 1998: 5).

Emotional reactions like anxiety, guilt, loss, self-blame, physical and psychosomatic illnesses can be associated with caring for a loved one who progressively deteriorates with degenerative and incurable diseases like AD (Mace & Rabins, 1991:200). Such emotions can be intense and sustained over long periods of time. Managing symptoms of AD like aggressive behaviour that can emerge over the course of the illness can also present major challenges for caregivers (Mace & Rabins, 1991:34).

Losses experienced by caregivers can include the loss of companionship and connection with their spouse as the disease progresses; in time this can also be associated with an increased risk of carer isolation (Mace & Rabins, 1991:200; Gallo 1990:430; Harris 1993:556). However while many caregivers report experiencing a range of intense feelings like grief, guilt, anger, aggression and embarrassment, many people also simultaneously report a great sense of satisfaction and abiding loyalty that are associated with their care for their loved one (Cahill 2000:55).

Positive social and medical support has been strongly associated with the health and wellbeing of caregivers (Parks & Novielli 2000:2613). The involvement of general practitioners (GPs) appears to be a significant factor in this context as GPs provide opportunities for carers to discuss their concerns, feelings and management strategies, given that they are unable to share such matters with the person being cared for (Parks & Novielli 2000:2613).

## Experiences of Male Caregivers

Although women currently comprise 71% of all carers in Australia providing 'informal' or community-based care, the likelihood of men providing such care increases steadily as they age (Access Economics 2005b:3). However, much less is known about the experiences of male caregivers, particularly when caring for a spouse with Alzheimer's disease (Cahill 2000:53). An American study recently described the

experiences of a small number of male carers of wives who were diagnosed with AD (Pennington 2003). These caregivers reported needing support to cope as they experienced the helplessness of their situation; they also reported feeling robbed of their 'golden years'. At the same time however, the caregiving provided by the men was reported to be an expression of their love for their spouses (Pennington 2003).

Such positive orientation to caring has been confirmed in other studies which found that men desired to care well for their spouses and they acted out of a sense of duty, love and commitment; a problem solving approach also appeared to characterize their caregiving (Cahill 2000:55; Harris, 1993:555; Rose, Strauss, Neundorfer, Smyth & Stuckey 1997: 91). Other research described how male carers gradually incorporated the caregiving role into their self identity; they demonstrated a strong injunction to care for their spouses and derived satisfaction from their caring roles (Cahill 2000:53; Houde 2001:15).

Male caregivers have been reported to experience social isolation and loss of companionship however and pre-existing social networks are important in reducing caregiver burden (Cahill 2000:64; Russell 2004:121; Houde 2001:17-18). Seeking appropriate help or support may not necessarily be easy for caregivers. An American study of 178 male caregivers reported that multiple factors accounted for low use of services including lack of knowledge about services, lack of availability of services and also in some instances, a resistance to seeking help (Houde 2001:17-18).

Australian studies report similarly where male caregivers appear to want to be seen to cope by not seeking out help, such attitudes could be a barrier to accessing relevant services (Cahill 2000: 68). Where they are utilized, support groups have been found to be important for the mental health of male caregivers as has respite care (Mace & Rabins, 1991:163; Mittelman, Ferris, Shulman, Steinberg, Ambinder, Mackell: 1995:792).

## **The Case Study**

This study aimed to document, through an in-depth case study approach, the experiences and narrative of a single male caregiver with a spouse affected by AD. Case studies are useful in research as the basis of qualitative analysis is a rich and detailed description leading to broader understanding (Marlow 2001: 292). This understanding has the potential to yield vital information that may either support existing practice or suggest new approaches (Marlow 2001:292-3). Documenting the experiences and story of a caregiver in detail can be of interest and importance to other caregivers as it can assist in normalizing their experiences and emotions, thereby implicitly offering them support, encouragement and food for thought about a range of issues. The study had the approval of the Human Research Ethics Committee of Central Queensland University.

## **Method**

The single case study participant for the study was recruited in the South East Queensland region through liaison with a local Alzheimer's Association Queensland (AAQ) Support Group. Two in-depth interviews, spaced 5 weeks apart, were

conducted with the participant. A loosely structured interview schedule guided the interview but allowed the participant to describe his experiences in his own terms. Interviews were audio-taped with the participant's consent and were later transcribed for analysis. Data were analysed according to the main themes embedded in the caregiver's story and experiences and with reference to current literature. Findings are presented in narrative form and relate to the main dimensions of the participant's caregiving experiences. Details regarding the participant, his wife or the community they lived in which had the potential to identify them have been omitted. The account includes direct quotes from the interview transcripts and these allow the reader to gain a sense of the participant, his ideas and his experiences as they were expressed in his own unique manner.

## **Findings**

For purposes of the narrative, the participant chose to adopt the pseudonyms of 'Fred' for himself and 'Alice' for his wife. Fred was born in 1935 and was 71 years old at the time of the interviews; Alice was the same age. Fred and Alice were married in 1959 and had three children. At the time of the interviews, Fred and Alice's children were living in Queensland but at some distance from them.

### ***Alice's diagnosis***

In 2001, when Alice was 65 years of age, Fred noticed particular changes in her behaviour especially her apparent forgetfulness regarding matters she would normally have remembered. He reported however that he had been noticing changes and signs like that for some time before this. When Alice appeared to forget details, Fred recalled thinking "Alice should know that". Around the same time, a good friend of Alice's asked Fred "What's wrong with Alice? She is repeating the same topic of conversation". Fred felt guilty and a "bloody idiot" for not picking it up sooner.

After the discussion with their friend, Alice saw their general practitioner (GP) who did not make a diagnosis but he referred them on to a specialist; this doctor did not make a diagnosis either however. Fred contacted the local Alzheimer's Association of Queensland whose staff suggested he and Alice contact a doctor who conducted neuropsychological testing regarding AD; a referral was also made for Alice to have a Magnetic Resonance Imaging (MRI). Following these procedures, Alice subsequently had the diagnosis of Alzheimer's Disease confirmed. Fred was given comprehensive information on AD at this time including suggestions about coping strategies. Fred noted in the interview that he has not yet read all the literature but feels that he "should have done so".

### ***Experiences with health professionals***

Fred now regularly visits the GP with Alice because she would not be able to communicate her needs and might forget what she is there for if she went alone. Fred finds his GP is interested in his and Alice's experiences. He also reports learning while on a tour of local nursing homes that the GP attends the nursing home if he has a patient there; Fred found this comforting as he considers it very important to have a GP who would visit Alice in a nursing home if she was in need of medical attention. Fred also independently researches on the Internet before attending appointments at the hospital or with the doctor so that he can ask about specific drug trials.

A few years ago, Fred and Alice were invited to take part in an international drug trial related to AD involving 550 people. Towards the end of the trial however, Fred received a letter to say that the trial had been cancelled. Fred was upset and intends to correspond with the company; he wants to know whether Alice was receiving the placebo or the active ingredient in the trial. Fred thought that Alice had actually been improving since she had been taking the medication but he had no idea what it was. He had taken Alice to Brisbane when the trial was first set up and felt then that they were doing an important thing for research into Alzheimer's Disease. When he received the letter from the drug company he was very disappointed and felt it was very impersonal and that they had just been 'guinea pigs'. He thought patients and carers should be kept much better informed when these trials were being conducted.

Fred has also been invited through the local hospital to join a group of carers who complete daily reports about their loved ones that are submitted monthly as part of a research database that is being developed regarding AD sufferers. Fred thinks this could be of long-term benefit for caregivers to know that there is a database.

### ***The carers' support group***

Fred belongs to a carer's group in South East Queensland that meets on a monthly basis. Fred reports that the mutual fellowship within this group is helpful in that "we realise we are not on our own to a certain extent". The groups have helped Fred cope and through these he has also been able to access literature about various aspects of being a carer. Fred comments about his realisation that there are a lot of care organisations and he wonders if perhaps they should be centralised to provide care. Fred had not accessed the Dementia Help Line or other telephone support services as he has not needed advice as yet about looking after Alice at home; he reports that he would access these services however if he needed to.

### ***Respite services***

Fred has not used respite services at all as yet, but he knows that others in the carer's group have done so. Sometimes Fred is the only male in the group but he observes that many female caregivers have used respite services.

Fred feels confident about leaving Alice at home alone for shorter periods. However, to attend the support group Fred leaves Alice in the care of a friend. Fred says that this gives him a bit of a break. Other friends have also offered to care for Alice.

### ***Fred's experiences of others' attitudes to Alice***

Fred is clear that what other people say doesn't really worry him. He doesn't hesitate to take Alice out socially although she is unable to communicate well. Fred's attitude is that if people are only fair-weather friends, their friendship is really not worth having. Fred and Alice have a few very good friends although some of them do not live nearby. Fred says that he is not as reliant as Alice was on having lots of friends and that he copes fairly well in that respect. He says that he does not know what society thinks about men being caregivers. He has not heard anything derogatory; he stated that he would not tolerate criticism of his role as caregiver.

### ***Fred's life in recent times***

Fred considers it fortunate that he was able to retire early and thus be in a position to care for Alice. Fred says “at the moment the inability to travel probably affects me more than it affects Alice”. Fred considers that normal routine and surroundings are important however and he doubts that they will be able to get away on holidays very frequently. Fred accepts this but says that there is more travelling that he would like to do. Fred and Alice also have another family support in the form of Cindy their puppy. Cindy is a great diversion for Alice who really enjoys the puppy’s company. Fred thinks Cindy is a big help as she entertains and amuses them both.

### ***Fred and Alice's relationship***

Reflecting on their 47 year relationship, Fred states that he feels “duty bound” to care for Alice and certainly couldn’t walk away from her need to be cared for. Fred says “you don’t desert someone like that”. He spoke about knowing one another for so many years, about love and about signing their pledge ‘for better or for worse’. Alice is the mother of their children and Fred says that a “person doesn’t walk out on that sort of situation if coping is possible”. Fred thinks that he has to do everything he can although it can seem like a “bit of a losing battle”.

Fred’s concerns for himself were minimised by his focus on Alice and the fear that the time may come when she does not recognise others. If the time comes that Alice doesn’t remember him, Fred says he will just have to face it. Fred describes feeling as if he has been robbed when he considers this but then wonders whether these thoughts are selfish.

### ***Alice's behaviour changes***

Lately there have been a few slight signs that indicate that Alice might become more aggressive in some circumstances. This is quite a change as Alice has always been a very passive person. Fred shares that Alice is more forthright than she has been in the past and is a little bit less tolerant of some things.

### ***Fred's health***

Caring for Alice is a constant job and has had many effects on Fred, his health and his life. Fred says however that his saving grace has always been “having a sense of humour...I think that helps me”. Several years ago, Fred related that he had had a heart attack and underwent a five-way bypass from which he recovered well. Fred is fairly happy with his progress overall although he has not done as much exercise as advised; he admits to worrying about his health and intends to attend better to his own health soon.

Fred says that he is pretty busy and finds it difficult to fit everything in. He had untreated hypertension for a number of years (possibly hereditary); when he did receive treatment, he realised he had been living with this condition for a long while. Fred’s hypertension is now controlled with medication. Fred describes infrequent sensations in his chest and once had a bad brief stabbing pain but he didn’t tell anyone about it.

### ***Financial considerations***

Fred says his main financial strains have been caused by the loss of his Senior Health Care Card that was cancelled due to his income level. With both his and Alice's medications, the Card would have saved them around \$25 per script and thus hundreds of dollars each month. Fred has considered employing someone to assist with Alice's care at home although he has also heard from others that people can be better off in care situations like nursing homes where they have company.

As part of his preparations for Alice's long term care, Fred intends to approach the Aged Care Assessment Team to get Alice's name onto the waiting list for an assessment. Home and Community Care have advised Fred that he is not eligible for any unpaid help. He currently pays for about 3 hours of fortnightly home help for basic cleaning, vacuuming and dusting.

### ***The future***

Through the carers' support group, Fred has visited local care organisations and this has given him insight about where he might like Alice to go if the time comes. Fred is clear however that he wants to look after Alice at home as long as he possibly can. Fred is concerned for his family if he was to pass away and he intends to get both his and Alice's wills up to date soon. Their sons live at reasonable distances and are not able to be part of their everyday lives.

Fred stated that he has to get everything organised so that Alice could go into care if needed. This worries him and his solution is to keep himself fit so that he can continue to care for Alice, but this is a pressure upon him. Fred acknowledges that it may come to the stage where Alice would be better off in care, because she may not know where she is and might not recognise people.

### **Discussion**

This paper describes the experiences of a single male caregiver 'Fred' who lives in South East Queensland and who cares for his wife 'Alice' who has Alzheimer's Disease. Qualitative research provides insights into the lived experiences of people within the context of their unique lives and histories (Marlow 2001:292-3). While aspects of Fred's caregiving experiences may resemble others, the narrative account brings his own unique contextualised experiences to life and allows them to be located and described within his own frameworks and terms of reference.

Narrative accounts of male caregivers have been under-represented in the literature although men, as with women, can be primary caregivers in the home setting (Access Economics 2005b:6; Cahill 2000:54). Fred's early experiences of not being easily able to secure a clear diagnosis of Alice's condition are consistent with other people's accounts and can reflect an uncertain and concerning time for many patients, family members and their future potential caregivers (Mace & Rabins, 1991:68). The importance of public education around this issue has been strongly advocated by Alzheimer Associations and support groups as has the need for clear communication around the diagnosis of AD and the provision of relevant information to individuals and their families is also emphasised (Cahill 2000:68). Furthermore, the education and increased awareness of all health care professionals regarding the challenges and



implications of the diagnosis in the early, as well as subsequent, stages of Alzheimer's Disease is vital (Alzheimer's Australia 2005; Cahill 2000: 68-9).

Fred was relieved when he finally received information regarding AD from the AAQ but he also actively sought information about the condition and relevant drug trials in an ongoing way; he reported that his GP is supportive. While there have been some concerns about inadequate information for caregivers and lack of awareness about available resources (Fortinsky & Hathaway 1990:604), Fred did not experience this. Fred had a professional health career background and was competent in seeking information compared with other caregivers.

Fred's experience of the carers' group is consistent with findings that such support can help buffer or mitigate the challenges of caregiving (Gallo 1990:430). Information about coping strategies, stress management techniques, supportive counselling, behaviour management training and respite services have also been described as useful in these circumstances (Parks & Novielli 2000:2613). Fred accessed minimal assistance from family members and used few community services overall although he appreciated the short breaks that he did have. These findings were consistent with those of other studies reviewed (Houde 2001:13; Pinquart & Sorensen 2003:112; Watts & Teitelman 2005:282). Fred's capacity to pay for support services is a critical feature of his and Alice's situation.

Informal supports including family, friends and dog Cindy were important to Fred and also presumably to Alice. Support groups assist in meeting the psychological and educational needs of caregivers for people with AD and most caregivers have reported the benefits of knowing they were not alone and in helping them cope and prepare for the future (Chang, Brecht & Carter 2001:39-40). The importance for elderly people with dementia of having pets or animals in their lives has also been documented (Filan and Llewellyn-Jones 2006:597).

Fred's health status was also relevant in his account, an issue discussed by other researchers (Cahill 2000:67). Fred's health was of concern to him both for his own longevity and in terms of his wanting to be able to care for Alice well into the future (Mace & Rabins 1991:200). Fred's reflections about the future, as with other caregivers, are tinged with regret for lost dreams, restricted lifestyles and decreasing capacity to enjoy retirement years with his long-standing partner (Mace & Rabins 1991:200).

However, Fred appears to have adjusted to his care giving role and clearly intends to continue. Fred also describes the satisfaction he has gained from undertaking his care of Alice. Such an attitude is congruent with other research findings which indicate that caregivers often express feelings of responsibility, duty and love, and wanting to offer the best care possible for their spouses (Cahill 2000:61).

This was a small study with a single participant only. While it sought to present an in-depth account of a single male caregiver, broader data are required to inform more generalised understanding and service provision requirements, including possible gender-specific interventions. In addition to gender, individual differences and history

as well as cultural and geographical factors determine people's experiences and perceptions (Cahill 2000:67).

## Conclusion

Caring for a person with AD is simultaneously complex, challenging and rewarding for both men and women caregivers alike; it requires knowledge, skill, support and emotional resilience. The experiences of male caregivers are less well documented and understood than those of females, although an ageing population and trends towards community-based care in Australia are likely to result in both men and women caring, and being cared for, at home and in family and community-based contexts. Documenting caregivers' accounts gives voice to their experiences while simultaneously raising awareness and facilitating greater understanding of their experiences by other caregivers, health care professionals, policy makers and the broader community.

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