



Who cares for the carer?

The often forgotten patient

BACKGROUND Dementia not only affects the patient but also those nearest the patient most notably the carer. It is known that caring for a patient with dementia can adversely affect one's psychological, physical, social and financial health.

OBJECTIVE To highlight the needs of the carer of a patient with dementia and suggest means by which general practitioners may provide the necessary support for these carers.

DISCUSSION The GP has a key role in providing support to the carer of the patient with dementia. General practitioners and carers can work as partners in the long term management of dementia thereby reducing the adverse health effects on the carer.

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When a patient is diagnosed with dementia there is usually a second patient, the family carer. There is considerable evidence that being a carer has adverse psychological, physical, financial and social effects. Doctors and other health professionals should consider the carer as a patient in his or her own right as well as an informant, legal consent provider and monitor of treatment outcome.

The general practitioner has a key role in providing support to the carer and can refer carers for counselling or more structured interventions (which have been shown to reduce carer distress and assist patients to stay at home longer), or to support organisations such as the Alzheimer's Association. Linkages with other services such as the Home and Community Care Program, community Aged Care and Aged Care Assessment

Teams can be helpful. General practice management of dementia is best conceptualised as a partnership between patient, carer, other service providers and the doctor, over a prolonged period with different challenges at each stage of the dementia. Even after the patient has died, the GP has a role in helping the carer face bereavement. Carers want GPs to help, and GPs can find it very rewarding to work with carers as partners in the long term management of dementia.

The growing number of patients requiring medical, social and institutional care for dementia poses a significant challenge to our society. It is estimated that the world population of patients with dementia will increase from the current figure of approximately 18 million to 34 million by the year 2025. Within Australia, the prevalence of dementia doubles every five years after the age of

65 years, affecting 5% of people aged 65 years and over and 20% of those aged 80 years or over.¹

Effects of dementia on carers

Dementia is not just one person's illness - it affects those nearest to the patient as well, most notably the carer, usually the spouse of the patient. The day-to-day responsibility of caring for a patient with dementia exacts a psychological, physical, social and financial toll upon the carer. Psychological morbidity, such as depression, is common,^{2,5} and can persist even after the patient with dementia is placed in residential care.⁶

The physical health of carers may also suffer,⁷ with studies reporting worsening of chronic conditions such as hypertension, poorer self rated health, and more prescription medications, doctor visits

and physical symptoms.^{3,8,9}

Those with poor psychological health are even more likely to have physical morbidity.² This implies a need for the doctor to be vigilant in monitoring the physical health of the carer as well as the patient and encourage the carer to attend for regular review.

Social isolation may also be experienced by carers.¹⁰ Friends may become awkward or uncomfortable when confronted with the symptoms of dementia,¹¹ eg. lack of communicativeness or displays of disinhibition. The responsibilities of the caregiving role may force carers to abandon or substantially reduce their leisure pursuits and hobbies, or to cease employment, thereby reducing opportunities for social contact.^{11,12} A US survey found 55% of carers reported having to give up pleasurable personal activities and 52% had less time for other family members.¹³ A survey of Australian carers found that half had seen a person from outside their home only once a week or less often.²

Finally, there are considerable financial costs to families caring for patients with dementia. These include direct costs such as medical consultations, investigations, pharmaceuticals, provision of personal and nursing care and later, residential care; as well as indirect costs, such as loss of earnings by the patient and by family carers if they have to relinquish employment.

The amount of time that carers spend providing support is substantial but varies, with estimates of time spent assisting with activities of daily living and instrumental activities of daily living ranging from 50–120 hours per month.^{14–17} As the disease progresses, the amount of time spent providing direct care increases. Compared to an average of 4.6 hours per week spent caring for an elderly person with normal cognition, an additional 8.5 hours per week was spent caring for a patient with mild dementia, and an additional 17.4 and 41.5 hours per week was spent caring for patients with moderate and severe dementia respectively.¹⁸

The financial costs associated with providing such levels of care has been found to vary depending on the method used to estimate, eg. market costs for hours of care provided, loss of carer earnings. The associated additional yearly cost of providing care was US\$3630 for patients with mild dementia, US\$7420 and US\$17 700 for moderate and severe dementia respectively.¹⁸ Similarly, the median yearly cost of care has been estimated at US\$10 234 for those with severe Alzheimer disease and US\$4318 for those with moderate Alzheimer disease.¹⁴

Residential care placement

When it comes to the decision to place a patient with dementia in nursing home care, characteristics of and factors relating to the carers themselves tend to be as important as patient variables. Institutionalisation is more likely among carers who are experiencing greater psychological distress,¹⁹ and when carers are not the spouses of patients, eg. when they are their adult children.²⁰ Breaking points for carers include the amount of time spent caring for the patient, loss of own identity, patient misidentifications and clinical fluctuations, and nocturnal deterioration of patient.²¹

Factors that increase and decrease stress

A higher frequency of disturbing behaviour, cohabitation with the patient and less support from family and friends have been found to be related to higher burden and more depressive symptomatology.^{22–23} The wellbeing of female spouse carers is particularly influenced by the volume of patient problem behaviours, with emotional lability of the patient the strongest predictor of impaired wellbeing of the carer.²⁴ Being a spouse (rather than a child, relative or friend), low self rated health and care giving competence, high numbers of hours for assistance, patient's behavioural disturbances, and younger age of the carer were associated with depressive symptoms.²⁵ Low marital cohe-

sion and satisfaction among spouse carers are associated with more depressive symptoms.²⁶ Other patient factors which have been shown to affect carer levels of depression are the burden of functional limitations, agitation and depression in the patient.²³ Protective factors for carers are greater perceived support and use of emotion focussed coping skills.^{27,28}

Interventions for carers

Given the extent of strain and burden experienced by carers as a result of their role, it is not surprising that many efforts have been made over the years to devise interventions or treatment programs to alleviate this problem. These have included:

- programs to educate carers about the disease process
- training to improve coping skills or problem solving
- support groups, and
- counselling.

Recent reviews have found that the evidence to suggest the benefits of interventions for carers, in terms of improved psychological wellbeing or burden, is inconsistent.^{29,30} Improvements in carer's knowledge of dementia is often found (for studies that use this as an outcome), but unfortunately this does not necessarily correspond to improvements in psychological wellbeing or burden. A meta-analysis of interventions found that 23 out of 36 (64%) interventions were successful, where success was defined as a significant change in one of the main outcome measures or an effect size of 0.5 or more.²⁹

Practical measures for GPs to help carers

Initial steps

The partnership between the GP and caregiver is crucial in the continuing management of the patient with dementia. Diagnosis is the first step. Diagnosis rests greatly on the history provided by an informant, best obtained without the patient present. Practical measures, such

as recommending enduring power of attorney, enduring guardianship and monitoring driving and work abilities rely on cooperation with a family carer. Institution of specific medications may require proxy consent from the carer who will usually be the one who ensures compliance and monitors response and possible side effects.

The GP should also focus on the carer. How is the carer coping? Is he/she feeling depressed, anxious about the future or worried about passing on the risk of dementia to their children? Carers want time to discuss such issues as well as practical management strategies as outlined above.^{31,32} The main barrier identified why people do not join community self help groups is they have not been told about them.³³ At the World Alzheimer's Conference Working Group in 2000, carers themselves identified knowledge as critical to their continuing provision of care.

Referral to the Alzheimer's Association can be a boon for the carer (see Appendix). The association can provide written information, brochures, videotapes, specific courses and individual telephone or face-to-face counselling free of charge. Other help can be obtained through community aged care services and aged care assessment teams.

Middle steps

Carer distress can occur at any stage, is not related to the degree of cognitive impairment but is strongly driven by the occurrence of behavioural and psychological symptoms of the dementia.³⁴ Behavioural and psychological symptoms of dementia such as depression, aggression, wandering and shadowing, occur mainly in the middle and later stages of dementia.

General practitioners can assist carers in the management of behavioural and psychological symptoms by explaining that the dementia is the cause of these behaviours and that it is not the patient being deliberately difficult. They can also help by judicious prescribing of medica-

tion³⁵ and by calling in an Aged Care Assessment Team or community dementia nurse to assist. Carers can assist the GP by undertaking behavioural management strategies and by monitoring response to interventions.

Later steps

As the dementia progresses, the carer will need more help with the provision of basic daily care to the patient. Paradoxically it may become easier as the behavioural and psychological symptoms of dementia subside, eg. the constant questioning ceases as the patient becomes more aphasic. Carers however, face new challenges as they decide on placement of their loved one in residential care often after more than half a century sharing the same bedroom. Guilt is common, often exacerbated by family tensions about such decisions. When the patient dies, the funeral that never ends may reach a finale but the grief often commences afresh. The role of carer, which may have dominated that person's life for some years, is lost. The patient with dementia may not have been able to communicate, but was still the centre of the carer's life.

Conclusion

The management of carers is integral to the good care of a patient with dementia. As such, carers should be regarded as partners, alongside patients, doctors, and other health professionals in the long haul of the course of dementia. Psychosocial interventions have the capacity to reduce carer distress and delay nursing home admission, and they are also cost effective. Prescription of psychosocial interventions should be made with the same rigour and specificity as in prescribing medications.

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Appendix

Australian Alzheimer's Association
Dementia Helpline 1800 639 331
www.alzheimers.org.au

Alzheimer's Association ACT
PO Box 108
Higgins, ACT 2615
Phone: (02) 6254 5544
Fax: (02) 6254 2522
Email: mmcgrath@alzheimersact.asn.au

Alzheimer's Association Tasmania
Old Vicarage
St John's Avenue
Newtown, Tas 7008
Phone: (03) 6278 9897
Fax: (03) 6278 9878
Email: debbie.slater@alztas.asn.au

Alzheimer's Association New South Wales
PO Box 6042
North Ryde, NSW 1670
Phone: (02) 9805 0100
Fax: (02) 9805 1665
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Alzheimer's Association SA Inc
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Alzheimer's Association Northern Territory
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