



Focus

Dementia: the privilege of caring

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Introduction

What more cruel disease is there that robs people of their memory, personality and even the ability to recognise the people who love and care for them? This article identifies ways GPs may help patients and their families cope with the effects of dementia. The diagnosis of Alzheimer's disease is not easy, either to make definitively or to convey to the patient and family. It is the most common form of dementia and in most cases develops gradually over 10-15 years. Eventually it renders sufferers unable to care for themselves.

It has been estimated that one in 20 people over 65 either have, or will develop, dementia of some kind and that the incidence increases with age, rising to one in three by age 85. Increasing life expectancy has enormous implications for the provision of services for older people.

For GPs, there will be an increasing number of affected people in the average practice. At present around 70 per cent of people with dementia are cared for in their own homes, usually by one carer, often also elderly. The British Alzheimer's Disease Society report entitled *Right from the Start* based on a survey of carers and GPs, says: "Primary health-care teams have a key role to play in helping patients and their carers. They need to act not as gatekeepers but as a pathway to other services."¹

The report confirms that GPs do not find this role easy and 70 per cent of those responding to the survey felt they had not received adequate training in the management of dementia. Only a quarter of the carers felt their GP's knowledge was "very good".

Another area of concern expressed in the UK report¹ is the apparent failure of GPs to recognise the needs of the carers themselves in their "day in, day out" relentless task, sometimes referred to as the "36 hour day".

So what can be done to promote a "partnership of care"? A survey of carers identified four areas of need:

- information
- skills training
- emotional support
- respite.

KEY POINTS

- Information about dementia should be offered early to give the carer and sufferer informed choices
- Legal matters, such as arranging an enduring power of attorney to ensure a person's wishes are carried out, should be addressed as early as possible
- Practical help, eg, laundering, shopping, meal preparation and strategies for bathing, lifting and feeding are required
- GPs who show a real interest in both the person with dementia and the carer will be in a good position to offer extra help
- GPs can play a significant role in emotional support together with support groups for information and a "safe place" to air feelings of anger, frustration, guilt, grief and desperation
- Every carer needs a "break" before the stress levels result in "burnout", elder abuse or breakdown

Information

Information about dementia should be offered as soon as practicable. This allows the carer and sufferer to make informed choices: what is available; what will suit me; what may I need later on; how may I access help and what will it cost?

Information needs to be presented in a variety of ways, from the GP to the support group settings provided through the Alzheimer's Foundation and other bodies. Videos have proved very helpful, especially if viewed as a family, including younger members.

Leaflets, books, audio and videotapes are available through branches of the Alzheimer's Foundation, ADARDS (Alzheimer's Disease and Related Disorders Society) and specialised resource centres. Information about community support services, home help and financial and welfare assistance can be obtained through the above bodies and Age Concern. The Citizens' Advice Service will have local addresses.

Legal matters, such as arranging an enduring power of attorney (EPOA) to ensure a person's wishes are carried out, should be addressed early with clear directions, eg, as to resuscitation and aggressive treatment, to help both the family and medical teams.

Most people find it hard to retain a lot of information given at once, so the ongoing relationships in general practice provide opportunities for reiterating this, and offering further information as issues arise.

Practical assistance

The second need identified by carers lies in the area of practical skills and assistance. The requirements may range from provision of household help, laundry, shopping and meal preparation to strategies for bathing, lifting and feeding. Some dementing people go through a phase of "wandering" and the provision of safety locks, personal alarms and identity bracelets should be discussed if this becomes a problem.

Carers' health and stamina, ability to cope with changes in their lifestyle, and to develop creativity in problem-solving will affect their ability to manage. However, the GP who shows a real interest in both the affected person and the carer, will be able to judge when and how other help should be introduced.

Emotional support

The third area is complex but one in which the GP may be able to play a significant part if time and opportunity allow. The cost of caring may include financial costs due to loss of employment, reduction of social contacts and opportunities for personal recreation, as well as the stress of being in the caring role.

What are some of the emotional pressures? The stress of having to be there all the time or guilt at not being able to do this. The anger and grief engendered by the gradual deterioration of the once familiar personality. The physical demands of day to day care, the reversal of role, eg, a son or daughter bathing, dressing and feeding their parent and the unpleasant tasks associated with inappropriate toilet habits and incontinence. The embarrassment felt when public behaviour is out of character and the isolation experienced by subsequent withdrawal from social activities.

It is frequently reported by the main carer that, either because the person presents well for a short period, and/or appears to be in such good health, their concern is not regarded as serious by casual observers. It may be dismissed as exaggeration by family, minister and even GP until an episode is experienced by them.

There are many accounts of misunderstanding of the situation which, coupled with apprehension, keep friends from getting too involved, and leave the carer with no outlet for their emotion. Sometimes abuse of the patient by the carer occurs out of sheer frustration.

Understanding and opportunities for expression of feelings can help the carer continue the role. The GP, social worker, fieldworkers from the Alzheimer's Foundation and attendance at a group of similarly placed carers, are sources of help. Support groups, which provide information and above all a "safe place" where feelings of anger, frustration, guilt, grief and desperation can be aired, are invaluable. However these are not suitable for everyone, and the GP may be able to suggest other ways to provide the necessary outlet.

When the dementing person is being cared for by a younger family member in their home, there will be different stresses. Some may be related to relationships, eg, between partners as to priorities, or with children regarding table manners. Three-generation households where the older member is constantly disruptive and exhibits antisocial behaviour, puts enormous pressure on the whole family. The GP is well placed to observe the warning signs of undue stress.

Respite

Every carer needs a "break" before the stress levels result in "burnout", elder abuse or breakdown. Respite care provision comes in many different shapes and forms, from daycentres, with transport and meals included, to full time care for a week or longer. Age Concern and other organisations have selected and supervised volunteers who will spend a few hours "minding" in the home while the carer has some time out. Some community centres and church groups offer a safe and friendly place for several hours on a regular basis, with a meal and activities. Financial assistance for dementia sufferers to attend daycentres and for regular residential respite care is available, after assessment. Although the sufferer may have some reluctance to attend, or to having a stranger in the house, even going so far as to accuse the carer of neglect and "leaving me", the time away is beneficial to all parties.

Case study

Mr A, aged 83, is cared for by his wife, in her late 70s in their home. After his shower he insists on dressing himself which takes time because he forgets the order in which garments should be put on. He likes to help with the breakfast dishes, but does not remember where they go. He follows his wife about all day, even to the bathroom, but can be distracted for a few moments to cut up vegetables or go into the garden to pick some parsley, though he does not remember what he went out for. He is restless and hardly sits still, is warmly hospitable to any visitors, but does not know who they are, and becomes increasingly active in the late afternoon, when his wife is ready for a break.

Getting him to bed takes an hour. In the night Mr A gets up to the toilet, then tries to go outside for a walk but eventually is persuaded back to bed. This is repeated several times till morning, when the round starts again. Mrs A is reluctant to use sleeping pills for her husband as she fears he may become dependent.

Mrs A develops pains in her chest and visits her GP who, after a thorough examination, asks how she is coping. After some tears she explains she feels she is coping poorly. Five areas of concern are identified: lack of time for herself and subsequent irritability with Mr A's constant presence; difficulties in dealing with his dysphasia and restlessness; concern about medication and its effects; worries about the future for him and for herself; and feelings of isolation after a family member said "put him in a home".

Their friends feel awkward about visiting and the

What about the person who has dementia?

Most of this article has focused on the carer. What about the person faced with the diagnosis where they are still capable of understanding some of the implications?

Information about probable progress, practical advice and emotional support may be required. Such is the nature of the disease that experience in giving "bad" news will be called upon.

Practical measures, such as arranging an EPOA, advisability of driving a motor vehicle and ensuring the family have details of local support agencies, will help both the patient and family to take the next step. Available literature, written by sufferers, family and professionals, may help at this stage. As the disease progresses, understanding of the depression, confusion and frustration that may develop will be of great importance to both patient and family.

National resources

- Alzheimer's Society New Zealand Inc,

minister cannot see the problem as Mr A presents well for a short time.

Possible solutions:

- linking up with the local Alzheimer's Foundation fieldworker
- respite daycare several times per week for Mr A
- support groups where problems can be aired and frustration expressed (these are also a source of coping skills, as carers can exchange practical tips)
- information about possible options for care if Mrs A is unable to manage her husband
- reassurance she is doing a great job and must look after her own wellbeing in order to continue in the caring role
- district nursing service and legal and financial advice may be suggested to the family. Details of eligibility for financial assistance may be obtained from Work and Income NZ (WINZ).

National Office, PO Box 2808, Christchurch. Email: [alzheimers @ alzheimers.org.nz](mailto:alzheimers@alzheimers.org.nz)
Alzheimer's Society Auckland, PO Box 24042, Ph: 09 622 4230.

Branches are in most main centres. The Alzheimer's Society provides a range of information material, fieldworker service, support groups and access to their library. There is a regular magazine for members.

- Age Concern, National Office, PO Box 10 688, Wellington, and area offices. Email:

national.office@ageconcern.org.nz

Offers a range of services, information, books, videos and leaflets concerned with ageing.

- The Eileen Shamy Centre has a collection of material relating to the spiritual aspects. Contact: MMN, PO Box 5104, Auckland. Ph: 09 302 5390.

- A very helpful book for carers is Alzheimer's at your Fingertips obtainable from the Alzheimer's Society or on loan from the Eileen Shamy Centre.
- There are also valuable guidelines for the Support and Management of People with Dementia, National Advisory Committee on Health and Disability obtainable from the Christchurch School of Medicine, PO Box 731, Christchurch.

References

1. Right from the start – Primary health care and dementia. Alzheimer's Disease Society, 1995.
— Caring alone – looking after the confused elderly at home. Opie, A (ed). Daphne Brasell and Associates Press, 1991.
— Cayton H, Graham N, Warner J. Alzheimer's at your Fingertips. Class Publishing, London: 1997.
- *Jill Richards was instrumental in the setting up of the Eileen Shamy resource centre in Auckland as an acknowledgement of the outstanding work done by the late Eileen Shamy of Christchurch in understanding the spiritual needs of dementing persons.*