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Family carers

A focus on the carers of people with dementia

By Henry Brodaty, Alisa Green and Lee-Fay Low

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A carer: 'a family member (or friend), helping someone on a regular (usually daily) basis with tasks necessary for independent living'.

More than 2.2 million Australians aged 15 years and over are carers, according to the 1998 Australian Survey of Disability, Ageing and Carers. This is 15% of our population. Many carers are spouses and of these, about 75% are women. Thirty per cent of home carers are adult children and their partners, with daughters more likely than sons to be the main carer. It is estimated that people with Alzheimer's disease are cared for at home for an average of 3.7 years, receiving 286 hours of care per month.

As well as providing daily physical care, emotional support and practical help to patients with dementia, family members have a number of other crucial roles, including:

- Dealing with medico-legal matters;
- Providing information to doctors for diagnosis and assessment of treatment;
- Giving consent for medication and medical procedures;
- Ensuring compliance with medication;
- Attending to legal and financial matters;
- Assisting with/managing finances;
- Acting as enduring power of attorney;
- Providing enduring guardianship.

In addition, families looking after people with dementia bear considerable financial costs. Direct costs include medical consultations and investigations, pharmaceuticals, provision of personal care, nursing care and residential care. Indirect costs may include loss of earnings by the patient and by family carers. Most of the expenses for patients living at home are borne by their families.

Effects of care-giving

The demands of care-giving often result in carers experiencing:

- higher psychological illness and rates of depression and more limited social contacts than noncarers;
- poorer physical health, with higher levels of chronic medical conditions, greater use of prescription medications and more doctor visits;

- weakened immune systems;
- higher levels of alcohol use and smoking;
- poorer sleep patterns, eating habits and nutrition.

Care-giving can also exacerbate pre-existing conditions such as hypertension.

Predictors of care distress

Caring for a person with a chronic mental condition is more stressful than caring for a person with a physical illness or disability. Female carers experience higher rates of psychological illness, and carers are more likely to feel distressed if they had an unsatisfactory relationship with the person with dementia before the diagnosis was made.

Behavioural disturbances are the single largest predictor of psychological distress in carers. Disturbances include incontinence, immobility, night-time wandering, proneness to fall, difficulties with communication, sleep disturbance, disruptiveness, constant demands and aggression.

Most studies have found no association between the person with dementia's cognitive status and the carer's psychological health. Rather, decline in functional abilities is associated with restriction of the carer's activities and the increased burden upon the carer. Carers who use emotion-based coping strategies for example, expressing feelings of inability to cope, tend to be more distressed than those who use problem-focused strategies. Social support can provide a protective buffer against stress in carers.

Nursing home admission and carers

In general, factors associated with carers are more predictive of nursing home admission than patient characteristics. Institutionalisation of the person with dementia is more likely in cases where children are caring for their parents, among carers who have higher psychological distress, as well as among those with financial or family problems, greater severity of dementia or a faster rate of progression.

Intervention for carers

Intervention programs can reduce carer stress or burden. Two randomised controlled studies showed that in addition to reducing carer psychological morbidity, carer intervention programs can delay nursing home admission for almost a year.

The first study involved ten days of counselling, information and practical advice being provided, along with role plays and skills training for groups of carers and their charges in a residential setting (Brodaty & Gresham, 1989; Brodaty, Gresham & Luscombe, 1997).

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The second involved four family counselling sessions and two individual counselling sessions, and further contact and weekly support group meetings as needed (Mittelman et al, 1995).

The management of the carer's health is important. Carers should be regarded as partners in the long haul of dementia care, given the significant and multiple roles they have in the long-term care of the person with dementia. Psychosocial

interventions can maintain the health of carers by reducing distress, facilitate good care of persons with dementia and delay nursing home admission.

(Henry Brodaty is Professor of Psychogeriatrics at the University of New South Wales. Alisa Green and LeeFay Low are psychologists working in the Academic Department for Old Age Psychiatry, Prince of Wales Hospital, NSW.)

WA TRANSITIONAL CARE UNIT EASES ACUTE-CARE BED PRESSURE

The increasing relevance of transitional care units for elderly hospitalized patients awaiting hostel or nursing home placement has been demonstrated by the Care Awaiting Placement Unit (CAPU) attached to Sir Charles Gairdner Hospital in Perth. It is the first facility of this type to be operated by a tertiary public hospital in WA and is located in the neighbouring acute-care Hollywood Private Hospital.

The high demand for transitional care beds by tertiary hospitals is reflected in the CAPU's 98% bed occupancy rate during its first 12 months of operation from July last year. During this time, there were 146 admissions and 125 discharges in the 22-bed unit. The average length of stay was six weeks with a range of four hours to 11 months. The Commonwealth resident classification scale (RCS) was used to assess 120 residents. More than 86% scored 'high care/nursing home' level of dependency (RCS categories 1-4) and of these, 45% scored the highest dependency levels (categories 1-2).

CAPU Clinical Nurse Manager, Jo Rowe, said that patients were assessed in hospital to determine whether they were medically stable and ready for discharge. However, the open ward layout and staff numbers limited eligibility for admission to the CAPU. For example, the unit could cater for patients with varying levels of physical and cognitive ability but could not appropriately meet the needs of those with overtly aggressive or intrusive behaviour. She said the multi-disciplinary unit comprised medical, nursing, physiotherapy, social work, occupational therapy, speech pathology, podiatry and dietetics staff.

"A specifically designed checklist has been introduced to capture an overview of each CAPU resident's RCS dependency level," Ms Rowe said. "The checklist translates acute-care discharge information into the RCS 'language' used by residential facilities. This assessment is documented on admission to the CAPU, updated on discharge and forwarded to the nursing home or hostel as part of the discharge documentation. Feedback so far has shown this approach assists residential facility staff in designing the interim care plan required prior to the 28 day assessment period for their initial RCS application for that resident."

The transfer document designed by Ms Rowe and the RCS is available on the ARCHI website at http://www.archi.net.au/content/file/download.phtml?type/File/id/341/field/file/name/CAPUForms_SC_GH.pdf

For further information contact Jo Rowe.
Telephone: (08) 9346 7284.
Email: Jo-Anne.Rowe@health.wa.gov.au