Going to Stay at Home: support when it matters

Meredith Gresham, Deborah Moore and **Colm Cunningham** describe a novel program that combines caregiver training with a residential respite stay to reduce carer distress, prevent an increase in behavioural symptoms and enable the person with dementia to remain living at home for longer

Family carers play a critical role in the lives of people who are living with dementia. The impacts of this role on family carers can be profound. Despite this, an overwhelming number of family members choose to support their loved one to remain at home in the community. Although around 70% of people with dementia in Australia are estimated to be living in the community supported by the care of family or friends, more than half of spending on dementia by the Australian Government has been directed to residential aged care (AIHW 2012a; b).

Impacts of the caring role may have negative physical, psychological, social and financial outcomes. Carers undertake countless daily activities as well as often assuming the roles and responsibilities that were previously performed by the person with dementia. The progressive nature of dementia eventually results in carers needing to provide support for a family member with a high level of disability. In addition, the changes that dementia can bring to former relationship dynamics may leave the carer experiencing greater levels of stress than those who are caring for someone with other chronic conditions or disability.

Behavioural and psychological symptoms associated with dementia, such as aggression, agitation or psychosis can be associated with increasing carer stress. Higher levels of carer stress have been shown to correlate with earlier and increased rate of placement in residential care (Rabinowitz *et al* 2007; Schubert *et al* 2008). Stress does not always decrease following admission to residential care. A two-year study of 517 family carers in the US found that the 152 carers who admitted their family member to residential care still continued to care for their loved one, although in an "altered but still stressful way" (Zarit & Witlach 1993). Stress became more complex, not only relating to the guilt of placement but also potentially exacerbated by poor quality interaction with care home staff (Almberg *et al* 2000). Carer stress may also persist up to two years after the person with dementia has been admitted to residential care. Furthermore, carers often report having poorer health (including more symptoms of depression) and greater use of health services themselves.

Support for carers

Support services in Australia generally are focused on providing practical assistance (eg Community Care Packages, centre-based care) when the person with dementia requires significant support for activities of daily living. Carer support groups operate nationally and offer an opportunity to share experiences but are usually limited to only a few hours each month. Other services available include literature for self-education and telephone support services such as the Dementia Australia Helpline or Dementia Support Australia.

Residential respite care offers carers a short-term break. However, although respite is the most requested service, rates of uptake of this service in Australia have remained low. The decision to access respite care can often be a stepping stone towards permanent placement in formal care with over 50% of respite admissions converting to permanent care (AIHW 2010).

Combining respite with training

The course of dementia is long and years may lapse between diagnosis and the provision of support. Structured, post-diagnostic intervention and support is lacking. However, combined information, education and respite care have been shown to assist carers to maintain the person with dementia living at home (Elvish *et al* 2013). A previous randomised controlled trial conducted at Sydney's Prince Henry Hospital in the 1980s, where people with dementia and their carers attended a 10-day training course, resulted in carers experiencing lowered psychological stress, better general health, and increased time until placement in residential care for the person with dementia. This program still showed positive effects eight years post-training and was shown to be cheaper for health and aged care systems over the long term (Brodaty & Gresham 1989; Brodaty & Peters 1991).

Through this program, carers gained skills and knowledge of what to expect, how to cope and how to harness formal and informal assistance. Carers demonstrated increased confidence, as well as positive impacts on their wellbeing, anxiety, depression and quality of life. Carer training provided early in the course of dementia also had significant positive effects on the outcomes of people living with dementia, enabling carers to proactively manage situations that may have produced negative outcomes.

Co-author Dr Meredith Gresham with a participant in the residential cottage during the Going to Stay at Home training program.
Photos: The Dementia Centre, HammondCare

Going to Stay at Home study: key findings

- Carer depression and burden remained stable, despite increasing dependence of the person with dementia.
- Carers' needs were being met.
- Reduction in behavioural symptoms in people with dementia.
- Reduction in transfer to permanent care.

Going to Stay at Home

The Going to Stay at Home program (Gresham *et al* 2018; Gresham *et al* 2014) was designed as a novel intervention method that combined the principles of the Prince Henry Hospital training program and respite care. It aimed to reduce carer distress, prevent an increase in behavioural symptoms and enable the person with dementia to remain living at home for longer. Funded through the (former) Department of Health and Ageing, the program was conducted in an eight-bedroom self-contained cottage, comprising one of HammondCare's residential aged care cottages in Miranda, a suburb south of Sydney. Participants were recruited through referral by their health or care service, or through self-referral.

Overall 90 pairs consisting of a person living with dementia and their carer participated in a comprehensive training program while staying in the cottage over a period of seven days from Sunday afternoon to the following Saturday morning. During this time, groups of three-to-six carers participated in an intensive program which involved attending 14 sessions that focused on various aspects of supporting someone with dementia. These included sessions on: psychological support to reduce distress and depression; education and information about dementia and its progression; understanding the change of roles and effects on relationships that may be brought about by dementia (re-roling); combating isolation; improving coping and home care skills; problem solving and techniques to manage behavioural symptoms; developing personal, family, community, and professional support systems; and planning for the future, such as legal and financial planning, and coping with emergencies. A typical schedule for the Going to Stay at Home program is shown in Table 1 (see next page).

The schedule was arranged so that carers could initially 'tell their story' and promote the understanding that other carers shared aspects of their experience to decrease feelings of isolation. Education about dementia and other practical information were programmed early in the week, allowing sessions that dealt with more challenging aspects of care, such as incontinence or end-of-life care, to be delivered later in the week after carers had time to build support within their group. Sessions lasted between one and two hours and were led by experienced health professionals using experiential learning, refocusing lifelong skills and coping mechanisms on new challenges presented by dementia.

While the carers were attending training sessions, the people with dementia participated in a program which focused on daily domestic, creative, exercise and social activities in the cottage, as well as outings. Information about dementia and practice of simple mnemonic (memory) techniques was also made available, if desired. Social and leisure activities, such as movies, table tennis, lawn bowls, music and dancing, were arranged for everyone to participate in together during the evenings.

Nineteen programs were conducted over a 12-month period, allowing both the person with dementia and their carer to meet others in a similar situation. Where possible, groups were arranged to include couples from similar geographic areas, allowing the possibility of forming ongoing support networks. One program was also conducted in commercial serviced apartments in a regional town in NSW to explore the 'portability' of the program.

The program was evaluated using pre-program measures and repeating these at six and 12 months to determine whether there was any ongoing impact. Transfer to permanent residential care was compared against a similar group of people with dementia who received residential respite care, but without the carer training component (Gresham *et al* 2018).

Positive outcomes

Key outcomes of the Going to Stay at Home program were that:

- there was an increase in the number of carers' needs being met
- there was a reduction in transfer to permanent care
- there was a reduction in behavioural symptoms in people with dementia that were responses to both situational stressors and psychiatric symptomatology, such as depression, paranoia and mania
- carer depression and burden remained

stable, despite increasing dependence of the person with dementia.

After the program, the needs of carers being met increased significantly. These specific needs included knowledge and information regarding how to support a person with dementia, practical tasks, communication/management of daily activities, financial/legal entitlements and managing behavioural symptoms.

There was a marked increase in the number of people with dementia remaining at home 12 months after completing the program. In fact, only 15 (17.6%) of people with dementia (n=85) who had attended the program were transferred to permanent care, compared with 63 (52.9%) of a similar group (n=119) who received respite care in the same organisation but without the carer training component.

Behavioural symptoms in people with dementia also decreased significantly, despite the severity of dementia increasing over time. This was possibly attributed to the positive impacts of the program in meeting the needs of carers through developing a better understanding of dementia and how to manage distress-provoking situations for the person with dementia.

There was no significant change in carer burden, psychological distress or depression, however this was over a 12-month period during which most people with dementia experienced an increase in dementia severity and decrease in functional ability.

Overall, the Going to Stay at Home program was successful in delivering effective education and information to carers about dementia and its progression, as well as improving carers' coping, home care skills, problem-solving and management of behavioural symptoms. Carers reported that the program being carried out in a residential setting was beneficial and did indeed provide respite, as there was no meal preparation, housework or shopping to attend to and the stress of getting to the training was 'once only'.

In addition, carers were able to observe staff model skills and to try new skills themselves in a supportive environment. Participating in the program alongside others in a similar position also helped with issues of social isolation, with each group offering each other mutual support and comfort in sharing of problems, solutions and experiences. Importantly, the program focused not only on education and skill development, it included adding fun back into life. The evening program included dancing, table tennis and a dinner outing.

Future implementation

The Going to Stay at Home program is a feasible and practicable model with benefits for both the carer and the person with dementia. The program provides knowledge and information to carers about supporting people with dementia, especially regarding avoiding behavioural symptoms as a response to stress. It is likely that the education contributed to the reduction in behavioural symptoms that was observed over the 12-month period following the program, which in turn may have led to increased numbers of people with dementia remaining at home. In addition to knowledge acquisition and skill development related to caring for their loved ones, carers learnt about community services that are available to support them, and how to proactively seek their assistance as symptoms progress and needs change.

The success of the program in the regional town in NSW supports the idea that this program can be carried out in a range of geographical locations. This would be most beneficial to those living in rural communities where there may be limited access to healthcare and social support networks, and so more knowledge and confidence in various aspects of how to care for a person with dementia would be highly valued in these areas. An important lesson learnt from this study is that not only could a similar program be implemented in other locations, but it could also be applied to other chronic illnesses where carers play a pivotal role.

It is critical that there are strategies in place to provide assistance to carers who support people with dementia, and other chronic diseases, in order to increase the confidence level of carers in implementing learned skills and managing challenges, as well as looking after their own health and wellbeing. The current health policy and funding models available in Australia place emphasis on acute disease treatment, rather than prevention and proactive management strategies, however the cost of this approach will increasingly overwhelm health systems and budgets with an ageing population.

Dementia costs are currently set at over $A14 billion each year and forecast to exceed $A1 trillion within the next 40 years (Brown *et al* 2017). Annual costs of formal residential care alone are estimated at about $A88,000 per person

A Going to Stay at Home physiotherapist-led exercise circuit class in the cottage garden

Table 1: Going to Stay at Home sample timetable for carers

Day	Morning	Afternoon	Evening (examples)
Sun		Welcome / Orientation	Socialising
Mon	Combating isolation	Medial aspects of dementia Relaxation	Sausage sizzle
Tues	Fitness and physiotherapy Reminiscence and reality orientation	Communication Assertion	Classic movies or dancing
Wed	Re-roling Nutrition and diet	Using activities therapeutically Simplifying work and safety in the home	Carpet bowls
Thurs	Nursing skills	Planning for the future Using community services	Carers' dinner out
Fri	Caring for self Relaxation	Carers' choice of topic	Table tennis competition
Sat	Farewell		

(Gnanamanickam *et al* 2018). In contrast, the Going to Stay at Home program was, at the time of writing, offered by HammondCare as an ongoing service at a cost of approximately $A3000 per dyad, so the cost of the program would be covered by staying out of residential care for just 13 days (Gresham *et al* 2018). It is therefore vital that there is a 'cultural shift' towards providing more early intervention programs, such as the Going to Stay at Home program, that help carers to support their loved ones effectively, and in turn reduce the use of health and community services. ■

The program included daily domestic, creative, exercise and social activities in the cottage

Further information

Further details, articles describing the program and the results are available in open access format. The protocol paper is at https://www.springerplus.com/content/3/1/330 and the results article can be found at http://bit.ly/GTSAH-results. The project was evaluated by Dr Megan Heffernan and Professor Henry Brodaty at the University of NSW.

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