

A preliminary evaluation of the Short Break Stay Program

Respite care for people with dementia

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Recognising the need for a respite service which provides real support and reassurance for carers of people with dementia, Brotherhood of St Laurence Aged Services devised the Short Break Stay program at the Banksia Community Respite Centre. There is clear evidence that the program, which provides a three-day stay for people with advanced dementia in a homelike living space staffed by experienced personnel, has been a resounding success even beyond what was anticipated by the managers, providers and carers who developed and delivered the program.

Key findings

This preliminary evaluation suggests that the Short Break Stay Program is highly successful in meeting the respite needs of carers and the high care needs of their care recipients. Carers have given the program whole-hearted endorsement for a range of reasons.

- The Short Break Stay program offers an innovative dementia-specific, respite care service enabling a three-day break for carers which is long enough for them to receive some tangible respite from their caring role but short enough to avoid unduly disrupting the care routines already established at home unlike the standard fortnight in residential aged care facilities.
- The program staffing ratio of 2:6 and the person-centred care approach enable close attention to each individual.
- Carers valued highly the availability of staff to spend time with them to learn about their care recipient's preferences and needs, as well as the regular communication provided during the client's stay.
- Carers appreciated the careful matching of clients with staff as well as with other clients to ensure

some commonality among the clients taking a short break at any particular time.

- Carers appreciated the efforts made to replicate the care that clients received at home and, especially, the attention paid to transitions into the Banksia Centre and back home, which for people with dementia or cognitive impairment can often cause great anxiety and distress.
- The Banksia Centre offers clients and carers a smooth and seamless transition between day and short-break respite.
- Carers were confident that the Short Break Stay program included access to specialist services if required.

Background

As rapidly increasing numbers of people in later life elect to be cared for in the community rather than entering a residential care facility, there is a pressing need to redesign support available to carers. Caring around the clock for a person with a cognitive/physical disability such as dementia, stroke, or brain injury is extremely demanding and the challenges associated with such care are growing and need attention.

Deloitte Access Economics (2011) has estimated that by 2050, 943,000 Australians will be living with dementia. In 2011 there were 68,397 people with dementia living in Victoria. This is projected to increase to 245,831 Victorians by 2050, an increase of 250 per cent.

Among eight Department of Health Regions in Victoria, Southern Region has been ranked the highest in terms of prevalence and incidence of dementia, with 16,000 existing cases and 4,800 new cases of dementia in 2009 alone. Of the eight local government areas in the region, the Short Break Stay

program is targeted to the three in the southern part—Kingston, Frankston and the Mornington Peninsula—although requests for the service have started to come from other parts of the region.

In spite of these figures and the level and intensity of care required to support a person with dementia to remain at home, there is a shortage of suitable respite services (Michael 2010). The majority of the very limited number of respite care places are offered by residential aged care facilities which have non-negotiable requirements about the minimum length of stay, while the number of community respite care places is very small. Carers appear to be rejecting the respite care provided by residential aged care facilities. According to AIHW (2010), only 27 per cent of individuals approved for residential respite care actually used these services.

Carers of people with dementia have been dissatisfied with existing services because they are not meeting their needs. Most carers do not want to place the person they care for in a facility for the mandatory minimum of two weeks, especially a facility without expertise in dementia care. The experience only exacerbates problems such as the following:

- A change in environment can often trigger a change in behaviour or exacerbate existing behaviours, so that when the care recipient returns home, the carer faces a new set of behavioural challenges.
- Carers often feel guilty for using respite services and struggle to relinquish care. Carers Victoria found that most first-time carers using respite services experience increased anxiety about the person who has gone into care.
- Carers often find it difficult to let go and trust that everything will be all right for the person they care for.
- The paperwork required to arrange residential respite care is copious and complex.

When carers experience any or all of these issues they report that the respite experience has been negative, the very opposite to its intent.

The program

The Short Break Stay program was designed to address these issues. It is a high-care program which offers carers respite while the person they care for stays for a three-day period (Sunday to Tuesday) in a specially designed, homelike living space with six bedrooms, a

full kitchen and associated utility areas. This living space is especially equipped to provide for people in the later stages of dementia and other neurological conditions, and has discreetly located security measures. Carers can arrange a short break stay up to once a month, subject to vacancies. Unlike respite care in aged care residential facilities, the Short Break Stay respite program does not require a ACAS assessment. Thus it is available to people who are not receiving an aged care package.

Research methodology

The evaluation of the Short Break Stay pilot program reviewed project implementation and the impacts, outcomes and the effectiveness of the delivery model. A program logic model provided the evaluation framework and both qualitative and quantitative data collection methods were used. To triangulate the qualitative data, carers, staff and project partners were invited to contribute their views and experiences through focus groups, interviews and a carer survey.

Findings

A much-needed break

Carers who took part in this evaluation had been caring (typically for a long time) for someone with either dementia or a similar neurological/psychological condition, resulting in difficulties including challenging behaviours, incontinence and communication problems. Both the evaluation discussions and the satisfaction survey indicated that the program was instrumental in helping carers to accept respite care services as important to their capacity to ‘hang on’ despite the demands of providing round the clock care and to keep the person they care for at home for as long as possible.

Carers reported that the program had enabled them to ‘recharge their batteries’. They reported they had caught up on sleep, visited friends or met other commitments, and experienced a sense of peace and freedom without having to worry about the person that they cared for.

While the large majority of carers said they would like to see the program continue beyond the pilot, some suggested that offering other lengths of stay (ranging from one night to a week or more) or more frequent stays, could be helpful.

Individual, expert care

The high staffing ratio for the Short Break Stay is unique among services, with two staff (a combination of personal care workers and enrolled nurses) on duty day and night for a maximum of six attendees. Apart from formal qualifications, staff members are chosen for attributes which include confidence, the ability to relate to others, empathy, active listening skills and the ability to work with people who have limited communication skills.

Most carers said they wanted a respite program to provide the very best of care and to treat the person they cared for with respect. Carers appreciated the program's person-centred approach which began with the welcome:

They immediately put her at ease because they know her by name regardless of who is doing the greeting—they all have the same caring attitude it makes me feel good.

All the staff have experience not only in managing the symptoms of dementia but also in managing behaviours associated with confusion, fear and agitation. Carers appreciated how the program catered for individual needs, including those related to food or physical abilities.

Clients are matched with others who are at a similar stage of dementia, taking into account cognitive levels as well as physical care needs. However the program also offers activities in an informal and flexible manner to cater for individual preferences. A carer commented:

The program provided the feeling that it was like being in a family.

Communication

The staff understand that carers need time to develop confidence in the Centre's staff and the program and work towards establishing that trust. When carers begin to use the respite program they are provided with a communication book as well as open access to staff to discuss any concerns. A carer commented on:

the two-way communication that occurs between staff, carers and clients, as well as getting back a communication book from staff and being able to deal with issues as they arise.

Transitions

Without careful management, a change in environment can often trigger a change in behaviour or exacerbate existing challenging behaviours in the person with

dementia so that when the care recipient returns home, the carer faces a new set of behavioural challenges. Carers were relieved that there was little evidence of disorientation when the care recipient returned from a short break, unlike their experience of two-week breaks in other facilities. As one man said:

I like the fact that my wife goes in there and comes out just the same as she went in. You know, she never looks like she's had any problems at all. And the staff too, the staff are excellent and friendly.

Support for carers

Staff are also available for carers to discuss their concerns about managing dementia and obtain advice about coping at home with their care recipients. They also link carers to other services offered by the Brotherhood of St Laurence, such as the Memory Lane Café Program and the Dementia Library.

Networks

A strong relationship has been built between the Brotherhood of St Laurence and the Commonwealth Respite Centre which has provided funding for the program and been an active participant in the Steering Committee. There has been an increase in referrals by Baxter Village, a local retirement village, of clients who require a program to cater for high-care needs. In the Southern Region, a network of community care and residential care service providers meets regularly to discuss common concerns. These relationships have laid a valuable foundation to continue advocacy for quality respite services.

Opportunities for improvement

The external evaluation of this pilot program enabled opportunities for improvement to be identified and incorporated into the ongoing program.

Carer suggestions

While carers overwhelmingly reported that the Short Break Stay program had met most of their needs, they also had ideas for further enhancement of the program. In particular they suggested:

- increasing the service to a weekly or fortnightly frequency
- allowing the program to occur over the entire weekend period
- extending the length of the program
- providing transport assistance.

Staff suggestions

Staff members working in the program suggested that there is a need for:

- improvement in the handover of information from one shift to the next
- clearer guidelines and information about administration of medication provided by carers during admission
- staff training to deal with client resistance to personal care routines and clearer communication with carers
- containing client wandering at night into other clients' rooms.

Conclusion

Overall, Short Break Stay is an innovative program that provides a homelike experience for people who have dementia. Using the service has been a positive experience for carers and care recipients alike as confirmed by the number of repeat visits over the first twelve months. The main concern for the future is to secure ongoing funds to ensure continuation of the Short Break Stay program, as well as its expansion as more and more carers come to demand such a service.

Ultimately, carers deserve more support and assistance to sustain their caring roles. They have the right to choose how that support is provided. The Short Break Stay program was designed to address the burden that carers carry and, most importantly, to focus on the management of behaviours often associated with people with more advanced dementia so as to maintain their sense of wellbeing.

In establishing the Short Break Stay program, Banksia Respite Care Centre has recognised the need for a respite model which ensures that people with dementia are provided with appropriate support which in turn delivers positive outcomes for their carers.

About the project

This evaluation considered the initial implementation of the Short Break Stay program, developed by Brotherhood of St Laurence aged care services and made possible by the financial support of the Commonwealth Respite Centre. The Brotherhood has since received one-off funding to deliver another five short break stays, each providing for six care recipients, between February and June 2012. Further short break stays have not been offered, due to the lack of ongoing funding.

Related resources

Read about another Brotherhood of St Laurence initiative related to dementia care in *Caring for carers: evaluation of a support program for carers of people with dementia* (PDF file, 387 KB) by Ashley Carr, Helen Kimberley and Monica Mercieca. The report may be downloaded from the Brotherhood of St Laurence website.

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