

## The too hard basket: Community respite for people with dementia and challenging behaviours

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- 1.0 Background
- 2.0 The too hard basket
- 2.1 Community and In Home Flexible Respite - Southern Sydney
- 3.0 Partners in care model
- 3.1 Components of respite care
- 4.0 Issues that have arisen
- 5.0 Have we met the needs of both carers and the person they care for?
- 6.0 Reference list

### Background

The Benevolent Society was established in 1813 and is Australia's oldest non-profit organisation. It has been at the forefront of social innovation and delivering high quality services which respond to changing community needs. It provides a range of services for older people, from healthy ageing to intensive support, across metropolitan Sydney, and is a major provider of community services. Our mission is to provide services that put people first.

### The too hard basket

Respite services have been criticised for not meeting the needs of people with dementia and challenging behaviours. Challenging behaviours are defined as disruptive, aggressive, or socially unacceptable behaviours that mean a person finds it difficult to access traditional respite services. For carers of this group, there were very few options available, as the person with dementia fell into the "too hard basket".

*Mrs M is a single parent who cares for her father, Valentina, who has diagnosed dementia. They are from a Russian background and Valentina does not speak any English. Mrs M cannot access day care or nursing home respite because of her father's aggressive behaviour when he is away from her. Mrs M has a casual job where she is on call. She also needs to have time with her children. What options are open to her? Not many!*

A person who is caring for someone who has been diagnosed with dementia and challenging behaviours, has a double burden of care. Life can become an unending round of care with no respite available because no one else will take

on the burden. The environment becomes tense and this leads to further challenging behaviours. All too often we hear stories about care that is provided that meets the care service needs, or may meet the needs of the carer, but does not meet the needs of the person diagnosed with dementia.

We also hear about care that is provided as a sitting service where the carer does nothing to stimulate the person diagnosed with dementia, and indeed, meets their own needs by watching TV, reading or just generally ignoring the person they are there to provide respite with. Care is provided with no regard for matching interests, gender and personality.

### **Community and In Home Flexible Respite - Southern Sydney**

Because of these problems, funding was offered by the Commonwealth Government under the National Respite for Carers Program (NRCP) to provide respite services for people with dementia and disordered and challenging behaviours.

In June 2000, The Benevolent Society received some of this funding to set up a program called "Community and In Home Flexible Respite - Southern Sydney". It covers the local government areas of Rockdale, Kogarah, Hurstville and Sutherland in Sydney.

The program provides in-home and out-of-home respite services for people diagnosed with dementia and challenging behaviours which restrict their access to existing services. It offers a variety of caring hours, overnight, late evening, weekend, as well as full and part day and 24 hour care. Up to two self care units within our own retirement villages can be used for short and long term respite stays. We provide in-home respite, offering a variety of hours of care in a flexible manner.

Up to 20% of the funding will be allocated to emergency respite in consultation with the South East Sydney Carer Respite Centre, which is also auspiced by The Benevolent Society. Volunteers will be used as friends and support people and trained for this role by a Co-ordinator.

We have set up this service as a flexible model of respite care that would be responsive to the needs of the carers and also to the needs of the person diagnosed with dementia. Carers want meaningful interaction between the paid carer and the person with dementia. Carers also want to be acknowledged as an expert in the care of their relative.

### **Partners in care model**

The model described below can be visualised as consisting of three overlapping (rather than distinct) circles, showing both the individual priorities of the partners as well as their common interests.

#### **Primary carer**

- Holistic assessment of the primary carer
- Develop care plan
- Identify special attributes for community carer
- Broker community carer
- Refer to other services as needed

### **The Benevolent Society Community and In Home Flexible Respite**

- Holistic assessment to ensure that all needs are identified and met
- Well trained, culturally appropriate community carers
- Works in partnership with the primary carer
- Identifies needs that it cannot meet and refers on
- On-going communication with primary carer in order to address needs as they arise

### **Care recipient**

- Holistic assessment of care recipient
- Develop care plan
- Identify special attributes for community carer

We did not want to be just another dementia service or just another respite service. We wanted to be a service that gave holistic care to both the carer and the person cared for (OR the person with dementia - please, not the caree!) in a flexible and innovative manner and which included quality of life domains for both. Tapper (1997) states that maintaining life is no longer a sufficient goal. Enhancing and improving quality of life is achievable and should be the goal.

The goals for the program are to provide quality of life to both the carer and the person with dementia, to provide the care that the carer needs, when the carer needs it, where the carer needs it, and to ensure that we have a holistic picture of the person diagnosed with dementia so that we can provide respite that is supportive, stimulating and focuses on their abilities.

*Mrs K is the carer for her husband, Mikhael. Her daughter, who supports her, was going overseas, and Mrs K was sick. Mikhael is a wanderer, needs constant attention and has other behavioural problems that have stopped him going to day care or to mainstream hostel care. Mikhael has lost his English language ability. Mrs K felt that she could not care for Mikhael on her own whilst her daughter was away and wanted to have her husband cared for out-of-home while her daughter was away. She felt that a hostel or nursing home admission was not the best for Mikhael. What are her options?*

In any respite situation there are at least two people, the primary carer and the person diagnosed with dementia. The needs of both can be met in a sensitive and complementary way.

### **Components of respite care**

I believe there are two important components to respite care:

1. To meet the individual needs of the carer in a way that will reduce stress. The care must be at a time when the carer wants it, in a place that the carer is happy with and by staff with whom the carer feels confident. The carer must also be a partner in developing the care plan and monitoring it.
2. To provide respite that identifies the individuality of the person diagnosed with dementia, maintains the personhood of the person diagnosed with dementia, and creates an environment of support for both the carer and the person being cared for.

To achieve these goals we developed an assessment that could identify all domains for both the carer and the person living with dementia. We start by assessing the needs of the carer and identifying how to best meet those needs within our limited budget.

The second step in the assessment process is to identify how we can best work with the person living with dementia. We decided that the "Ecosystemic Biopsychosocial" model proposed by Caron and Goetz (1998) was a good base to start as it looks at all domains. They argued that a holistic method was needed because they believe that a person's behaviour comes not from one domain but from our whole personhood of lived experiences. If we can identify what is impacting on the person diagnosed with dementia, we can in some cases negate the impact or minimize the behaviours that are causing stress, both directly to the carer and indirectly to the person living with dementia. This we hope, will not only help the person diagnosed with dementia but also the primary carer by doing away with the barriers and creating an environment that supports both.

Most primary carers want and are desperate for respite, but they also want the best care for the person they care for. They still see the personhood of the person they care for and believe that in spite of the challenging behaviours, quality of life issues can still be addressed and can make a difference to the person with dementia and therefore to themselves. Tapper (1997) has identified that problem behaviours are emotional responses and describes the concept of enablement that focuses on remaining abilities in a positive way.

We chose a brokerage model of service provision as we believe that in this way, we can better meet individual needs in an appropriate and culturally sensitive manner. A number of referrals are for carers whose first language is not English, so we use a number of providers in order to meet different needs.

We were able to set up a unit in one of The Benevolent Society's local retirement villages, which we can use for out-of-home respite. We have furnished it to a comfortable standard. People who stay there for overnight or longer are encouraged to bring pictures, photos, doona covers etc to make the unit more recognisable.

Carers are encouraged to visit the unit in order to become familiar with it. We keep in regular contact with the carer to ensure that we are alert and responsive to changes as they happen.

*What could we do for Mrs M? Community and In Home Flexible Respite was able to provide culturally appropriate respite, both in home and out of home, with carers her father was familiar with and therefore would accept. Mrs M was also linked in with the local Carer Respite Centre who provided extra support using the same community carers. By providing community carers who were familiar and culturally appropriate for Mrs M's father, we took him out of "the too hard basket".*

*What could we do for Mrs K? We assessed Mikhael, identifying all domains in his environment that either impacted on his behaviour or that could. We also identified his social history, his likes and dislikes, and the characteristics of a community carer who could meet his needs. We provided out-of-home respite for 14 days in the retirement village unit we set up. Mrs K provided culturally appropriate food, our carers spoke Mikhael's language, understood his customs and could relate to the music he loved. Another person taken out of the "too hard basket".*

## **Issues that have arisen**

While we have been able to help a number of carers in difficult situations, we have had to solve some problems along the way.

There were some practical problems with setting up the retirement village unit. We did not realise that the unit's front door could be opened from the inside even when locked. Needless to say, we found this out the hard way.

Some of the nearby residents of the retirement village were not comfortable with having different people in and out of the unit. One of our clients was outside with his carer and started to peer in the next door windows which caused concern to the occupants. We have set up protocols to inform these residents when we will be using the unit. We also have regular meetings with the residents to address any concerns they may have, but to also try to make it a positive experience for them as well. We stress that their support and friendliness are ways in which they can help both the person with dementia and their relative who is having a break from their caring responsibilities.

We underestimated the degree of protectiveness of family carers. This impacted in two ways:

- In the initial assessment the family carers were reluctant to tell us the full extent of the problem. By the time carers are referred to our program they are often overwhelmingly tired, angry, feeling very alone and have been shunted from one place to another with doors closing all the time behind them. They feel that if they tell us the full story, we will refuse them too.

- The family carers are reluctant to let go, even though they are desperate for help. They find it difficult to believe that we will be able to offer the kind of care they know their relative needs. Because this is a new service, we get a number of referrals of people who are not appropriate because their needs can be met by mainstream services. Time is needed to refer on and the danger is that these carers will once again feel they are being pushed away.

## **Have we met the needs of both carers and the person they care for?**

We have been able to do this for a number of carers referred to us.

We have supported carers who had nowhere else to turn. We have supported both carers and the person with dementia they care for in a way that is individual and meets the personhood, cultural and linguistic needs of the person with dementia. We have remained responsive to the changing needs of both.

However, we very quickly found that the group of carers who were being referred to the program had much higher needs than we could meet. The most frequent request for respite is for weekends which is far more expensive to provide than respite on weekdays. The next most frequent request is for regular overnight respite, which once again, can be very expensive if the person with dementia is active during the night, and we have found most are.

The type of care that is requested and needed is at the high end of the market when looking at cost. This makes the service an expensive one to run.

We have negotiated with other service providers such as Community Options and Home Care to share the care through subsidising extra hours. Another strategy is to work with our local Carer Respite Centre to provide extra care. In both these cases, we remain the service that organises and provides brokered care. We have also found that there are those who can afford to pay some fees. Any fees from clients or part payments from other services are put back into our pool of service provision funds thus increasing the opportunities for respite to both existing clients and potential clients.

We will be setting up peer support, linking carers into Alzheimer's groups and training volunteers to meet the social needs of carers.

We know we can provide respite that meets the needs of both the carer and the person with dementia and challenging behaviour, but we face the reality that the amount of respite that we can provide is never enough.

## **Reference List**

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