

A Home Based Model of Dementia Care

Introduction

I think it's important to realise that, in offering care to older people with dementia, we are providing something that none of them want. I said to an old lady, who was clearly unhappy about accepting help, *"What you would really like is to be independent, so you didn't need us coming in to help you."* She looked at me hard and replied, *"You never spoke a truer word."*

Another client burst into tears at the end of a discussion with her family about the assistance she required. The last straw was when we suggested a day when our service would begin. Many of our clients tell us, *"It's no fun getting old."*

Maintaining dignity and self-respect

I would like to claim that we have found the answer to making old age fun. While I'm sure some people do go on enjoying life to the end of their days, I'm afraid I haven't found a way of guaranteeing it.

What I can offer is a model of care that maintains an older person's dignity and self-respect, and supports them in a manner which helps them to feel they still have some control over their lives. I believe that home based services are the best option for most people suffering from dementia, until the disease has progressed to a severe stage.

There are several reasons for this:

- They want to stay at home and are intimidated by suggestions about moving to a new environment.
- They often don't recognise that they need help at all. It is therefore important to offer assistance in a manner which is as unthreatening, non-disruptive and discreet as possible.
- By staying at home, long-established routines, which are remembered well after short-term memory has failed, can continue uninterrupted. This helps to maximise a person's independence.
- Challenging behaviours can often be reduced by allowing the person with a dementing illness to behave in a way which feels normal to them but would be far less socially acceptable and harder to accommodate in a residential facility. Our client who prepared breakfast in the morning for her long-departed family of six did it as part of what was, to her, a normal daily routine.

- The cost of providing help to someone in their own home is far less than the cost of maintaining them in a residential facility, until they require constant supervision.

Quality models of care

If we accept then, that older people with dementia will want stay in their own homes for as long as possible, in ever-increasing numbers, it becomes highly desirable to develop models of care which meet certain criteria of quality.

- The method of service provision must be acceptable to the client and offer maximum satisfaction and quality of life. This means that services must be very flexible and responsive to individual needs.
- The assessment of a person's need and provision of service must be holistic and ongoing, taking account of changing social and emotional needs as well as physical requirements.
- The careplan must take account of the risks involved in the person staying at home and reduce these as much as possible
- The service must be cost-effective, fair and equitable. We must be able to use funds economically in a way that provides the best range of assistance to a broad-based client group.
- The care provided must give adequate reassurance to families that it offers the best solution to the problem of meeting the clients' needs at this particular time.
- Finally, the service must be accountable. We should be able to demonstrate the quality of outcomes achieved and the processes used.

The model of care that I am going to describe is based on Community Aged Care Package (CACP) funding, provided by the Federal Government. I believe CACPs are an ideal model of funding for the care of people with dementia because the prescribed outcome standards and guidelines are designed to be very responsive to the needs and wishes of the individual. However, I think the main strengths of the model have developed out of CACPs rather than being exclusive to them and therefore could be adapted to other programs.

Four stages of care

I would like to consider four stages of care: assessment, initial service plan, ongoing service provision and termination.

Assessment

Assessment for CACPs is usually a joint process between a member of the local Aged Care Assessment Team (ACAT) and the CACP co-ordinator. Referrals may come to one or the other from any source; we encourage ease of access.

In assessing the care needs of someone with dementia it is obviously important to consult with family members, friends and neighbours and existing service providers including the GP.

One of the advantages of the ACAT being involved at this stage is that it facilitates other issues being considered, whether home modifications are required, for example, aids and appliances necessary or whether various existing medical issues need to be addressed.

We find that problems have often been missed because the person with a dementing illness cannot adequately describe their physical symptoms or perhaps those symptoms are overlooked as being a consequence of the dementia. The ACAT representative is also useful in community service provision as an independent assessor who can give credibility to the service provider as far as the client is concerned.

At this assessment stage we are building bridges to ensure good communication systems with the key people in the client's life. The feelings of family members are an important consideration throughout our contact with the client. At the beginning they are distressed and anxious, often torn between feelings of guilt that they cannot meet the needs of their elderly relative and worry about whether it is possible for that person to remain at home.

Relatives are trying to cope with a person they no longer feel they know very well. The mother who was fastidiously clean and houseproud no longer cares about putting on clean clothes, refuses showers and ignores the state of her home. The father who was the head of the household has become insecure and lacking in confidence but irritable because he does very little all day and knows this isn't the way things should be.

The families of people like this often have an almost overwhelming desire that their elderly relative is placed in a residential facility because this will remove the responsibility and anxiety about how that person is managing on their own.

Our response to this situation can be summarised as follows:

We will take responsibility for ensuring that your relative will be as safe and comfortable as possible in their own home. We cannot remove all the risks but we must remember it is your relative's choice to remain here for the time being.

We respect that choice and your relative's right to live in the manner which they have chosen. We will not try to change the way they live but we will offer them a supportive relationship and develop strategies to ensure they receive the essential help they need.

We hope that we will be able to reassure relatives in such a way that they can continue to be involved without feeling angry, inadequate or guilty.

Initial service plan

At the time of assessment, the prospective client is frequently not comfortable with the idea of accepting outside help so we have to negotiate an initial service plan which will enable us to monitor their well-being and increase our assistance over a period of time to meet their need.

This is where the role of community carer is crucial to the success of the program in enabling the client to stay at home. Continuity of care is important. Many times, we have started a service for a client, with their agreement to do no more than call in and say hello. We have had cases where we did not get past the cup of tea and a chat stage for weeks. In these circumstances, we have to content ourselves with providing the most basic and essential help, ensuring the client is taking food and medications, and keeping well.

As the client gets to know the carer, a level of trust develops which allows for more help to be provided. Continuity of care means that the carer knows how much a client is able to assist with each activity herself, the manner in which the service is to be provided and the daily routines, which she has developed, which are important to her feelings of comfort and security.

We consider her preferred social activities as well as helping her with meals, personal care, housekeeping, shopping and other essential tasks. The careplan is always flexible so that if the client would rather go to the hairdresser than allow us to do the laundry, then, as far as possible, that is what we will do.

Cooperation and communication with other people involved in assisting the client are important, not only to minimise the risks of gaps in service provision but also to avoid misunderstandings.

Over and over again relatives will report to me that when asked the client says: *"No, no, no-one came today"* and we need mutual trust between all concerned to know that the appropriate care is being provided although the client doesn't remember.

Where does our moral duty of care begin and end? I suggest that while our clients are able to tell that they want to stay at home, then that is where they have the right to remain.

Of course we cannot eliminate all the risks. For example, some people with dementia want to continue their lifelong habits of going out. Usually they follow a route they have taken many times before and can find their way home. Carrying their name and address is a useful safeguard, in case they get lost.

Sometimes they become fearful of going out alone but can put themselves at risk in their own homes. Our carers complete a hazard check list which identifies risks to themselves or their clients. In extreme cases, we have had to disconnect a few gas cookers. We have replaced burnt out kettles with jugs

that turn themselves off. We try to be available to assist with showers or meals or taking medications, to ensure the client's safety at these times.

My point is not that these problems don't arise or that they are always easy to solve but that with patience, tolerance and understanding, a way round most difficulties can be found.

We cannot guarantee safety but we haven't lost a client yet!

Ongoing service

The third stage, of ongoing service provision, may start from the second day or may not begin for weeks. This is when we feel the client is allowing us to assist in a way that meets their needs as much as possible without making them feel they have lost control.

For the client, the most significant aspect of service is the relationship offered by the carer. As they often do not recognise the extent of difficulty they are having in coping with everyday tasks, it is not very important to them whether someone is cleaning their house. In fact, they may feel it is quite unnecessary. But, although memory fades, feelings can still be strong.

Emotionally, our clients may become very dependent on their carer not because we take the place of family but because we are part of their daily lives. Ideally, one person should provide all help. A client will refuse help offered by a stranger which she has been receiving daily for months from a person she recognises and trusts.

A regular carer may have developed ways of providing services, which are acceptable to the client, but cannot always be provided by a relief carer in the same manner. When memory and cognitive ability deteriorate someone with dementia relies even more on feelings.

An unpleasant event will leave them feeling angry or upset but not knowing why. A stranger coming to help makes them feel uncomfortable but the person they recognise, even if they don't know their name, makes them feel better. This, in turn, enables the client to function at her best level.

You know how your own performance is affected by feeling agitated, depressed or upset. I heard this described as "stress makes people stupid." How much more so for the person with dementia who has been deprived of the ability we have to remember, to reason and to rationalise. That is why consistency, continuity and a peaceful environment are very important for someone with dementia.

This can be a stressful situation for our community carers and offering them appropriate support and supervision is very important. It is hard at first not to emphasise our reality to clients. We have to learn to adapt our approach to the client's reality (in other words, we support the principles first outlined by Naomi Feil in her *Validation Therapy*.)

In these circumstances, we need to be aware that the direct intervention of the co-ordinator becomes less important. As far as the client is concerned, a visit from the service co-ordinator may be no different from a complete stranger calling. The carer's role towards the client, family, neighbours and others becomes the key factor in determining the quality of service provision.

End of service

Termination of our care for a client at home may occur for several reasons. Our clients may go to nursing homes or dementia centres and a few have elected to go to hostels, because they find the loneliness and isolation of being at home alone is overwhelming.

Sometimes, physical illness can make it too difficult to provide appropriate care but usually we don't consider residential care until a client has reached a stage where they are so disoriented in time and space that they no longer feel comfortable living alone or don't recognise their partner or home.

In some cases a bad fall or similar crisis can bring about a sudden deterioration. Our support to our client and their family continues until a satisfactory placement has been made and often because of the relationship, which I have described, extends indefinitely in an informal capacity.

Management

As I have mentioned, this model of care places great responsibility on the community carer, to constantly reassess the needs and wishes of their client. Often the client's relatives or friends look to our worker to provide support or advice to them as well.

This has implications for management. Conventionally, I think community service coordinators have taken responsibility for formulating careplans, instructing and supervising staff and monitoring clients' progress. This can lead to workers having a rather blinkered approach to client care. For people with dementia living in their own homes, often alone, this is simply inadequate.

A team approach

I would like to suggest that a team approach to caring for people with dementia is more effective. Sharing responsibility and giving the worker freedom to make judgements and take decisions results in a better standard of care.

Allowing a trusting relationship to develop between client and carer enables care to develop as the clients needs grow. This utilises what Eva Cox calls social capital, the potential we all have through our relationships to contribute something extra to the common good.

My carers talk about the bond which develops between themselves and their clients which prompts them to go out of their way to look after their client to anticipate their needs, to think of additional ways of making their lives safer or more comfortable.

A new kind of leadership

Managing this kind of service demands a new kind of leadership. We have to inspire a belief in what we are doing which unites our team in common objectives.

There is no point in asking most of our clients if the carer has visited, let alone what tasks have been carried out. We have to trust our staff. Our workers share responsibility for developing care plans, allocating time for different tasks and completing time sheets.

They have a high level of commitment to their clients and to each other. Their motivation to undertake training is based on their own perceived needs for greater knowledge and understanding. In a difficult situation or emergency the coordinator works beside them to support them.

To summarise, a team approach:

- Helps carers to receive the support, supervision and training they need.
- Encourages objectivity about what is best for the client even when we have made a commitment to keeping her at home.
- Enables relief carers to receive the information they need to maintain clients' comfort levels, thus ensuring the same standard of quality care 365 days a year.
- Can also include the clients network of friends and relatives and other service providers so that a cooperative system of care can be provided.

In this context a coordinator really is a coordinator but the concept of case management assumes a new meaning.

Our team uses small group performance appraisals. This facilitates joint learning processes and development of new strategies to deal with problems. Carers draw on each other's experiences and work constructively together. Our evaluations are based on client or client's advocate feedback and comparison of our work practices with CACP outcome standards which emphasis a client's right to self-determination and social independence.

Conclusion

I would like to think we can nurture the political support we have received recently to enable more people to stay in their own homes, where they feel safe, for as long as possible.

To do this, as I have said, we need to develop a different attitude to care in the home. This must include a greater level of understanding and acceptance in the community, of the needs and wishes of people with dementia.

We must also promote a better awareness, among GP's and other health professionals, of what can be achieved by community care.

I am confident of our ability to successfully push back the boundaries of how long we can keep people with dementia at home. We need the support of our whole society to allow us to carry out this task.

For further information

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