NZCCSS Conference – Napier 2008

enliven
Positive Ageing Services
PRESBYTERIAN SUPPORT
UPPER SOUTH ISLAND

Dementia Care in the Community – New Ideas and Innovations

Gaynor Duff and Valda Reveley

>>>>>>>>>>>>>>>>>>>>>>>> >>>>>>>>>>>>>>>>>>>>>>>>

INTRODUCTION

Recently there was an article in the Chch Press about Terry Pratchett, the best-selling fantasy author, who now has Alzheimers disease. He spoke of how Alzheimers: ósstrips away your living self a bit at a timeô, depicting it as: óa nasty disease, surrounded by shadows and small, largely unseen tragediesô Later in the interview he so aptly described his illness as óan embuggeranceô and emphasised that ó I am not deadô He was angry about the lack of support for people like himself.

This presentation will look at what our agency, Presbyterian Support, Upper South Island, has been developing in an endeavour to make a difference in the lives of people with dementia, like Terry, and for their carers.

To quote our CEO, Vaughan Milner, ï much of our work with people ós in the thin space between hope and despairô- the thin space it would seem Terry is in. This is where we can make a positive difference through building services in which the values of ócompassionate and effective relationships are just as important as looking at the presenting problemô

OUR HISTORY

Over the past 24 years our agency has been at the forefront in developing services for people with dementia in NZ.

In 1984, in Christchurch, Presbyterian Support opened the first dementia-specific rest home for people with dementia in NZ, Harakeke Home. This successful pilot project was carefully evaluated along the way. Much was learnt over that period.

It was soon realised that there was a dearth of community support for this client group in the time leading up to their need for their residential care.
Alzheimers Canterbury, (called ADARDS back then) had been in existence for just 3 years and whilst the organisation was providing much-needed support groups and information for carers there were still many gaps in what was needed.

So, once again Presbyterian Support (USI) initiated a research project, this time to have an in-depth look at what the ideal community services would look like if people with memory loss were to be supported at home for as long as possible. In 1986 this 2 .5 year research project commenced with carers and their families in the Christchurch community, using various standardised questions and scales to identify what support they had, the stresses placed on carers, the impact of caring on their health, and what might make life more manageable and fulfilling for both.

Many gaps were identified ï community social work specifically for people with dementia; the need for a sitter service; a course for carers who wanted to learn more about the illnesses - how to cope and how to care; balancing the needs of both the person affected and their carer; respite care; and day

activity programmes; were just a few of the many areas requiring development.

Presbyterian Support (USI) employed a community social specialising in working only in this area. With Alzheimers Canterbury we began courses for carers ï these had very positive outcomes - and later a volunteer sitter service was initiated by Alzheimers Canterbury. Presbyterian Support (USI) was able to designate a respite care bed within itôs dementia-specific home ôHarakeke Homeô that could be booked up to a year ahead thus enabling families to plan holidays and other special events.

In 1990 Presbyterian Support (USI) opened a dementia-specific day centre, Harakeke Club. At first this was within Harakeke residential home in a designated and separate area. This was successful to a degree but it was difficult to hold to our high ideals when Club members, as we called those attending, didnôt like the proximity of the rest home and outdoor areas they shared with residents. The residentsô dementia was usually more advanced and it made Club members fearful that residential care would be the next step on their journey too.

So, this lead to the next step -in 1995 the development of a purpose-built, stand-alone day centre, specifically for people with dementia ï Harakeke Club, with a link-way to the rest home. This new model was an outstanding success! We had learnt from the first day centre model so much that we could incorporate.

Presbyterian Support (USI) has gone on to develop other innovative community services to support people with dementia. From the start we have recognised that the needs of carers and clients may differ and have kept both the person with dementia and the carersôneeds in mind as we have planned services. Our integrated services for people with dementia and their carers vary across our region, depending on local needs. These services currently include social work, counselling, day programmes, falls prevention services, and in some rural areas ï a meal service, home maintenance and transport.

The focus of this presentation is on just three components of our services which are the Harakeke Clubs, HomeShare and HomeLink.

<u>HARAKEKE CLUBS</u>

We now have three Harakeke Clubs in our region - all referred to as day centres with day activity programmes. For people with dementia and their carers the notion of ôday careô has connotations of child care so we avoid that term. In Christchurch the new purpose-built venue for Harakeke Club brought with it many positive changes.

From the time we moved into the new venue Club members took ôownershipô of the programme content, in choosing the menu and even doing the garden. Behaviours of Club members changed. They became more settled, not wanting to go home and not trying to escape. They were less agitated, aggressive and restless. There was much more social interaction and their

carers felt more able to be involved. The day programme itself is adult, age-appropriate and allows for client choice.

Some time back we found that Club members wanted to linger over their morning cuppa, talking with others on arrival at the day centre. Now they get a fresh pot of tea made and put on their table so they can sit on as long as they like. There is no push to get them participating in group activities if they don't want to. This recognises the importance of social interaction. The programme needs to be flexible. If the day is warm and sunny the activity plans may change to suit. Instead of being inside it might mean a game of lawn darts and ice cream in a cone outside.

Staffing

The *right* mix is vitally important. Part of the success of the day programme can certainly be attributed to the *right* environment but even more important is the *right* staff.

Nancy Mace, the author of one of the earliest books about dementia, 'The 36 Hour Day', researched the elements of good dementia programmes. She said that you can recruit staff with all the right qualifications for work with people with dementia, but more important is the right attitude and people cannot be trained for that. We have proven this to be true over the years and would now rather re-advertise a position if there isn't a suitable applicant than appoint a person without the heart for this work.

One aspect that we have endeavoured to develop over recent years is making intergenerational connections between Club members and other age groups. We have a kindy along the road and the children have been brought along to entertain. Babies and children are welcome – everything stops when they arrive! Staff have been encouraged to have their children or grandchildren visit. Many of our volunteers are young. Some are students on placement e.g. Speech and Language Therapy students. Others seeking an opportunity to practice English. The interaction with younger people brings a different dynamic to the day centre.

Currently each day centre is staffed by a fulltime coordinator, an assistant (30 hours/week) and a paid driver (25 – 30 hours)

Volunteers, who are suitable, are offered the opportunity to do paid relieving work. Like most day centres we are very dependant on volunteers assisting us – we could not run the day centres without them. They are precious and we feel privileged that they choose to give us their time and all the 'extras' they bring to the day centres. We have women who had been caring for their husbands become volunteers.

There may be as many as 65 different clients attending each day centre each week. All three day centres have been especially designed and built for this purpose so we are fortunate to have separate spaces within each centre where we can have different activities running simultaneously for smaller groups of Club members.

As much as anything we hope their day at Harakeke Club is one of fun and laughter. We think we have the balance right ï if popularity of the service is anything to go by.

HOMESHARE:

In 2006 Presbyterian Support (USI) in Ashburton researched, developed and established a HomeShare based on a service model in Britain. Currently in six Home Clusters there are currently 28 clients. This innovation was fully funded by Presbyterian Support (USI).

We were fortunate to have a staff member, Jo Challis, arrive from the UK with the knowledge and experience of the model in action as she had worked in the Suffolk County Social Services Department, where they very successfully ran what was, and is, called the Home Share Day Care programme. Our researcher and the Ashburton team were able to build on her knowledge and the contacts she maintains in the UK. Suffolk has just celebrated 19 years of the programme and there are similar programmes in Peterborough and Hackney.

Presbyterian Support (Upper South Island) has HomeShare operating out of two parts of our region. HomeShare North Canterbury is a Pilot programme through a CDHB Innovations Fund contract which will be evaluated over a two-year period. The area of coverage for the service is North Canterbury (Rangiora) and Amberley in the Hurunui District.

Hosts:

- Selection is through application. An interview is held, referees checked and a police check done. All successful hosts undertake 20 hours of training which must include First Aid.
- Hosts are contracted and thus self employed and responsible for their own ACC & PAYE.
- Hosts are entitled to claim expense reimbursement for the food and transport provided.
- The hostôs house & environment is assessed for suitability by the Coordinator and Occupational Therapist before a contract is signed, to ensure safe and suitable physical access at the Host home.
- Mileage is reimbursed using a formula if the Host provides the pickup & return home; volunteer backup for transport is arranged if this is the best option.

Access to the service:

- Client entry is by assessment through the InterRai tool.
- Referrals are from GPôs, Health professionals or agencies such as Alzheimers Canterbury, those providing home assistance and/or personal care or Presbyterian Support (USI) Social Workers or Coordinators. All referrals go through to the NASC service for an InterRai assessment.
- Entry is through an Interdisciplinary team approach which includes the Coordinator, Occupational Therapist & Social Worker.

- The Coordinator receives the referral and based on the information received, will invite one of the team for the initial home visit if this is required and/or appropriate.
- Discussion is held with the client, and if appropriate the family member/carer, who will ascertain the clientôs needs, abilities and their goals, their home situation and any pressures there may be for either the client or the carer.
- A suitable match is made and the client is introduced to the host/s.

Profile of a cluster/group:

- There may be a dementia specific group ï two clients per group
- The client may still be living alone but for a dementia specific group they are likely to live with a carer.
- A small group can be less threatening than attending a day centre.
- It can be set up to support any identified group as required.
- Programmes can be tailored to suit clients
- Small groups suit people who do not and probably never have liked larger groups.

Profile of a client:

Someone who has an identified need, they may have a dementia, may be anxious, frail, lonely, isolated, have fallen, and who without help, may have to go into long term care sooner than they would have if they and their carer or caring network did not get support and a programme which would allow for other possibilities.

Profile of a Host:

- A single independent person, with identified skills and abilities for supporting a client group for a day.
- A couple who wish to offer hospitality and share something of themselves and their situation.
- Our experience has been that they are people who lead full and busy lives and who are interested in people.

Activities:

- Programme for the day, which is usually 6 hours including transport, is determined by the client with the host and fellow attendees.
- Building on the interests and the abilities of the clients which may include them helping to prepare and cook their meal for the day with the host or interacting with their peers and host through conversation.
- To date the sense of ease and belonging and interaction with clients from different walks of life happens naturally with each bringing their experiences to the mix.

Benefits of the HomeShare model**:**

- New friendships are made and supports established for clients and carers alike.
- Groups can be tailored to suit

- It is a non-threatening environment once introductions have been made and relationships established.
- Carers feel supported and less isolated and they have come to know each other.
- The interdisciplinary team is available to clients & carers which provides for wrap-around support.
- The model is suitable for general groups as well as for those with a Dementia, these groups are able to host up to 4 in a home cluster.
- Groups can be established where there is a need, a host and clients, this is an ideal model for an isolated community.
- The beauty of this model is that it can be set up to support any identified group if required eg cultural, community isolated, early onset dementia or gender specific.

Challenges:

- The model had to be introduced to Health professionals in the communities, this took time and the concept took time to assimilate.
- InterRai tool implementation was slow as it was new to this Region and all Needs Assessors have to be trained in the use of the tool

Comments:

- Despite the initial slowness in getting started, the willingness of the Assessors, the InterRai Trainer, the Hosts and the HomeShare team along with the vision of the Agency itself, ensured this pilot has been given every opportunity to prove its worth.

HOMELINK:

There has often been a missing link in the continuum of care for older people living at home and the lack of social supports meant people went into care sooner than they or their carers desired.

The CDHB older persons health strategy vision is ñto assist older people to participate to their fullest ability in decisions regarding their health and well-being and in family, whanau, and community lifeò The CDHB Planning and Funding division consulted with us and others regarding the need for more support in the community and decided to provide a new contract ñCommunity Supported Independent Livingò We successfully tendered, along with another agency which is providing mental health support and a service for those with more advanced dementia. Our service covers the Rangiora area in North Canterbury, Ashburton in mid Canterbury and Christchurch city.

In May 2007 we began the service we named HomeLink.
There are two parts to the service provision - frail elderly and people with dementia.

Staffing

The CDHB required us to have health professionals coordinate the service.
A project manager was appointed then an Enrolled nurse, Registered nurse and OT. Support workers are guaranteed 20 hours.
For the programme to succeed it was critical right people were appointed.

We identified that the ideal support workers would need to be:

- creative and flexible
- observant
- good advocates
- practical
- have common sense
- have good community knowledge

We have had no difficulty recruiting and retaining excellent staff for this service. They tend to be more mature women (no male support workers - though this would be good), who have a range of life experience in a variety of jobs. The common link is that they all love being with older people and want to make a difference in their lives. It is probably one of the more rewarding ways to work with older people. The support workers do not do any domestic assistance of personal care. Their role adds to the quality of life of the older person and makes a positive difference for their families too.

When trying to explain the difference with this service we often say we are ódoing with, not doing for clientsôe.g. taking the person shopping rather than going and doing it for them.

<u>Process for a Client:</u>

- All referrals via NASC service
- 65+ years
- Frail or mild to moderate dementia
- Living in community
- Assessed by HomeLink coordinator
- Goals are set
- Regularly reviewed

Interdependence such as this requires collaboration; advocacy; referral to other Enliven services; and referral to other agencies.

Case e.g.
To give an example of the work that is done one gentleman had always enjoyed messing around (he wouldn't call it that!) with tools in his shed.
However, he was no longer safe with these so one of the goals for the support worker was to help restore a safe area that he could work in. More potentially dangerous tools were removed. This meant he was happier and his carer knew he was safe.

In another instance a socially isolated woman with dementia decided that for her weekly outing, she would like to go to the beach. And this she did. When the support worker asked here what else she would like to do she said she'd like fish ' n' chips at the beach – in paper. Such simple things we all take for granted but what a difference they can make.

There is a lot of advocacy on behalf of these clients too e.g. getting a second-hand fax machine for a man whose hearing was now too impaired to hear the telephone. He can keep in touch again.

Benefits

- For carers ï something to look forward to; respite
- For the person with dementia - social activity and external contacts.

It has become important to develop an interdisciplinary team that will meet regularly to ensure staff are working towards the same outcomes. Initially we plan to narrow our focus on a Community Support Team for People with Dementia. We even have a name for our team in Christchurch - ôFirst in Mindô

Think of Terry Hatchett who was mentioned at the beginning of this presentation. As he said ñI am not deadôï our roles are to ensure that people like Terry, and those who care for them, can live full lives, with hope, within the limitation of their illness.