

Presentation

Chaplains' Workshop

Saturday 27 August 2011

Grief and loss in families and carers of people with dementia

Introduction:

I thought it may be helpful for me to give you some background to show where my interest and passion for this subject comes from.

My mother had dementia and we cared for her at home until it became too challenging and she became a resident here at Selwyn Village in the Confused Elderly Unit. She subsequently had to be moved into a dementia unit and came to live at Meadowbank Village (where I was then living), she then was moved into private hospital care at Meadowbank. She died in 2006. During that time, as a family, we had our struggles both with the physical aspects of Mother's care when she lived with us but also with the emotional aspects and grief which we underwent. My sister still has not recovered from the grief and as a researcher, she fascinates me because she constantly says things like "I don't think Mum had dementia . . . I think she was just lonely after Dad died . . . if we had got her into a Retirement Village where there was lots going on, she would have been fine. She might still be alive." These days, I just say something like "Mmmm" because no other intervention seems to work! No evidence to the contrary works. When Mother was at Meadowbank, my sister would visit her and then she would say "Mum is always unhappy". So I would take photos with my mobile phone when I popped in to see our Mother – at all times of the day – she was always happy! They did not count. Maybe that simply illustrates our weird family background but the fascinating thing is that I have met other people with family members with dementia who seem to have the same script!

I am a Presbyterian minister- and have been since 1972 when I was ordained. My background was largely in parish ministry until I became too disabled for that and moved to Meadowbank in 2002. I am also a member of the New Zealand Association of Counsellors and have a small counselling practice where I specialise in grief and trauma as well as seeing addicts who have dual diagnosis issues. Currently I live in a community where most people have dementia in varying degrees and I exercise my ministry as chaplain there. I run a therapy group for family members of people with dementia as well as spending a great deal of time ministering to people with dementia. I also see family members on an individual basis for counselling. I do a lot of staff training and I think I am the staff member who knows just about everyone on site. The PhD study arises out of my experience and my passion to help family and professional caregivers to deal with the grief that comes from looking after someone with dementia.

The problem

Living with a person with dementia can be challenging, demanding, exhausting and raises many issues for the caregiver. The so-called “caregiver” burden is composed of all sorts of feelings and tensions and anxiety – all tied up with grief.

The grief begins when the PWD is still at home and continues. The burden of caring for someone with dementia does not actually end when that person is placed in long term care.

As I work with family members I become increasingly aware of the fact that family members see themselves as being in a “trustee” role in terms of the PWD. For example, as death draws closer, sons and daughters will say things like “I’m not sure what mum would want but she made us go to Sunday School when we were children and I think she used to go to Church” or “Do you people still have the last rites?” As I look back on my experience with my mother, I am aware that I took that role too.

As the disease progresses, I notice that family members make up their own scripts about the situation. Here are some of the things that people say:

“If we had realised sooner . . . we could have . . . (moved her to a retirement village where she would have had lots of company and things to do instead of living on her own)

“I should have noticed sooner and taken him to a doctor . . .” (doctors “fix” things you see)

“I don’t think it’s dementia . . . she is just really lonely”

There is, of course, lots of denial and I don’t think we should knock denial – it can keep us sane for a while as we are adjusting.

Another comment made by spouses: “I feel as though I am single again” – loss of relationship.

Caregivers often become incredibly embarrassed by the actions and words of their loved ones and then they feel guilty about their embarrassment.

I believe that dementia and the thought of getting it strikes fear in the heart of each one of us. It intrigues me that when we are afraid like that, we seem to have a super abundance of jokes! It used to be the same with HIV and AIDS.

The 2010 report from Alzheimer’s New Zealand stating that by 2026 over 24,000 New Zealanders will suffer from dementia and that number will rise to over 146,000 by 2050 is a statistic which strikes fear into the hearts of many people and leads us to wonder “Where will we find people to care for all those sufferers and how will our health system cope?” It also raises the question of how can we assist those who carry the responsibility of caring for such people.

In New Zealand, as in other parts of the world, the burden of care rests largely on the shoulders of family members and in the later stages of the disease on professional caregivers. Research documents the fact that such caregivers suffer in a variety of ways including

increasing isolation from friends, financial difficulties, fatigue and stress. For elderly spouses caring for equally elderly partners the burden is great and underlying all the stress is grief at the gradual loss of the personality they have come to know and love over the years. Researchers speak of “caregiver burden” and grief is most certainly at the heart of that burden.

Caregivers ask themselves many questions: “Are my feelings normal?”, “Why did I lose my temper with him/her?”, “Will I develop dementia myself?” “What could or should I have done to prevent this?” “How long will this last?” “Should I have kept him/her at home longer” In fact, the questions seem endless and many could be added to that list. Add frustration and fatigue to the mix and on many occasions it all seems too much. Grief continues throughout the rest of the life of the person with dementia and does not diminish when he or she is placed in residential care. Likewise, after death the grief continues as people reflect on the experience or others remind them that the death was “a blessing”. This means that caregivers may feel some ambivalence and even guilt at the grief they feel when their loved one dies.

The grief itself has been described in a variety of ways: anticipatory grief, relentless grief, chronic sorrow and disenfranchised grief. Some overseas research has also looked at ways in which professional caregivers grieve as they form close relationships with those for whom they care. However, there are gaps in the research. I am aware from my experience that professional caregivers form strong bonds with many of our residents with dementia and inevitably experience grief. It is important for us to acknowledge that and, as chaplains, to be available. I do quite a lot of staff training and in those sessions leave time for staff to talk about the things that bother them. I also make a point of attempting to address the issue of how they are coping when I see them. Of course, the prerequisite for that kind of conversation lies in knowing the staff before issues arise.

I suspect that when the PWD has been admitted to residential care, family grief is affected by the relationship family members have with the professional caregivers. That is something I will be checking out in my research.

How can we help?

As chaplains and clergy we have a unique opportunity – we can get to know everyone. Getting to know the person with dementia and his or her family can be enormously helpful. I am blessed that our site is small – we have 81 (55 hospital level and 26 rest home) beds, 15 cottages and approximately 60 people who come to day-care. Most of the people on-site have dementia of some sort. We no longer have a dementia unit and by the end of the year our day-care will close because Oceania is planning a lot of development on site which will actually change the nature of the place. So, we have a great deal of grief among families and staff.

My office is next door to the recreation area where day people come and where residents join them for activities. We also have a Church service in that area once a week and another service in the hospital area. Diversional therapy staff have an office next door to mine. So I have the ideal opportunity of getting to know everybody and when people come to enrol their

loved ones for day-care, if I am there, I am always introduced to them. Outside my office, there is a notice board where our therapy groups are advertised. For me, having a high profile helps! I make a point of spending some time in recreation – sometimes have afternoon tea and play boccia every so often. Most of the day-care people opt to come to Church and some come on Fridays specifically because we have Church then. The majority of our residents come to Church too. Some family members of residents also attend.

Family members need to have the opportunity to “say it how it is” – to express the grief that can become bottled up – and not be judged for having normal feelings. Family caregivers seem to go through 3 main stages – this has been called “the caregiver career” by Lindgren (1993). Although her article is quite old and I wouldn’t want to use her stages as a template, I do believe that it is helpful to note that people do actually go through such stages (there may of course be sub-stages too). Lindgren outlines these as: the exploratory stage, the enduring stage and the exit stage. When a person is newly diagnosed – usually as a result of displaying some strange behaviour – life feels very strange. Changes need to be made – maybe the husband will need to stop driving – maybe he can’t work – maybe the wife can no longer cook safely – the spouse with dementia may follow the other one around – he or she may wander – say strange things to people – not know night from day – sun downing may begin – roles have to change. I could, of course, continue that list. Spouses notice that intimacy goes, life becomes uncertain, you husband or wife becomes your child, sons and daughters become parents to their parents and that is incredibly challenging. So people try to find help – some help is very good but sometime it is not. They may find a day-care and with fear and trepidation allow others to begin to care for the person they love. Alzheimer’s’ support groups are great. However, overseas research suggests that we need to have a three pronged approach to helping people – support groups are great but we also need to provide education and ongoing therapy – both group and individual to help people through this incredibly trying time of life.

We help by being available and learning to recognise when intervention is appropriate and what type of intervention is appropriate. I believe it is important for chaplains to know what type of intervention is appropriate for us to use. If you are not trained as a counsellor - please be careful! Refer the person to someone who belongs to an accredited counselling organisation!

To sum it all up, I think that the main thing that we as chaplains and clergy have to give to PWD and their carers is love. One person defined preaching as “one beggar telling another beggar where to find food” and I believe that is part and parcel of our ministry to our people. I love going into our recreation area and being with the people there – there is a mix of love and laughter and pain and grief that is part of everyone’s experience. I feel blessed to be part of such a community and if I can convey some of that to family members and staff who are hurting then that is great!

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Alheimers New Zealand (2010). National Dementia Strategy 2010 - 2015.
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