SPIRITUAL CARE OF THE FRAIL ELDERLY WITH ALZHEIMER'S DISEASE

by

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Introduction

I visit and take Holy Communion to the residents in several rest homes and I want to discover ways of being more effective in this ministry. Among those I visit are many who are very frail and suffer from Alzheimer's Disease. I want to find ways to bring God's love to these people and seek a response from them. My research has covered their spiritual care, focusing on communication and building relationships. I have also considered how this relates to spiritual direction.

Dementia[1]

Dementia is the name given to a set of symptoms causing a decline in the person's ability to think, to reason and to remember. Dementia is caused by many things, some of them curable. Other dementias like Alzheimer's Disease arise from conditions that are progressive and irreversible. They are called primary dementia. This is an organic disease of the brain where the cells die resulting in the loss of powers of the brain. Some symptoms are increasing forgetfulness, confusion, change in personality and behaviour and everyday skills. Alzheimer's Disease accounts for 50% of all dementia and passes through three observable stages:

1. Forgetfulness stage - minimal to mild dementia.
2. Confusional stage - mild to moderate dementia.
3. Dementia stage - moderate to severe dementia.

This disease can strike anyone but is most common among people over 65 years of age. It is sometimes called the Silent Epidemic and affected approximately 38,000 New Zealanders in 1996.

Communication and Building Relationship

ADARDS handout sheet on communicating with people with dementia illness offered me good practical advice.[2] Some points that I noted were; keep conversations simple, speak slowly and clearly, wait for a response (people with dementia need time to frame an answer), avoid questions, use non-verbal forms of communication like touch and gesture, use self-included humour, try to maintain eye contact, learn not to fear silence. Sight and hearing difficulties may make dementia seem worse than it is so this needs to be checked out with the caregiver.

As a base for my research I have used Eileen Shamy's excellent book More than Body, Brain and Breath - a Guide to Spiritual Care of People with Alzheimer's Disease. She says "We can try to be with these people in their reality, building relationship and choosing to be in each person's reality of the present moment."[3] The two bright stars in the night sky of dementia are:

1. the ability to feel and respond to feeling remains intact in the person with Alzheimer's Disease long after they have lost the ability to understand. "Small islands" of ability remain in the brain and these can be acknowledged and used.
2. the remote memory can be cued sometimes well into the progressive stages of Alzheimer's Disease.

[1] A.D.A.R.D.S. (Alzheimer's Disease and Related Disorders Society.) Information Package, Dementia.
[2] A.D.A.R.D.S. Information Sheet No2., Communication.
[3] Shamy, Eileen. More than Body, Brain and Breath. p I65.

Some tools for conversation and encounter are:

1. an initial orientation to the present reality.
2. affirmation and response to feelings.
3. memory cueing.
4. use of traditional symbols.
5. the power of touch.

I chose two people to visit over four months to see if I could apply these principles.

Edna, 83, is in the early stages of Alzheimer's Disease (forgetfulness) and has lived in a rest home for the past two years. She is up and about, likes to chat with the other residents and enjoys walking to the nearby shops.

June, 78, has been in residential care for six years. She is in the later stages of Alzheimer's Disease and requires total nursing care. June has lost her ability to communicate with words but she makes talking noises, which enable her to respond with her voice.

I also used these principles during the worship at the rest homes I visited.

1. An initial orientation to the present reality.[4]

Shamy says it can be helpful to begin by bringing the impaired person into the present realty as it is defined and experienced by most people, but also to be ready to respect that this person's reality may be different from ours. Our responsibility is to find a way to "reach" or communicate with them in their reality. We should not pressure them to stay in our reality, but try to bring the person into the reality of the present moment. For example, when I visit June she is usually sitting in an armchair, so I kneel down in front of her so that we are on the same level, and taking her hand gently in mine I greet her. "Hello June, I'm Ngaire - I'm from St. Matthew's church (this is reinforced by me wearing a cross and a name badge written in large clear letters). I visit you on Thursday. Today is Thursday." I wait for some response, then continue, "We are at Sunrise Home. You live here. I'm visiting you, June." I would probably wait for a response before saying something about the weather or season. June usually responds by focusing her eyes on mine. I have no way of knowing what her reality is but when her eyes meet mine I know we are communicating and she is with me in this moment.

Each time I visit Edna she doesn't remember me because her recent memory is deteriorating and I know she has little knowledge of my visit after I've gone but perhaps she recognises me as a "familiar friendly". When we meet and I give her my name she says, "Now where do I know you from?" So I introduce myself again and say, "I'm Ngaire, I visit you here at Marsden House." and she usually says, "Oh, yes that's right. It's nice to see you." I know she doesn't actually remember me but she preserves her dignity by answering in this way.

[4] Shamy, Eileen. More than Body, Brain and Breath. p 138.

2. Affirmation and response to feelings.

Shamy says that during a visit she is aware of listening on two levels.[5] On one she may be hearing a lot of unrelated pain, complaining, perhaps a story of "working hard all morning in the garden with no one to help me. He said we would go to see Grandpa. He didn't come. I want to go to my Grandpa's house." At one level of listening what she hears is nonsense, a jumble of confused memories. This man is 86 years old and his grandfather has been dead for a long time. She does not collude with that, nor deny it, but pays attention at another level. Behind the confusion, what she hears in his feelings is more likely to help her reach meaningfully into his reality. If she can affirm his feelings in his reality she can be with him as a sympathetic friend. Then they are in relationship, and there is mutuality too because at some time, like most people she too has felt as he does now. So it is possible to share the pain rather than attempt to fix it.

Once when I visited June she was sitting in her chair crying. I knelt down by her and said, "You're feeling upset today," I took her hand gently in mine. She continued crying and I used a tissue to wipe her face, saying, "You're feeling sad today June. Can I wipe your tears? You're feeling really unhappy today." The sobs continued as I stroked her hand and said "there are lots of tears there. What are the tears saying?" I sensed a feeling of isolation and loneliness in "my gut" so I decide to go with that and said, "You're feeling lonely June, sad that you're all alone and nobody cares." Her crying got louder and I stroked her arm to comfort her. "It must be hard, feeling so lonely, isolated, all by yourself." I continued stroking her arm. Her crying gradually subsided and she focused her eyes on mine. She gave a deep sigh. I continued to sit with her, holding her hand and stroking her arm. We sat quietly together and I was aware that I had entered her reality of distress and loneliness in some measure, bringing us to a position of relationship and mutuality. Then I continued our time together by reminding her, "I'm Ngaire - I visit you."

My experience with Edna taught me the importance of having some knowledge of the effects of Alzheimer's Disease. I knew from her history that she had a strong faith, still attending church each week with her family. She had always had a deep love for the Scriptures but during the time I visited she became quite defensive if I suggested we read the bible or if I offered to pray with her. I was concerned when I first encountered this defensiveness but I learnt from my reading and by talking to her caregivers that this is a typical reaction of one who is struggling to cope with memory loss and wanting to keep their independence. Now I am careful to help Edna keep her dignity, be sensitive to her feelings and not over-step her boundary of independence.

3. Memory cueing.

In Alzheimer's Disease the recent memory is lost first but even into the most advanced stages of the disease the remote memory remains. When an experience from the past is remembered, with that raised memory come feelings associated with the original experience. The ability to feel and respond to feelings remains intact in a person with Alzheimer's Disease so we need to learn as much as possible about the person's memory processes before the disease took over. What cues were

[5] Shamy, Eileen, More than Body, Brain and Breath. p 69.

most effective in the past for organising information and for remembering? Were they colours, smells, sounds, music, voices, textures?

June's daughter told me that her mother belonged to the Methodist church where she sang in the choir. Her faith had been very important to her. I wrote to June's friend who told me that they had sung together in the choir for forty years and she sent me a list of songs and hymns that were favourites. When I visited June I sang one of these, "What a friend we have in Jesus", softly to her. She responded almost immediately by focusing on me and began to make her talking noises. I sensed her reaction was a positive one and she was making a connection with this song. As I left her later I felt confident my words of prayer, "Thank you Jesus, you are our friend, you love us and you are always with us," were touching her and that she was experiencing something of God's love and care. Since that time I have always sung one of her old favourites during my visit and this brings a sense of connecting and mutuality between us. When I leave June to speak to another resident I notice she continues to watch me for some time which gives another indication of her response to our relationship.

4. Use of traditional symbols.

It's not easy to speak of God to people with dementia because they have little or no memory of the conversation and they cannot keep it focused. Shamy suggests traditional symbols used in different ways can assist them to sense the loving presence of God with them.[6] Symbols such as incense, icons, a crucifix, holy pictures, oil, flowers, candles, dance or mime may be used to help those who now experience God through their senses rather than through their intellect. With this in mind I use a candle, a cross, a bible and flowers on a table during the service of Holy Communion in the rest homes I visit. The information booklet with the video Is Anyone There? gives ideas for using symbols in worship suggesting candles are a good focus, representing light and reminding people of celebration - birthday candles. The cross is a well-accepted symbol of Christianity and the bible as the Word of God is a powerful focus.[7]

Recently I took a bunch of freesias from my garden to place on the worship table. Some of the residents enjoyed smelling the strong scent and there were comments like, "I used to grow freesias", "These cream ones take over the garden", "I love freesias", "Oh, freesias - springtime." The flowers were cueing memories, orientating to the present - springtime, and giving a sense of enjoyment, mutuality and community. I was interested to see the reactions in another group after we had finished our worship. I passed the wooden cross around for the folk to look at and commented, "My husband made this from kauri he had in the shed." This generated interest too. One man ran his fingers over the wood, "Yes - kauri - I liked to work with kauri." Another rubbed it against his cheek, "I love the feel of wood," while another held it reverently for a moment, "The Cross of Christ," he whispered. I think that these examples alone convince me of the value of finding and using symbols in worship and interaction with the frail elderly.

[6] Shamy, Eileen. More than Body, Brain and Breath. p 148.
[7] Christian Council for Ageing. U.K. Video: Is Anyone There? Booklet 2, p 5.

One day when I visited Edna I showed her a picture card of Jesus the shepherd with the sheep, and carrying a lamb in his arms. She recognised the religious picture as one she had seen before, and commented that there were times now when she felt Jesus carrying her. Here too the picture brought a response, though brief, as Edna spoke of her feeling.

5. The power of touch.

As we read the gospels we see how important touching was to Jesus. There are many times recorded where he touched people and often people tried to touch him. In the touching there was healing and power. As I described with June, I have found holding and stroking an old person's hand as we sit talking together usually has a calming and comforting effect, especially with the mentally frail people. During our worship times a hand on the shoulder or taking hold of their hands when I give "The Peace" helps me connect with the person. I am more likely to get a response than if I had just used words. One lady was lying still, her eyes closed. I took both her hands in mine and holding them gently said, "The Peace of the Lord be with you, Mary." I waited a moment stroking her hands, then she gave a deep sigh. I waited a bit longer, aware of God's presence with us, before moving on to the next person. Responses will vary. These may be verbal like, "Thank you dear," or, "God bless you too," or the person may focus their eyes on mine or give a smile. From my experience here I know there is a kind of healing that touch evokes though I'm not sure what exactly has taken place.

Conclusion.

As I have used these tools I have discovered they have great value in assisting me to communicate and build a relationship with the frail elderly with Alzheimer's Disease. This research has given me a deeper understanding of their needs and I believe I can bring God's love to them now in ways that are often effective in finding a response from them.

Spiritual Direction.

Barry and Connolly define spiritual direction as help given by one Christian to another which enables that person to:

1. pay attention to God's personal communication to him/her.
2. to respond to this personally communicating God.
3. to grow in intimacy with this God
4. to live out the consequences of this relationship.[8]

From my research I believe it is possible to apply numbers one and two to those who suffer from memory loss and confusion, and this relates well to my intentions stated in the introduction: to bring God's love to these people and to seek a response from them. However, because of their disabilities there is no way of gauging numbers three and four. It seems unlikely that is possible to advance spiritual growth here, though we can never discount the work of God's Spirit in anyone's life.

[8] Barry, William A. & Connolly, William J. The Practice of Spiritual Direction, p 8.

From my experience I believe that I have discovered key ways to companion, be a spiritual friend and trusted listener to the frail elderly with Alzheimer's Disease. I am convinced too, that gathering to worship in ways relevant to their special needs is an other important part of this companioning. Services that are short, simple, and planned so that memories are cued, feelings affirmed and all communication takes into account their diminishing abilities, will add to their quality of life. Inviting friends, family and caregivers helps to form community too. Recently, in one rest home, I was privileged to lead a memorial service for a loved resident. This provided another aspect of being a companion where the elderly could express their love and grief.

Bibliography.

Books:

Barry, William A. & Connolly William J. The Practice of Spiritual Direction. Harper: New York, 1982.

d'Apice, Mary. Noon to Nightfall. Dove: Australia, 1989. San Francisco, 1982.

Edwards, Tilden. Spiritual Friend. Paulist Press: U.S.A., 1980.

May, Gerald G. Care of Mind, Care of Spirit. Harper: San Francisco, I982.

Nouwen, Henri. Can You Drink This Cup?
_____ Our Greatest Gift. Hodder & Stoughton, London: 1994.

Nouwen, Henri. and Gaffrey, Walter. Aging. Image Books, Doubleday: New York, 1976.

Shamy, Eileen. More than Body, Brain And Breath - A Guide to Spiritual Care of People with Alzheimer's Disease. ColCom Press: New Zealand, 1997.

Papers:

An Advocacy for the Churches Ministry to the Elderly Confused, Eileen Shamy.

Dementia - a Christian Perspective, Alison Froggat & Eileen Shamy.

How Can We Measure Spiritual Well-being? Errolyn Bruce.

In My Father's House, Patience Purchas.

Ministry to Alzheimer's Sufferers, Bryan Kirk, Challenge Magazine, July I998.

Muriel's Blessing, Robertson McQuillen.

Pastoral Care of the Aging, J. Patrick Vaughn.

Spiritual Well-being in Older Adults, Jo-Ann Hungelman & Eileen Kenkel-Rossi.

Spirituality and Ministry to the Chronologically Gifted, Edward R. Killackey

Video:
Is Anyone There? Produced by Christian Council for Ageing, U.K. and available from Council for Christian Nurture, 6 Chandler Ave., Auckland 3.

Booklet 1. Spiritual Needs, Workshop Leaders Notes.
Booklet 2. Guidelines for Worship & Prayer.

Lectures:
Caring for People with Memory Loss, Gay Abercrombic, Manager, Selwyn Park, Whangarei.

Wanting to Communicate, I.H.C. Field-worker, Whangarei.

Interviews:
Ainsley Mackie, Nurse, Rest Home.

Ann MeCracken, Occupational Therapist.

Ann Wilson, Field-worker. A.D.A.R.D.S.

Rosalie Gwilliam, Chaplain, Rest Home.

Dawn Kennedy, Field-worker, Age Concern.

Rev. Ted Body, Minister, Uniting Church.

Pat Caroll, Counsellor.

Christine Baird, Nurse, Rest Home.

Hazel Holme, Friend of Alzheimer's Sufferer.

Barbara Watson, Daughter of Alzheimer's Sufferer.

Roberta Whitehead, Nurse, Rest Home.

Donna Smith, Care-giver, Rest Home.

Gail Bowyer, Care-giver and Activities Person Rest Home.

Information Packages:
Dementia. A.D.A.R.D.S. (Alzheimer's Disease and Related Disorders Society.)

Communication, A.D.A.R.D.S. Information Sheet No.2.