

**Spirituality
and
Residential Aged Care**
With a Special Focus on Dementia

by
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Introduction

My role in Pastoral Care in a residential aged care facility includes visiting residents, taking Holy Communion and facilitating chapel services. I also support staff and family members. Many of our residents suffer from Dementia, and my aim for this project is to explore ways of being a companion to them and their families, as I consider ways of working as a Spiritual Director. Working with people suffering from dementia, raises many questions including the following:

- What is spirituality?
- What are some of the issues for family members and the person coming into care?
- What is dementia?
- What does it mean to give spiritual care to those in residential care, especially those suffering from dementia?
- What is Spiritual Direction and how can a Spiritual Director journey with a person with dementia?
- What is the impact on a relationship between the spiritual director and those in care who receive spiritual direction?

Spirituality

Spirituality may be defined as an expression of a person's religious beliefs, although this is not the case for everyone. Religion is normally expressed through an aspect of worship and implies a belief in God. However, it is possible to define spirituality without mentioning God. For me, spirituality is about a person's deepest values. It is about a person finding meaning and hope in their lives, and has an aspect of sacredness in the meaning of relationships in terms of family, friends, community, the natural world and God. Pickering quotes P.G.Reed's definition as "*making meaning through a sense of relatedness/connectedness to dimensions that transcend the self in a way that empowers and does not devalue the individual. This may be experienced as having a purpose, satisfaction and values, through giving and receiving in relationships by a link with a higher being.*"¹

I believe it important for anyone working in a spiritual role to have an understanding of the spiritualities of their directees; in bi-cultural Aotearoa, understanding Maori Spirituality is vital. It is essential to work with an open mind in relation to spirituality and practices around other ethnic religions and cultures.

¹ Pickering, Sue, *Spiritual Direction, A Practical Introduction*, (London, Canterbury Press, 2008). P 9.

Issues coming into Residential Care

Residential care may be considered when a person can no longer look after themselves and/or family members do not have the skills to care for them at home. For example following a stroke, a fall, or it may be unsafe to have them live in their own home if they are beginning to forget things e.g. lock doors, turn off the stove.

Moving into care can signify many losses, e.g. loss of control over activities of daily living, loss of opportunity for intimacy and freedom, loss of choice, loss of independence, loss of sight and hearing. Low self-esteem and feelings of not being useful and achieving anything may also surface.

This is the time when family dynamics often come to their worst and best, as they face the challenges aging brings. As the transition into care happens, feelings associated with loss and grief may surface as families face many decisions. These may include the loss of the family home, and for some it can be the loss of the person as they knew them. Feelings of guilt about not being able to care for them - they may feel the pressure from others that they have failed. Anger, disappointment, and depression may surface. Family members may also experience a loss of faith which they have been accustomed to, and having the opportunity for Spiritual Direction, provides them with an option to tell their story and to explore aspects of spirituality and/or God in the transition. I have found that informal Spiritual Direction sessions have been as effective as formal direction sessions.

Dementia

Dementia is a defining symptom of several diseases,(Alzheimer's being the most common of these) of the brain in which a person experiences cognitive impairment over time. This process can happen over a five to twenty year period. The person begins to experience loss of recent events and then "*as the disease progresses, memory loss increases and other changes, such as confusion, irritability, restlessness and agitation appear in personality, mood and behaviour*".² The effect is devastating to the person and to family members.

Spiritual Care for the Aged

At some stage, most of us will experience someone we love moving into residential aged care, or we may be called to visit someone. We may even be the one to make the decision on behalf of the person going into care. Deciding to move into aged care can be a stressful time for all involved. Chittister suggests that "*Old people, we're told, become more difficult as they get older. No. They simply become less interested in maintaining their*

² Sligar, Sam J., *A Funeral That Never Ends: Alzheimer's Disease and Pastoral Care*, (The Journal of Pastoral Care, Vol. XLI, No 4, December 1987).

masks, more likely to accept the effort of being human, human beings. They no longer pretend.”³ I believe the services of a spiritual director can provide the opportunity to reflect on many aspects of life and death, and can assist those facing aging with the time to listen to their stories.

MacKinlay in *Spiritual Growth and Care in the Fourth Age of Life*⁴ believes that Spiritual care of the aging needs to include six spiritual tasks:

- Finding a meaning for them through loving relationship. This includes reconciliation with others and God, support in their feelings of guilt;
- Finding a sense of self-acceptance, i.e. accept the ageing process; living with disabilities, find meaning in frailty, and dealing with anger and grief;
- Using spiritual strategies such as praying with the person, Scripture or some other sacred resource, assisting the person to attend services of worship, exploring ways for the person to express their spirituality through music and art;
- Being present with the person, listening and connecting with them. It is important to build a trusting relationship and honour the integrity of the person;
- Find meaning in life through reminiscence as they look back over their life and explore the meaning of death;
- Keeping hope alive as the resident expresses their feelings of fear, hopelessness in both life and death.

Pickering in *Creative Ideas for Ministry with the Aged*⁵ mentions several points which people often speak about when talking with the aged. These include:

- Looking to see God’s real yet unrecognized presence in their life;
- Attending or not attending church is not about the person’s belief or lack of belief in God;
- Some still pray particularly for their families;
- Many have had a spiritual experience (e.g. a vision, dream or near death experience) which they have never felt comfortable in sharing;
- People may want to ‘put things right’ before it is too late;
- Many people in their history recall praying with someone or for them;
- Most people are able to recall an example of being loved by God.

Having an awareness of the points which both MacKinlay and Pickering raise in working with those in aged care can assist us to focus on their inner life. Many medical models of care ignore the spiritual aspect therefore a Spiritual focus is vital for touching the core of their well-being.

³ Chittister, Joan, *The Gift of Years*, (New York, United Tribes Media Inc. 2008). P183.

⁴ MacKinlay, Elizabeth, *Spiritual Growth and Care in the Fourth Age of Life*, (London, Jessica Kingsley Publishers, 2006). P 36.

⁵ Pickering, Sue, *Creative Ideas for Ministry with the Aged*, (London, Canterbury Press, 2014). P. 3.

Spiritual Direction in Dementia Care

Christian spiritual direction “enables a person to pay attention to God’s personal communication to them so they can respond and grow in intimacy with their God”.⁶ It is the place where a person can tell their story. The role of the director is one of being a companion on the journey, and it is important to allow the person to focus on the mystery of their experience.

It is not uncommon to find caring for a person with dementia difficult. Their communication often includes asking the same questions many times. Unfortunately they are not able to retain the answers to the question. Familiar comments and questions include: “I am scared of what is happening.” “I don’t know what it is, but I know something is happening to me.” “Why am I here?” “Why can’t I go home?” “Why am I being punished by my family and God?” Jewel in *Spirituality and Personhood in Dementia*, points out that it is not surprising that depression and dementia are not able to be separated.⁷ Other issues that arise are loneliness, fear, loss of independence, loss of dreams, and loss of bodily functions. The feelings are endless as they face the mystery of the future and each day.

Swinton writes on the theological dynamics of the human experience of dementia in *Dementia Living in the Memories of God*. He reflects on the question: “If you ended up having dementia, how would you like to be treated?” The answer I believe holds the key for Spiritual Directors working in this area “*If I got dementia, I hope that I will be loved and cared for just for who I am, even if who I am is difficult for me and for others*”.⁸

We spend a life time searching to discover who we are and what it means to live in peace and joy. Yet in the midst of confusion a person with dementia does not remember who they are. Perhaps the person may resonate with the prophet Jeremiah 17:10: “*Who really knows how bad it is? I the Lord search your heart and examine your secret motives.*” So what kind of love is required to journey with someone with Dementia as a Spiritual Director? The stories we tell express who we are, and identify us as well as include our hopes for the future and what is happening in the present moment. If a person with dementia has a story to tell, how can they tell it when they have lost their memory, intellect freedom and reason? I believe that the true self of a person with dementia is not gone. The gift is they are able to come before God, be loved by God even if they have forgotten who God is and who they are.

Family members as well as the person with dementia often have difficulty speaking about what is happening for them. Sometimes they cannot find anyone to whom they can speak

⁶ Barry, William A and Connolly, William J. *The Practice of Spiritual Direction*, (United States of America, Harper & Row Publishers, 1982). P 8.

⁷ Jewell, Albert, *Spirituality and Personhood in Dementia*, (London, Jessica Kingsley Publishers, 2011). P15.

⁸ Swinton John, *Dementia Living in the Memories of God*, (United Kingdom, WM. B. Eerdmans Publishing, Co, 2012). P2.

as they express their fears, hopes and concern for their loved one. It is common for a family member to be asked “Does she/he know who you are?” I recall a person telling me, that she knew who I was but was unable to recall my name. This highlights that there is more to knowing a person than remembering the correct name of a face. Bryden, a Christian woman who was diagnosed with dementia, says that as she journeys “*towards the dissolution of myself, my personality, my very essence, my relationship with God, I have an increasing need for support*”.⁹ What she is asking, is that she not be abandoned, for it is the Holy Spirit who connects and links our souls and spirits, not our minds or brains. She points out there is a need for someone to minister to her, to sing with her, to pray with her and to be her memory. From the connection of someone at a deep spiritual level, the person with dementia is nourished and supported in their spiritual journey.

As a spiritual director, it is important to be aware that “*dementia tends to affect relationships and challenge any cognitive sense of meaning, but does not deprive people of responding to what moves them deeply*”.¹⁰

The Spiritual Direction Relationship

An important part of a person’s spiritual process is a journey with someone in a trusting relationship exploring issues of meaning. One way for a spiritual director to work is with spiritual reminiscence (Appendix I) and this can be done on an individual basis or in a group. “*In spiritual reminiscence and spiritual care and direction, it is possible at least to share the burden one-to-one with another person who will simply listen, and not judge or tell the person what to do*”.¹¹ It is important for a spiritual director to build a sense of trust, openness and love in the relationship, and essential that the person is affirmed in their identity as a person of worth in the image of God. Spiritual reminiscence is a respectful way to support the person with dementia as they share their journey and their deepest fears in a safe place.

If spirituality is about finding zest, energy and meaning in a person’s life and expressing the feelings, how can a person with dementia explore the issue of dementia in spiritual direction? I believe it is in the relationship between the director and the directee. It will be in the communication that takes place, even if it is in silence, in the being present in the moment and listening. Making a connection is important in the relationship and this includes respect and being non-judgmental. It is important for a director to reflect both the feelings and the content, asking open-ended questions with compassion.

Fundamental to working as a spiritual director is the commitment to honour a person’s identity and to sustain a compassionate and secure environment in which the person can

⁹ Jewell, Albert, *Spirituality and Personhood in Dementia*, (London, Jessica Kingsley Publishers, 2011). P 51

¹⁰ Jewell, Albert, *Spirituality and Personhood in Dementia*, (London, Jessica Kingsley Publishers, 2011). P16.

¹¹ Jewell, Albert, *Spirituality and Personhood in Dementia*, (London, Jessica Kingsley Publishers, 2011). P 49.

feel safe and accepted. To give up on communication would be a denial of the opportunities for meaning and even relationship. It is possible to have a life of meaning in dementia. Allowing the person with dementia to tell their story and letting their stories become alive is important so that the person with dementia can maintain an identity even though he/she may forget that identity. Perhaps the answer to the question “*Who am I?*” may be something like, “*I am the stories and memories that I have about myself, the stories and memories that you have about me, the stories and memories that others hold of me. These stories are the components which enable the person with dementia to remain a person, with an identity, a purpose and a meaning*”.¹²

Impact on the Spiritual Director

When we realize that people with dementia are displaying normal behaviour rather than displaying strange reactions, we can appreciate their reality in a more compassionate manner. Pickering quotes from M. Goldsmith’s publication *In a Strange Land: People with Dementia and the Local Church*, giving some ideas on how to work with people with dementia¹³. These include:

- giving the person time to notice you are there, before you interact with them;
- introducing yourself;
- slow our speech down and give time for responding;
- use of short sentences;
- avoid complex language;
- allow time for silence;
- attend to feelings;
- don’t take it personally if you are rebuffed;

I believe the above suggestions are beneficial for the work of a spiritual director. They require us to shift our focus to the person and not on the disease. Working with someone with dementia confronts our own shadow and the part that we like to keep hidden. We may even find ourselves confronted with our own mortality and the challenges that face us as we age. It may be a challenge to speak gently and in a non-judgemental and non-threatening manner.

An image which is described in Jewell’s book *Spirituality and Personhood in Dementia* is that of a prism which reflects facts of light and colour as silence too can reflect facets of personality, meaning and spirit¹⁴. The director is invited to look deep into their eyes and observe facial expressions and body postures. Therefore supervision is essential in our work to assist us to name our own feelings as we work to keep abreast of our expression of anger, sadness, grief frustration, and confusion.

¹² Jewell, Albert, *Spirituality and Personhood in Dementia*, (London, Jessica Kingsley Publishers, 2011). P 17

¹³ Pickering, Sue, *Creative Ideas for Ministry with the Aged*, (London, Canterbury Press, 2014). P.144

¹⁴ Jewell, Albert, *Spirituality and Personhood in Dementia*, (London, Jessica Kingsley Publishers, 2011). P 61

My Experience and Learnings

Ten years ago, I didn't know much about aged care or dementia. In fact, I was rather naive. My first learning came in the first few months. I had been visiting residents and found many did not respond. I assumed that they had nothing to share with me. How wrong I was. One day while leading a chapel service, my eyes did not focus as I read the scripture, so I finished it from memory. At the conclusion, I heard this voice coming from a resident who had never spoken "That is not what I know." Today I am still embarrassed that I took for granted, that people suffering dementia do not hear or remember.

Over the years I have reflected on this situation and as part of my project I have implemented some of the points Pickering suggests. I have discovered it essential to spend time with the resident, not only getting to know them, but being with them in the present moment. Recently a resident came into our chapel and told me she often pops in to talk to God. She told me that he listens and doesn't try to distract her and answer her. I too have been guilty of this. I am aware that I can become driven by record keeping and productivity. It can be a challenge for me to shift my focus to the need of the resident at the given moment, and to patiently wait for a glimpse of beauty and gold. Discovering over time what brought joy to her before the disease, and working with colour, smell, and music, have been an effective way of recalling a memory and feeling for her. Symbolism has also been a way to bring a sense of a loving presence of God to her.

The use of touch can be healing when working with someone in advanced stages of dementia. It is a form of communication. I recall recently sitting at the bedside of a prayerful woman who could no longer speak. I offered to pray and she reached out and took my hand. Throughout the prayer she held my hand tightly, her eyes became fixed on mine, and she had a gentle smile. At the end of the verbal prayer I went to move away, but she clung tighter. With my other hand I stroked her wrinkled face and the smile and gaze returned. I waited in silence and became aware of the calmness and peace in the room – perhaps this was the loving presence of God. It was one of those moments where just being there in silence was a gift as I was aware of something happening although not certain what. There are many scripture passages that indicate healing through touch - perhaps this was one of them.

During sessions with a person with dementia, I feel sad as I sit with them and see them struggling to remember something they want to say. Feelings of frustration surface within me as I found myself being impatient at the time it takes. I often need to remind myself that in the struggle of what may seem a mixed story; God is truly present for the person.

Families often question "Can a person with dementia have a spiritual life?" Having witnessed how they fully participate in the Mass, remembering the prayers and afterwards

hearing comments such as “It is so wonderful to be here,” I believe the answer is yes. Confused people can touch each other’s hearts and share in the other’s sadness and joy. One day there were a number of people in the chapel including a woman who had just received the news her youngest son had died. At the moment of the Lord’s Prayer, the residents held hands showing their support and love for her.

Working among people who have dementia has enriched my life. I recall a magical moment when there was glimpse of beauty from a woman who I was supporting as we entered the chapel together. She was very confused and her husband of 70 years had come to visit. As we entered the chapel, she saw her husband and suddenly became lucid. She looked up her eyes sparkling and said “Darling, how long have you been waiting for me.” Then she slipped back into the fog. This moment bought tears of joy to the husband and me.

There have been times I have felt tossed around in a stormy sea as I listen to families and residents. Supervision has been invaluable in giving me hope as I trust that God will calm the storm of the sea. Working as a spiritual director with a person with dementia, I have found I cannot assume I know what or when something is going to emerge. This reminds me to give space for the spirit to move as I listen with intent. Often the response is in the form of a smile or tears rather than words.

Conclusion

I believe there is a place for Spiritual Directors in residential aged care through the integration of the skills of Spiritual Direction with those of Pastoral counselling. Spiritual Direction has a different approach from Pastoral care. It has a focus on faith, prayer and the wonder of where God might be in the midst of the person’s life. Having the opportunity to train as a spiritual director while working in the ministry of aged care, has been a journey that has enriched my life and highlighted the importance of God’s unconditional love and acceptance to be who we are. I believe this ministry calls me to focus on the journey, rather than the destination.

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Appendix I

Group Topics for Spiritual Reminiscence

These questions are based on the MacKinlay (2001) spiritual tasks of aging model.

Questions for participants to explore their life journey

A series of six themes of broad questions can be used to facilitate the process of spiritual reminiscence over six weekly group sessions. The questions below are suggested outlines of questions for each weekly session.

Week 1: Life-meaning

1. What gives greatest meaning to your life now? Follow up with questions like:
 - What is most important in your life?
 - What keeps you going?
 - Is life worth living?
 - If life is worth living, why is it worth living?
2. Looking back over your life:
 - What do you remember with joy?
 - What do you remember with sadness?

Week 2: Relationships – isolation

- What are/have been the best things about relationships in your life?
Use this as a starting point for exploring relationships with the group. Think of a number of questions, such as who visits you? Who do you miss? Who have you been especially close to?
 - Do you have many friends here? How many friends do you have?
 - Do you ever feel lonely? When? Follow up on things that might be associated with time of day, place, etc.
 - Do you like to be alone?

Week 3: Hopes, fears and worries

- What things do you worry about?
- Do you have any fears? What about?
- Do you feel you can talk to anyone about things that trouble you?
- What gives you hope now?

Week 4: Growing older and transcendence

- What's it like growing older, e.g. do you have health problems?
Do you have memory problems? If so, how does that affect what you want to do?
- What are the hardest things in your life now?
- Do you like living here? What's it like living here? Was it hard to settle in?

And other questions of a similar kind.

Week 5: Spiritual and religious beliefs

- Do you have an image of God or some sense of a deity or otherness?
- If so, can you tell me about this image? Do you feel near to God?
- What are your earliest memories of church, mosque, temple or other worship? Did you used to go to Sunday school, church?

Week 6: Spiritual and religious practices

- Do you take part in any religious/spiritual activities now, e.g. attending church services, Bible or other religious readings, prayer, meditation?
- How important are these to you?
- How can we help you to find meaning now?