Meeting the Spiritual Needs of those with Dementia in Residential Care

by Heather Lofthouse

A Research Project submitted in partial fulfilment of the requirements of the Spiritual Directors' Formation Programme of Spiritual Growth Ministries

Garden Blossoms I was lost in the Garden of my mind, A tangled confusion; My thoughts flitted with no aim. What was I just remembering? Where was home? Where was home? Where were the others? She tends the garden of my mind, Widens the crooked pathways, Darts to the very best flowers, Creates stepping stones from one to the other, Writes snapshots for me to hold. She shines the sun of her listening upon me, and My spirit blossoms.

E. B Ryan (Ryan, 2005)

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Introduction

The poem (Ryan, 2005) on the front cover describes just what it feels like to those with dementia – confused, lost with aimless wandering and yet within it all the spirit shines.

The aim of this study is to explore spirituality and dementia, to identify how to effectively assess or evaluate and provide interaction to meet the spiritual needs of those in residential care.

The geography of all residential care homes is changing. Currently it is estimated that within residential care a high percentage of residents have some cognitive impairment with many being diagnosed with dementia. Providing spiritual and pastoral care as a rest home chaplain to those with marked cognitive impairment is increasingly challenging. Residents are often alone with family and friends infrequently visiting. Staff focus on the practical care addressing the physical and emotional needs of the resident. There is often little time to meet the spiritual needs of these residents and yet understanding and attending to the spiritual needs of those with dementia is crucial in delivering holistic care.

This study focuses on identifying the current evidence from research to support chaplaincy to be effective in assessing and meeting the needs of those with dementia

Question: Is there <u>evidence</u> to support the <u>effective assessment of spirituality</u> in those with Dementia?

What Is Dementia?

Dementia has at present a high public health profile. According to a government poll in the United Kingdom (Alzheimer's Research UK, 2011) dementia is now more feared than cancer with 34% of retirees more concerned about dementia and health than any other issue. In 'Dementia and Spirituality' Kevern (2013) states 'this strikes at the very heart of who we are' with dementia affecting memory, communication ability and self-awareness characteristics that are at the core of being holistically human. Sadly, over 50% of those suffering with this incapacitating illness are undiagnosed including many living in residential care. Those diagnosed are often unable to be cared for by their loved ones and the community and are admitted to long-term residential care (LTC). Matthews F, Dening T (2002) in their Cognitive Function and Ageing Study. Prevalence of Dementia in Institutional Care cited by (Keast, October 2010) (Matthews, 2002) found that two-thirds (66%) of residents in LTC have cognitive impairment. Predictions are that this will increase and in my experience has increased to be as high as 80%.

Dementia is a syndrome due to dis-ease of the brain, characterised by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement. It is linked to a large number of underlying brain pathologies. Alzheimer's disease is the most common (60–70 %), with vascular dementia, dementia with Lewy bodies, Parkinson's dementia and

frontotemporal dementia presenting as other types of dementia. (Alzheimer's Disease International, 2009)

The New Zealand Framework for Dementia Care (Ministry of Health, 2013) has three guiding principles:-

- Following a person centred and people directed approach
- Providing accessible, proactive and integrated services that are flexible to meet a variety of needs
- Developing the highest possible standard of care

These principles are underpinned by five elements with early assessments including a standardised cognitive assessment tool and diagnosis, enabling those with dementia to live well, maximise wellbeing and meet the challenges of this life limiting condition. Interesting when so many are undiagnosed. The framework states that all should have 'their personal, cultural, spiritual and religious values and preferences respected and taken into account' (Ministry of Health, 2013). The challenge for all those delivering holistic and life fulfilling care is to how to do this effectively.

The stages of dementia as outlined in Figure One are key in helping to understand the spirituality of people with dementia (PWD).

Early Stage – covering the first and second year	Middle stage usually covering the second to fourth or fifth year	Late stage - fifth year onwards – may last fifteen years before death due to degeneration of the brain
The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as "old age", just a normal part of ageing process. The onset of the disease is gradual. It is difficult to be sure exactly when it begins	As the disease progresses, limitations become clearer and more restricting	The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious
Become forgetful, especially regarding things that just happened	Become very forgetful, especially of recent events and people's names	Usually unaware of time and place
May have some difficulty with communication, such as difficulty in finding words	Have increasing difficulty with communication (speech and comprehension)	Have difficulty understanding what is happening around them
Lose track of the time,	Have difficulty	Unable to recognize

including time of day, month, year, and season. May become lost in familiar places	comprehending time, date, place and events; may become lost at home as well as in the community	relatives, friends and familiar objects
Have difficulty making decisions and handling personal finances	Need help with personal care (i.e. toileting, washing, dressing)	Increasing need for assisted self-care (bathing and toileting). May have bladder and bowel incontinence. Change in mobility, may be unable to walk or be confined to a wheelchair or bed
Have difficulty carrying out complex household tasks	Unable to successfully prepare food, cook, clean or shop Unable to live alone safely without considerable support	Unable to eat without assistance, may have difficulty in swallowing
Mood and behaviour: – may become less active and motivated and lose interest in activities and hobbies – may show mood changes, including depression or anxiety – may react unusually angrily or aggressively on occasion	Behaviour changes may include wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations (seeing or hearing things that are not there). May display inappropriate behaviour in the home or in the community (e.g. disinhibition, aggression)	Behaviour changes, may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning) Unable to find his or her way around in familiar surroundings
Depression and withdraw	wal from social networks is co	ommon across all stages

Figure One: The Stages of Dementia

Adapted from Dementia a Public Health Priority WHO 2012 Downloaded 15.01.17

Those areas of cognition that are preserved are the long-term memory, the ability to express and understand emotions and in the early stages speech and grammar. (Ryan, 2005). The ability to understand and express emotions is crucial for those in caring roles in order for them to establish meaningful relationships with those with dementia and in so doing being able to begin to promote spiritual wellbeing.

What is Spirituality?

All human beings are spiritual in that all strive to find meaning and a purpose in life, in the context of the world. Spirituality is an essential dimension of our being – equal in importance to the emotional, physical and mental components required for wellbeing. It is for many difficult to acknowledge, often not spoken of and ignored by individuals and those caring for them. Too often, it is not a subject discussed with partners or family. In ministering to the vulnerable elderly permission, time and space is given for spirituality to be explored enabling growth and increased understanding. There are many attempts to define spirituality without there being a common consensus. Many link spirituality to faith and religion however it is so much more. Religion, an organised system of beliefs, values, practices and rituals is for some a way of expressing spirituality. Others may find meaning through connectedness with family, community; culture and creation (see Figure Two). Religion is one dimension of spirituality and may, for those working in ministry be a stepping-stone in beginning to explore in a broad sense all aspects of spirituality.

Honouring each person's spirituality in whatever way they wish nourishes and enables growth. An acceptance of faith and feelings of love, peace, joy and hope, combined with a sense of humour are the results of acknowledging and accepting spirituality across each of the dimensions.

Relationships and Connections With loved ones, friends and God

Beauty in the earth and all that is encompassed within – trees, flowers, mountains, rivers, & the sea

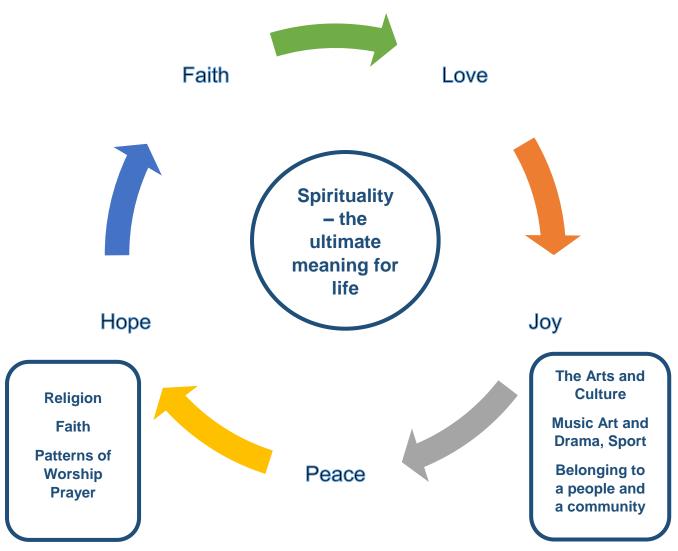


Figure Two: Understanding the Complexities of Spirituality (Adapted from Ways of Mediating the Spiritual Dimension, (MacKinlay, 2006))

Systematic Research Review

The aim of the literature review was to examine existing evidence that would support meeting the spiritual needs of those with dementia, identifying possible tools to increase the effectiveness in being able to connect, engage, assess, and understand spirituality in the context of dementia.

A search of the literature review using Google scholar, academic databases and government databases initially searched using the following terms- dementia and spirituality. This identified many qualitative studies carried out using a small number of participants. There was few quantitative studies. To narrow the search 'stages of dementia' was added to 'spirituality' with no results, and 'end stage dementia' which also showed no results. There was studies available on dying or end of life care and dementia however; these were not reviewed as part of this study.

Systematic review was added to the search terms dementia and spirituality to refine the search allowing the reduced number of studies to be manageable within

this small study. This identified four studies carried out between 2008 and 2016. (Keast, October 2010) (Agli, 2015) (Daly, 2016) (Beuscher & Beck, 2008).

Dr Peter Kevern (2013) presented a paper outlining the current state of research within Dementia and Spirituality. This also informed the findings within this paper. The access to only those studies freely available in web databases presented limitations to the study however were deemed sufficient to inform the study.

Criteria for inclusion in the appraisal of the study was:-

- Dementia
- Spirituality
- Systematic Review introduced to narrow and refine the focus

The common themes identified across the literature reviews are:-

- The ongoing importance of spirituality especially in early and middle stages and, although it is difficult to assess, those with advanced or late stage dementia.
- Person centred care includes spirituality in its widest sense. An increased awareness and sensitivity to the significance of spirituality is a good starting point in person centred care (Daly, 2016).
- Establishing relationships and making connections with others enhances ones spirituality (Keast, October 2010) (Agli, 2015). Connecting with others (family, friends, carers and ministers) both maintained a sense of security and of belonging (Keast, October 2010).
- Spiritual needs can be identified and interaction/intervention can be individualised to meet the need. Identification should include preserving a sense of meaning and purpose, fostering meaningful connections with the surrounding world, and retaining a relationship with God (Beuscher & Beck, 2008).

It was noted by Kevern (2013) that the actual research base is sparse and all commented on the limitations of interview-based studies findings in dementia. Many of those people with middle and late stage dementia are unable to provide reliable and valid information. Observation of emotions during spiritual encounters becomes key in increasing our understanding (Beuscher & Beck, 2008).

Dr Peter Kevern (2015) completed a study on the spirituality of people with latestage dementia titled: A review of the research literature, a critical analysis and some implications for person-centred spirituality and dementia care. Unfortunately, this was not available on any of the accessible databases and was therefore not able to be included in the study. It is an indication that end stage dementia is now on the research agenda which will guide further development in assessing and meeting the needs of those with late stage dementia

The following studies were also appraised as these contributed specifically to the study question.

- Assessment and Evaluation in Dementia one study on the evaluation of the spiritual needs of those with dementia (Goodall, M 2009)
- Communication and Dementia one study specifically addressing communication strategies in dementia (Ryan E, Martin L and Beaman A, 2005; McGhee J, 2011)

The appraisal with key findings is outlined in Appendix One.

Assessment and Evaluation

Margaret Goodall, a Methodist minister working as a chaplaincy advisor reinforced others findings with the need for the person with dementia to be cared for holistically using a person centred approach.

It was suggested that spiritual care could be effectively evaluated through the observation of emotions and feelings using what was termed the three R's approach

- Reflection on the person and their situation (assessment) –using the qualities of faithfulness, love, joy, peace/sense of self, goodness and gentleness (Fruits of the spirit as listed in Galatians 5:22,23) gave a workable framework for assessing spiritual health and raised awareness with all carers
- Relationship making focused and attentive connections interacting and intervening to a specific measurable need- developing an in depth relationship with others allows spiritual needs to be met
- Restoration observing responses using touch, eye contact, facial expression posture to identify any change to reinforcing the positive outcome of a spiritual intervention.

This gives helpful clearly identified tools to use when verbal feedback from the PWD is limited or absent.

Goodall (2009) stated emphatically that all staff are involved in offering spiritual care. This makes it everyone's business and raises the profile of and the importance of spirituality. The study identified that there needs to be an accountable lead able to coordinate care. This is an interesting finding, as all too often the spiritual needs are left to the minister or chaplain. All staff need to be involved and contributing to the assessment and care holistically of each person with dementia.

Communication Strategies

The key findings in this paper suggested as in the other papers that spiritual wellbeing in dementia focused on relationships with others. Person centred holistic care needs to be individualised and includes appropriate communication strategies. Communication strategies include both verbal and non-verbal using skilled interpersonal skills with one to one conversation in a quiet pleasant environment. Time is of the essence and like so many studies assessing and meeting the

spiritual wellbeing of the person is only possible if the relationship is positive, affirming and moving beyond the day-to-day pleasantries of conversation. The focus according to (Ryan, 2005) 'becomes presence and being, rather than progress and doing", which seem to align well with values and practice of contemplative spiritual direction.

Their study suggested the individual use of remembering boxes containing both symbols and pictures of significance to the person in stimulating memory and facilitate conversation. Families could be involved in developing these boxes during the early stages of the disease. The study emphasised the importance of enabling participation in religious occasions to promote spiritual wellbeing. Swinton (2012) suggest that those with dementia can indeed be fully present during these occasions.

"People with Dementia are living in a continuous present; they feel joy or sadness in the moment. Many value religious ritual and are fully present i.e. at the moment of taking communion even though they don't remember it afterwards." (Swinton, 2012)

An interesting finding, not suggested within the other studies and one that I support in my work suggested that even those most severely affected individuals had the ability to experience God. Many when offered the sacrament participate from an innate memory and connect with a smile and movement to familiar hymns and prayers.

Relevance to Spiritual Direction and Chaplaincy:

The study confirmed the appropriateness of using the knowledge and skills of spiritual direction both in assessing and in meeting the needs of those with dementia.

The following skills are therefore crucial:-

- Communication including active listening and interpersonal skills are key in establishing effective relationships and providing connections.
- Interaction needs to be open and honest without judgement.
- Environment needs to provide time and space
- Atmosphere needs to relaxed and positive
- The person with dementia needs to feel safe and trust the person initiating the interaction
- The use of appropriate and accepted touch, positive regard, maintaining eye contact, approaching from in front of the person with a positive facial expression (Goodhall, 2009) relaxes the person and invites participation
- Just 'being' rather than 'doing' and being comfortable to sit and observe and not feel it is necessary to converse.

These skills are paralleled in spiritual direction. Additionally to be effective questions should give choices, e.g. would you like to come to church today or would you like to sit and enjoy the sunshine coming through your window? Communication, verbal and non-verbal needs to be compassionate and with

feelings giving of oneself physically (open, relaxed posture), mentally (focused) and engaging spiritually. Observational skills can identify positive and negative change in the PWD.

Resources may help to interact effectively and encourage communication:-

- Life stories developed though spiritual reminiscence
- Remembering box with symbols and pictures of life, culture, patterns of worship
- Familiar prayers and stories
- Familiar words from the bible using an older translation
- Familiar patterns of worship including the use of well-known hymns and music
- Seeing God in the everyday and in the beauty of His creation

Assessment crucial in the early stages of dementia needs to take into account former religious practice, end of life meaning, the grief and the loss of recent and past times; finding new ways to interact with others in a new environment and finding hope (Beuscher & Beck, 2008). Spirituality may be heightened if it was an active part of life – a source of strength to sustain and give meaning through the daily challenges. (Agli, 2015). It is necessary to take into account that fear and anxiety may be present especially if the PWD views the illness as punishment – a commonly held view. To be able to connect in the quietness of sharing the present with messages of love, joy, peace and hope allows forgiveness of self within the challenge of meeting the need and in itself leads to healing. Walking with the person on this journey and reflecting on the fruits of the spirit as outlined by (Goodhall, 2009) will enhance the assessment.

Providing spiritual care minimises feelings of loneliness or abandonment and the stress of living with the disease. It maintains dignity and respect and promotes self-worth whilst making a difference to the persons' quality of life. (Daly, 2016) Supporting a PWD's spirituality has been shown to slow cognitive decline (Agli, 2015) allowing the PWD to find meaning and the courage to cope with the many losses and hope. Can we afford not to assess and address this need when research clearly identifies these benefits?

The research focused on the early stages of dementia with little mention of end stage dementia when the PWD has lost all physical and mental abilities. Kelvern (2013) suggests that there is 'implicit memory' in which we are able to offer meaning using familiar words and patterns of worship. We may offer to read bible stories pray and sing familiar hymns and these seem to ease the anxieties and agitation of residents. Unfortunately, the research studied had mixed views on the effectiveness of these interventions leading to a question. In these circumstances, should spiritual intervention be primarily communal and not focused on the individual? (Keast, October 2010). An area for further qualitative research. Loren Shook in Loss, Love and Laughter states from her experience *"We have seen many examples of people responding again, sometimes speaking again after a long silence when caregivers, pets and children shower love and affection on them...We know that without igniting the spirit, medical science alone cannot make a*

difference, however when medical science and igniting the spirit work together, the result is akin to magic" Loren Shook from Loss Love and Laughter, (Greenblat, 2011)

If we recognise and focus on the present – today - individual interaction can be hugely beneficial supported by small group work and encouragement to attend and participate in religious customs. Kevern (2013) concluded in his paper that spirituality is no different in dementia from other elderly people. Assessment is more difficult but together the above can meet the spiritual needs of all those in residential care.

Conclusion

As we age questions of faith and our relationship with God often become a priority. This is no different for those with dementia and in fact may well be heightened as they seek to understand and cope with the disease. The study has given me the confidence to seek and identify the spirituality across all stages of dementia as spirituality in daily living enables the development of coping mechanisms, an acceptance of the illness and the ability to find meaning and hope thus improving the quality of life.

Key to being able to do this effectively is the development of a relationship if at all possible in the early stages of the disease and to provide tools and resources to allow the person with dementia to connect to others, to life and to their spiritual being.

The study has increased my knowledge and understanding of both dementia and spirituality and researching the evidence base has given me a framework to work with in assessing and meeting spiritual needs. There is in my opinion evidence to support this approach in the early and middle stages of this disease but currently there is a gap in the research knowledge on assessment of those in the later stages of the disease. Forming a relationship and making connections with this group continues to present a challenge. The challenge being that it is everyone's business to acknowledge the enormity of the task. Agli (2015) states that 'there is a need for spiritual competence across all health care staff'. Care staff should recognise and understand their own spirituality in order to be able to respond holistically to need.

It is important to give all people the opportunity to explore their relationship with God including the elderly in our rest homes. Each person is unique and worthy of every need being meet fully as they enter their twilight years. In spite of the loss of physical and mental capacity, the person with dementia deserves care that enhances their spiritual and emotional well-being. Spirituality is the 'hidden persistence in their lives', it can grow despite the presence of dementia and the decline and loss (Kevern, 2013).

Christine Bryden a person living with dementia writes, "*Live each day as if it is your last day, and enjoy each moment to the full!*" (Bryden, 2015) A timely reminder for us all as we live to make a difference to others whilst on our own journey.

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Appendix One

Research Appraisal

	Title	Author	Date and Publisher	Criteria for Inclusion Satisfied	Type of Research
1	The Experience of spirituality from the perspective of people living with dementia: A systematic review and meta synthesis	Daly. Louise Fahey McCarthy, Elizabeth Timmins Fiona	2016 Sage Publications http://journals.sagepub.com/doi/pdf/10.1177/1471301216680425 Downloaded 12.1.17	Dementia Systematic review	Systematic review of eight research studies 2003- 2013
	hary of Findings Sense of self is in A sense of spiritur a provision of hop Spirituality may be God or a higher b Spirituality should	distinguishab ality may be h e Faith, belie e experienced eing was with not be ignore	irituality from the perspective of people living with dementia ble from spirituality heightened in the presence of dementia it was an active part of their live of and rituals over life sustain through the daily challenges of living with d through connection with others – family friends carers and ministers in them in their journey - active engagement minimises the feelings of l ed mpetence for all health care staff	dementia	
2	Spirituality and religion in older	Agli O, Baillly N &	August 2014 International Psychogeriatric Association	Dementia Spirituality	Systematic review of

	adults with dementia: a systematic review	Ferrand C	http:/www.cambridge.org/core Downloaded 5 th September 2016	Systematic review	eleven studies
	nary of Findings Spirituality benefit Maintaining religio	ts health outc ous practises	lity and religion on health outcomes omes - slows cognitive decline including social interaction symptoms reduces or stabilises the disease people to develop coping mechanisms, accept their disease and find r		ope and
3	A literature review of spirituality in coping with early stage Alzheimer's disease	Beuscher, L & Beck C	February 2008 Journal of Nursing and healthcare of Chronic Illness http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2007.02126. Downloaded 7 th September 2016	Dementia Spirituality Literature review	Literature review of six studies published between 1990 - 2006
focus	for future research hary of Findings Persons with early Assessment of the Enhancing spiritue Increased awarer	and clinical p y stage deme e PWD is crue ality promotes ness and sen	ure on spirituality and coping with early stage Alzheimer's identifying g ractice. ntia draw from spirituality to find meaning and courage in the face of th cial in the early stages of the disease s self-worth and improves QOL and assist in maintaining dignity and re sitivity to the significance of spirituality is a good starting point for perso mises the stress of living with the disease	ne many losse	S

4	A systematic	Keast	2010	Dementia	
	review of	Kevin,	http://www.managedhealthcareconnect.com/content/systematic-	Spirituality	

spirituality a	and Leskova		Systematic	
dementia in	Christine	e, Downloaded 27.1.17	Review	
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ummary of Findi	ngs			
 Importance 	of increasing a	wareness of the spiritual needs of those with dementia in	n residential care	
 Spiritual ne 	eds identified in	clude preserving a sense of meaning and purpose, foster	ring meaningful connections wi	th the
surrounding	world, and reta	ining a relationship with God		
Connecting	with others mai	ntained a sense of security and of belonging		
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		late their spiritual need Observation of emotions during s	piritual encounters is key in inc	reasing our
understand	•			
		nto account formal religious practice, final life meaning, g	grief and loss, finding new way	s to interact
	and finding hop			
0	•	ve a role - the use of compassionate speech based on B	addnist beliefs using vocabular	y based on
	current reality			
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5 Dementia a	nd Kevern I	Dr 2013	Spirituality	Systematic
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• Do we provide for PWD as an individual or in small community groups?

- Spirituality shines through is a 'hidden persistence in their lives, spirituality can grow despite the presence of dementia and the decline and loss
- Connectivity is key

6	The evaluation	Goodall	2009	Spiritual	Case study
	of spiritual care	Margaret	http://dem.sagepub.com vol 8(2) 167- 183	care	
	in a dementia	_	Downloaded 6 th September 2016	Dementia	
	care setting				

Aim: no aim clearly identified

Summary of Findings

- Person centred care responds to the whole person
- Assessment of spirituality is through the observation of emotions and feelings
- connections are made with touch, eye contact, positive facial expression
- Spirituality well-being can be effective measured by discerning the fruit of the spirit (faithfulness / sense of the spiritual, love, joy, peace / sense of self, self-control and patience / sense of the present, kindness, goodness and gentleness / relating to others in the PWD and the three R's reflection of the person and their situation (assessment), relationship (having an in depth relationship allows spiritual needs to be met) and restoration (observation and identification of change)
- One on one visits need to be focused and attentive allowing connections and the work of the spirit
- All are involved in offering spiritual care but there needs to be a lead person
- Any interaction needs to meet a specific identifiable need.

spiritual Lori, Downloaded December 2016 wellbeing Beaman among people Amanda with dementia Image: Control of the second se	among p	es to Ellen, Martin Lori, g Beaman eople Amanda	2005 The Journal of pastoral Care and Counselling, Spring – Summer 2005, Vol 59, Nos 1-2 Downloaded December 2016	Dementia Spiritual	Literature Review
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Aim: no aim clearly identified

Summary of Findings

• Spiritual wellbeing is usually found in relationships with self, others, God and creation

- With dementia, the focus is built on relationships with others.
- Late stage dementia results in disorientated to time and place and an unawareness of what is expected in conversation Communication involves individualised person centred strategies
- Facilitating conversation is helped using pictures and symbols individualised remembering boxes. This will stimulate memory and may be the way in to conversation Life stories and participation in religious occasions (music, prayers, sacrament are central to promoting spiritual wellbeing
- The place of time, space and a relaxed pleasant positive environment patience
- Communication strategies should include Nonverbal Verbal and Interpersonal skills
- 'The focus of pastoral care becomes presence and being rather than progress and doing" 'The abilities of even the most severely affected individual to experience God must not be underestimated."
- Affirming the personhood of the individual helps to connect spiritually
- Withdrawal from social interactions common but can be a sign of depression or the deterioration of the dementia. Depression will result in further withdrawal. Loss of sense of self feelings of being inadequate amongst others