

Remembering Spirituality: Spiritual Care Interventions for Persons with Dementia

Rev. Dr. Cindy R Wallace, BCC
Chaplain Manager,
Alexian Brothers Behavioral Health Hospital, Hoffman Estates, IL



Objectives: Attendees will be able to

- Recognize the aspects of dementia that affect the delivery of spiritual care
- Identify the primary spiritual care needs of persons with dementia
- Use interventions to reignite spirituality in persons suffering from memory loss



2

Dementia Includes:

- Alzheimer's Disease
- Parkinson's Dementia
- Dementia with Lewy Bodies
- Pick's Disease
- Huntington's Disease
- Frontotemporal Lobe Dementia
- Creutzfeldt Jakob
- Korsakoff's Syndrome
- Hydrocephalus
- Mixed Dementia



3

Facts and Figures from Alzheimer's Association

- More than 5 million Americans are living with Alzheimer's
- Estimates say that by 2050 16 million will have Alzheimer's
- In 2017 US will spend \$259 Billion on Alzheimer's and other dementias
- 15 million Americans provide unpaid care for loved ones with Alzheimer's and other dementias

AMITA HEALTH

4

Facts and Figures

- Alzheimer's is the 6th leading cause of death in the US
- 1 in 3 seniors die with Alzheimer's
- More people die from Alzheimer's than breast cancer and prostate cancer combined
- Since 2000, deaths from Alzheimer's have increased 89%

AMITA HEALTH

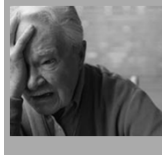
5

Fear and Anxiety

The biggest roadblock to spiritual care for persons with dementia is our own fear.

- Fear of the unknown
- Fear of being hurt emotionally/physically
- Fear of powerlessness
- Fear for our own future (Killick, 31)

"Cancer evokes concern; dementia evokes fear."
(Swinton, 187)



"The principal problem, then, is that of moving beyond our own anxieties and defenses, so that true meeting can occur, and life-giving relationships can grow." (Kitwood, 14)

AMITA HEALTH

6

Fear and Anxiety

"If we can identify and deal with our psychological blocks and come to terms with our own ageing we will begin to discover that the chasm separating 'them' from 'us' is not nearly as alarming and wide as imagined." (Shamy, 27)

- Spend time with persons with dementia
- Pace yourself, take time for reflection
- Humility- you will fail AND that's okay.
- Make plans for your own future



AMITA HEALTH

7

Fears and Anxieties Making Preparations

Find a partner next to you.
Answer the question on your Making Preparations handout
that correlates with the number card
you were given at the door.

AMITA HEALTH

8

Fears and Anxieties Making Preparations

- 1) If you were to lose all other possessions in a fire in your home, which two or three small objects would you save and why are they important to you?
- 2) If you had a bad day, what would be the single thing that would most console you?
- 3) You are about to set out on a long journey from which you may not return. Who are the persons closest to you? Write each of them a postcard-length message saying what you value most about them.
- 4) Make a list of the physical comforts which mean most to you?

AMITA HEALTH

9

Fears and Anxieties Making Preparations

- 5) What activity helps you start the day positively?
- 6) Describe two or three paintings or photographs which you would like to have close to you.
- 7) Name two or three pieces of writing (poetry or prose) which you feel you would never tire of reading.
- 8) Make up a day's menus consisting of your favorites foods and drinks.
- 9) Describe any particular fears or dislikes that you have.
- 10) Name and describe some special places in your life.

(Killick, 129-130)

AMITA HEALTH

10

Early Stages of Dementia

- Problems coming up with the right word or name
- Difficulty performing daily tasks at home or work
- Forgetting material that one has just read
- Losing or misplacing a valuable object



AMITA HEALTH

11

Early Stages of Dementia

- Increasing trouble with planning or organizing
- Loss of mathematical abilities-unable to make correct change
- Difficulty maneuvering in crowded areas
- Mood swings/paranoia/fear
- Difficulty sleeping



AMITA HEALTH

12

**Early Stages of Dementia:
Spiritual Symptoms**

- Unable to focus enough to read, pray, meditate or even recall memorized passages
- Unable to follow along in worship services with responsive readings, hymns, or sermons
- Questioning:
 - “What will happen to my faith when I can no longer remember?”
 - “Am ‘I’ still ‘me’ when ‘I’ have forgotten who ‘I’ am?”

**Early Stages of Dementia:
Spiritual Symptoms**

- Loss of peace and joy
- Increased fear, despair, helplessness
- Loss of identity/role-disease defines you



**Early Stages of Dementia
Case Study**

Cynthia Guzman: Early Onset Dementia

- [Cynthia's story](#)
- [Cynthia's story 2](#)
- [Cynthia's story 3](#)

**Early Stages of Dementia
Case Study**

**What Cynthia's
spiritual needs?**

Mid-stages of Dementia

- Forgetfulness of events or about one's own personal history
- Personality/behavioral changes-loss of social skills
- Loss of abstract reasoning and comprehension
- More noticeable language loss- handwriting deteriorates

Mid-Stages of Dementia

- Changes in sleep patterns
- An increased risk of wandering and becoming lost
- Repetitive behavior like hand-wringing, pacing
- Hallucinations



**Mid-Stage Dementia:
Spiritual Symptoms**

- Increased fear of failure, of others, of new events
- Shame
- Grief and loss
- Loss of relationship/Isolation
- Loss of spiritual coping skills
- Feelings of abandonment by God
- Loss of meaning and purpose



**Mid-Stage Dementia:
Case Study**

- Denise's Decision
- Randy's Mom
- Randy's son

**Mid-Stage Dementia:
Case Study**

**What are Randy's
spiritual needs?**

Final Stages of Dementia

- Increased difficulty in communication- repetitious, babbling, verbally incomprehensible
- Require full-time, around-the-clock assistance with daily personal care like eating, toileting, bathing



AMITA HEALTH

22

Final Stages of Dementia

- Lose awareness of family, friends, familiar surroundings
- Experience changes in physical abilities, including the ability to walk, sit, and swallow
- Become vulnerable to infections, especially pneumonia



AMITA HEALTH

23

Final Stages of Dementia: Spiritual Symptoms

- Loss of identity/self/personal stories
- Loss of community
- Loss of communication
- Loss of gentle, loving touch
- Loss of personhood



AMITA HEALTH

24

**Final Stages of Dementia:
Spiritual Symptoms**

"They have been robbed of their sense of knowing who they are in relation to themselves, God (or the transcendent other), others and the environment. . . 'knowing who I am' in relationship is central to spiritual health and well-being."



AMITA HEALTH

(Shamy,118)

25

**Final Stages of Dementia:
Case Studies**

Naomi and Gladys

Mom and Me

AMITA HEALTH

26

**Final Stages of Dementia:
Case Studies**

**What are
Joanne's and Gladys'
spiritual needs?**

AMITA HEALTH

27

Primary Spiritual Need

To be seen as a person of worth and value

"...dependence doesn't downgrade one's humanity or threaten one's personhood. Nor does it strip a person of her dignity. . . rather, it reminds us all of something that we often choose to forget: We are dependent, relational creatures." (Swinton,163)

Primary Spiritual Need

"I don't want to be forgotten or abandoned. I'm just not sure what it would look like to remember me when I have forgotten who I am and who they are, and . . . who my God is. . . The psalmist puts it this way: 'Can anyone in the land of forgetfulness talk about your righteousness?'" (Ps. 88:12)

(Swinton, 3)



Primary Spiritual Need

"The non-negotiable value and worth of the human person is recognized in the Abrahamic faiths. . . In humanistic terms too, the value of the human person is recognized as being **irreducible**. . .the worth and dignity of the person is **constant**, regardless of cognitive capacity or any other consideration."

(Shamy,69)



Primary Spiritual Need

How do we see the person who has dementia?

- One who has lost their voice?
- One who cannot make decisions?
- One who cannot take responsibility for themselves and their health care?
- One who is dependent and must be protected?



Primary Spiritual Need

- Partner in care
- Someone with communication and memory challenges
- A person with hopes and dreams and possibilities open to the future (Shamy,69)



Malignant Social Psychology

Refers to any social environments or interactions that *diminish* the personhood of people with dementia

"... the words we use and the concepts we assume ... have an impact not just on what we see and don't see, but also on what is actually there. . .

our words shape our worlds." (Killick, 46)

Malignant Social Psychology

Our attitude toward persons with dementia starts with the language we use.

- "He won't remember"
- "She can't understand you."
- "It's just like caring for a child."
- Talking about the person rather than to the person
- Ignoring them/not speaking when providing care
- Idea that person is no longer there- "just a shell"

Malignant Social Psychology



"I believe that I am much more than just my brain structure and function, which is declining daily.

My creation in the divine image is as a soul capable of love, sacrifice, and hope, not as a perfect human being, in mind or body.

I want you to relate to me in that way, seeing me as God sees me. . . I will trust in God, who will hold me safe in his memory."

(Bryden, 72)

Malignant Social Psychology

Chrisitne Bryden

Person Centered Care

**Person-Centered Care
Kitwood's 5 Great Needs:**

- Comfort
- Attachment
- Inclusion
- Occupation
- Identity



"As the whole cluster of needs is met, it is likely that there will be an enhancement of the global sense of self-worth, of being valuable and valued."

AMITA HEALTH

(Kitwood, 83-84)

Person Centered Care

"The antidote to malignant social psychology is positive personal relationships. . .moving beyond diagnosis to treat them with value and worth" (Swinton, 137)



Good care is relational care

"Spiritual health is nurtured when people experience relationship with their environment, themselves, other people and their God." (Shamy, 69)



AMITA HEALTH

38

Person Centered Care

- Rather than focus on what has been lost, "there is a need to keep telling the world that something remains." (Swinton, 66)
- "Instead of the "demented elderly", we have become people with cognitive deficits." (Bryden)



AMITA HEALTH

39

Spiritual Interventions Meaning Making

3 ways life can be meaningful:

- Giving to the world- realizing creative values
- Taking from the world- “experiences of love, truth, beauty, and whatever is good and noble.”
- Making sense of suffering without bitterness and despair (MackKinlay, 132-133)

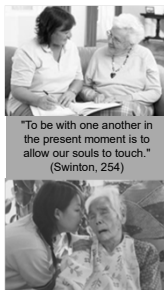


AMITA HEALTH

40

Spiritual Interventions Be present and listen

- Sit in front of the person, never behind, make eye contact
- Facial expressions & tone of voice=encouraging, warm, empathetic
- Allow the silences- they may be trying to gather their thoughts
- Avoid finishing their sentences for them
- Use short, simple sentences-no slang



AMITA HEALTH

41

Spiritual Interventions Validation

- Use empathy to match their emotion
- Tune in to individual's needs
- Ask open ended questions and avoid questions that highlight memory problems
- Don't ignore questions that are asked repeatedly, but answer with a question that might encourage conversation
- Rephrase
- Don't take things too personally.



AMITA HEALTH

42

**Spiritual Interventions
Spiritual Reminiscence**

"To be remembered is to be sustained; to be forgotten is to cease to exist." (Swinton, 217)

"For people with dementia, finding others who can remember them well is critical. . . Some of it is held by the individual; some of it is held by her community; all of it is held by God." (Swinton, 221)



**Spiritual Interventions
Spiritual Reminiscence**

Spiritual Reminiscence:

- Supporting identity through narrative story
- Finding meaning
- Affirming dignity of the person
- Affirms sources of hope
- Empowerment, self-esteem

(MacKinlay, 278-280)



**Spiritual Interventions
Spiritual Reminiscence**

- What is good in your life? What is hard for you now?
- What is life like growing older?
- How do your memory problems affect your life?
- What do you hope for? What do you look forward to?



Spiritual Reminiscence

- What gives greatest meaning to your life now?
What is most important?
- What keeps you going?
- Looking back over your life:
 - What do you remember with joy?
 - with sadness?



AMITA HEALTH

46

Spiritual Interventions Spiritual Reminiscence

- Do you have an image of God or some sense of deity?
- What do you think God is like?
- Do you feel near to God?
- What are your earliest memories of church, mosque, temple, or other worship?
- Do you take part in any religious/spiritual activities now?
- Do you pray?



AMITA HEALTH

47

Spiritual Interventions Memory Cueing

- Sensory experience- Flowers, shells, rocks, favorite treat, music
- Photos
- Poetry or other recitations read aloud
- Access to outdoor environment
- Quiet room/area with religious/spiritual symbols
- Worship services/sacrament designed specifically for persons with memory issues

(Shamy, 75-107)



Use prompts to provide mutual interest- photos, music, film, etc.; but don't insist on a response



AMITA HEALTH

48

Spiritual Interventions
Little Things- "Holy Resides in the Ordinary"
(Carr, Hicks-Moore, Montgomery, 410)

- Attributing spiritual value to everyday encounters
- Acceptance of the person for who they are
- Respecting religious beliefs and backgrounds
- Gentle touch
- Non-verbal communication
- Movement
- Be creative



Spiritual Interventions
Groups

- Crafts
- Writing Poetry
- Tactile experiences
- Puzzles, Trivia
- Music, dance
- Mandals
- Humor



Spiritual Interventions
Resources

- Flowers, leaves, rocks, grass, water
- Photos, magazines, postcards
- Instruments, singing, music, videos
- Poetry, well-known stories, books, trivia
- Crafts, art supplies, artwork
- Puzzles, bolts and screws, laundry, purses
- Your own story and experiences
- Anything that creates connection!



Spiritual Interventions Planning

Using the manipulatives
on your table
and our discussion as ideas,
what would your spiritual care plan
for Cynthia, Randy,
Gladys, or Joanne

Bibliography

- Brackey, Jolene. *Creating Moments of Joy for the Person with Alzheimer's or Dementia*. Purdue University Press, 2007.
- Burnside, Irene. "Group Work with the Cognitively Impaired." *Working with Older Adults: Group Processes and Techniques*. Jones and Bartlett Learning, 4th Ed, 2005, pp. 109-129.
- Bryden, Christine. "Dementia-A Spiritual Journey Towards the Divine." *Journal of Religious Gerontology*, vol. 13, no. 3/4, Jan. 2001, pp. 69-75., doi:10.1300/J078v13n03_05.
- Bryden, Christine. "Perspectives of a Person with Dementia 10 Years On." Plenary Session. 26th International Conference of Alzheimer's Disease International, 2017. www.alz.co.uk/adl-conference-2017-presentations.
- Carr, Tracy J., et al. "What's so Big about the Little Things?: A Phenomenological Inquiry into the Meaning of Spiritual Care in Dementia." *Dementia*, vol. 10, no. 3, 2011, pp. 399-414., doi:10.1177/1471301211408122.
- Davis, Robert, and Betty Davis. *My Journey into Alzheimer's Disease*. Tynedale House Publishers, 1989.
- "Dementia | Signs, Symptoms & Diagnosis." *Alzheimer's Association*. www.alz.org/what-is-dementia.asp.
- Dunn, Deborah. "Hearing the Story." *Ageing, Spirituality, and Well Being*. Jessica Kingsley Publisher, 2004, pp. 87-90.
- Easterling, Heather. "Behavioral Expressions in the Older Adult: Responding to Unmet Needs and Avoiding Negative Labels." AMITA Behavioral Institute Fall Educational Series. AMITA Behavioral Institute Fall Educational Series, 19 Sept. 2017, Hoffman Estates, Poplar Creek Country Club.
- Everett, Debbie. "Forget Me Not: The Spiritual Care of People with Alzheimer's Disease." *Journal of Health Care Chaplaincy*, vol. 8, no. 1-2, 1996, pp. 77-86., doi:10.1300/J080v08n01_06.

Bibliography

- Greenblat, Cathy S. *Love, Loss, and Laughter: Seeing Alzheimer's Differently*. Lyons Press, 2012.
- Killick, John. *Dementia Positive: a Handbook Based on Lived Experiences: for Everyone Wishing to Improve the Lives of Those with Dementia*. Luath Press Limited, 2014.
- Killick, John. *Playfulness and Dementia: A Practice Guide*. Jessica Kingsley Publishers, 2013.
- Kitwood, Thomas Marris. *Dementia Reconsidered: the Person Comes First*. Open University Press, 2012.
- "Living for the Moment." *Nursing Times*, vol. 87, no. NO 18, 1 May 1991, pp. 45-47.
- Mackinlay, Elizabeth. "Mental Health and Spirituality in Later Life: Pastoral Approaches." *Journal of Religious Gerontology*, no. 13:3-4, 2003, pp. 129-147., doi:10.4324/9781315808765.
- Mackinlay, Elizabeth, and Corinne Trevitt. *Finding Meaning in the Experience of Dementia: the Place of Spiritual Reminiscence Work*. Jessica Kingsley, 2012.
- Mooney, Sharon Fish. "A Ministry of Memory: Spiritual Care for the Older Adult With Dementia." *Care Management Journals*, vol. 5, no. 3, Jan. 2004, pp. 183-187., doi:10.1891/cmaj.2004.5.3.183.
- O'Connor, Thomas St. James. "Ministry without a Future: A Pastoral Care Approach to Patients with Senile Dementia." *Journal of Pastoral Care & Counseling: Advancing Theory and Professional Practice through Scholarly and Reflective Publications*, vol. 46, no. 1, 1992, pp. 5-12., doi:10.1177/002234099204600103

Bibliography

- Shamy, Eileen. *A Guide to the Spiritual Dimension of Care for People with Alzheimer's Disease and Related Dementias: More than Body, Brain, and Breath*. Jessica Kingsley Publishers, 2003.
- Shouse, Deborah. *Connecting in the Land of Dementia: Creative Activities to Explore Together*. Central Recovery Press, 2016.
- Stuckey, John C. et al. "Alzheimer's Disease, Religion, and the Ethics of Respect for Spirituality: A Community Dialogue." *Alzheimer's Care Quarterly*, vol. 3, no. 3, 2002, pp. 199-207.
- Swinton, John. *Dementia: Living in the Memories of God*. William B. Eerdmans Publishing Company, 2012.
- Trevitt, Corinne, and Elizabeth Mackinlay. "I Am Just an Ordinary Person: Spiritual Reminiscence in Older People with Memory Loss." *Journal of Religion, Spirituality & Aging*, vol. 18, no. 2-3, 2006, pp. 79-91. doi:10.1300/J496v18n02_07.
- VandeCreek, Larry. *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice*. Haworth Pastoral Press, 1999.

THANK YOU
