

# Spirituality in dementia

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Invercargill

# What does spirituality mean to you?



# From our ageing and spirituality workshops...

1. Connectedness-relationship
2. Felt state
3. Self-awareness
4. Meaning / purpose
5. State of harmony
6. Something beyond us
7. Evolving with time and crises
8. Miscellaneous

# spirituality

- “ that which is essential to our humanity, embraces the desire for *meaning and purpose*, and has personal, social and *transcendent dimensions*.”  
(Allen & Coleman) 2006, 205-206
- “that which lies at the core of each person’s being , an essential dimension which brings *meaning* to life... understood ... broadly as relationship with God, however God or *ultimate meaning* is perceived by the person and in relationship with other people”  
(MacKinlay 2001)

# Spiritual needs

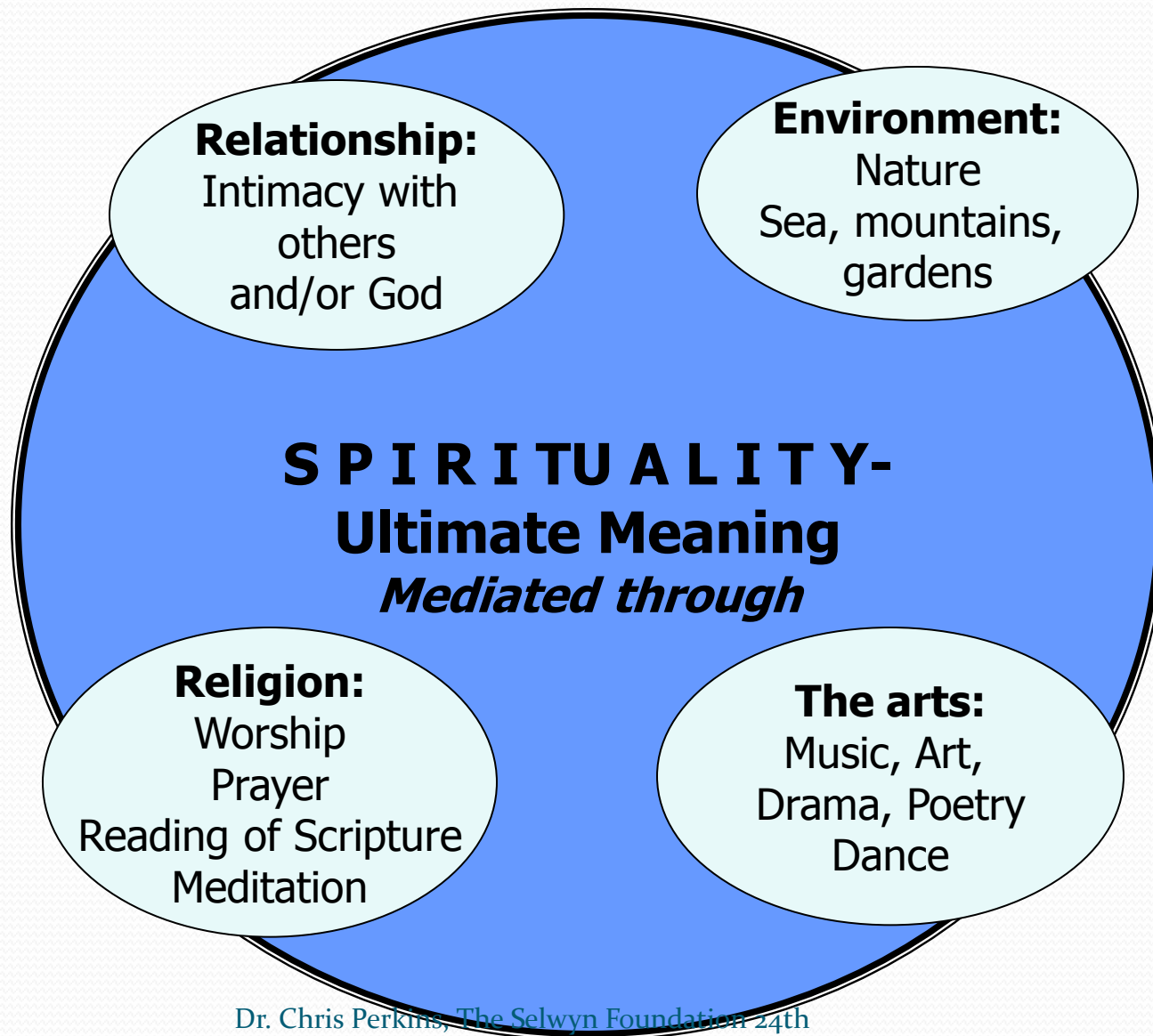
- Values and structures of meaning, faith, hope, purpose, forgiveness
- Relationships, need to nurture others
- Transcendence (dimensions beyond the self)
- Affective feeling (reassurance, comfort, peace, happiness, security, trust)
- Touching and holding
- Need for identification/sense of belonging
- Differentiation, self as separate being , mastery
- Need for affirmation, worthwhile, valued for one's uniqueness
- Communication (talking and telling stories, listening and being listened to) etc...

(Swinton 2001, Robinson et al 2003)



How do you experience  
spirituality?

# How older people express spirituality (Mackinlay 2001)



# Relationship



- Relationships, need to nurture others
- Affective feeling (reassurance, comfort, peace, happiness, security, trust)
- Touching and holding
- Communication (talking and telling stories, listening and being listened to) etc...

Nature:

transcendence -dimensions beyond the self



## The Arts

- Creativity
- Music
- Poetry
- Dance
- Visual arts
- Sport?



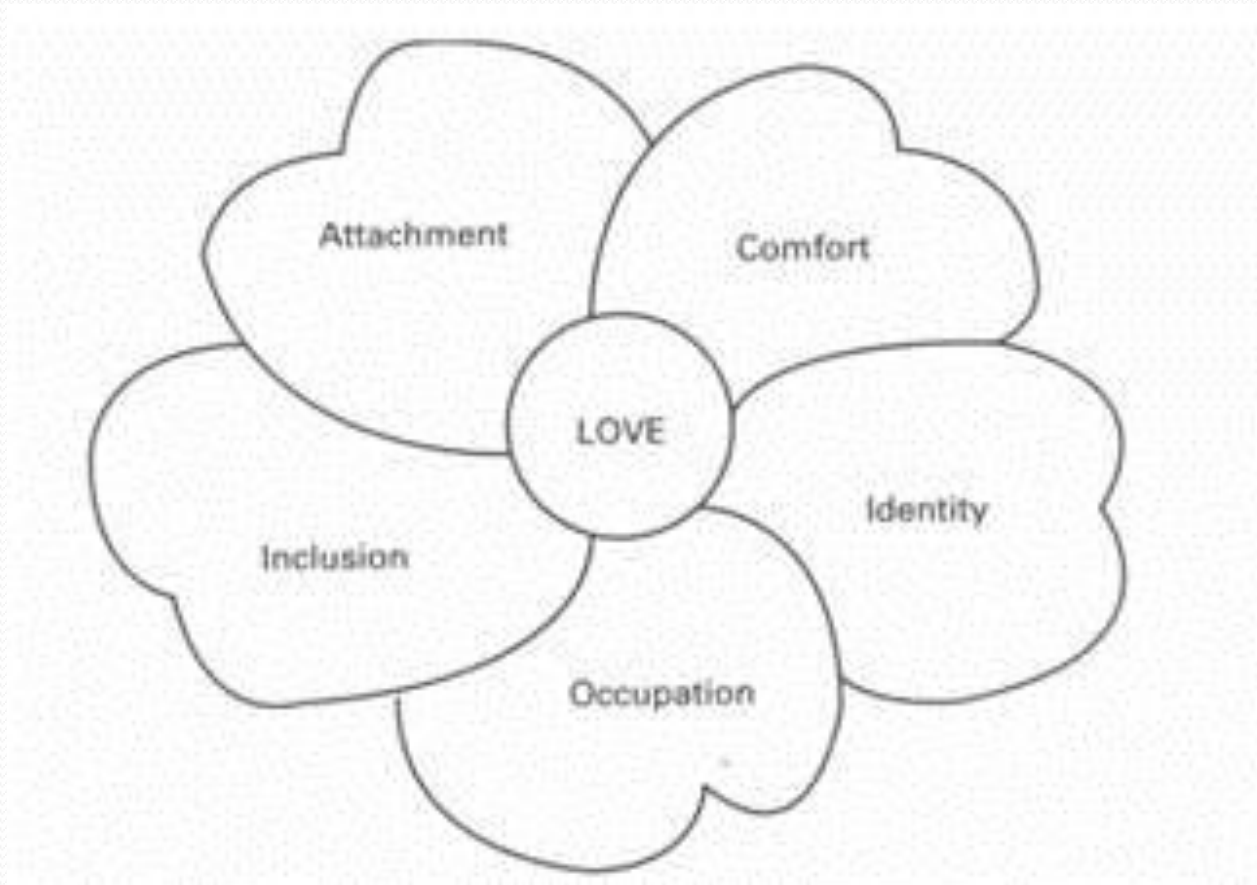
# Religion



- Values and structures of meaning, faith, hope, purpose, forgiveness
- Transcendence (dimensions beyond the self)
- Need for affirmation, worthwhile, valued for one's uniqueness

# Psychosocial needs in dementia

(Kitwood 1997)



# In dementia

- Spirituality is *no different* in dementia: only the brain changes. Intrinsic value of person is never lost (Goldsmith 2004)



# In dementia

- Difficulty expressing and meeting spiritual needs, fear of separation from God  
(Bryden 1998)



# In dementia

- Spiritual practices from youth may become more prominent



What would nourish you spiritually  
if you had dementia?

## John Swinton's hope

- “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”

# Challenges in aged and health care

- Getting to know the person / resident / patient
- Focus on the physical (or mental)
- Environment: safety issues (not setting the tables, not eating the flowers)
- Management: care vs profit, minimum staffing for minimal wages, immigrant workers
- Audit compliance, paperwork,
- Perceived lack of skills, lack of support and supervision
- Stepping beyond boundaries (“ opening a can of worms!”)
  
- PRESSURE OF TIME

# But

- “ it’s not about time -- it is the way people do things”

(Rev. Jill Richards.)

# You find spirituality when you look for it...

Ask person with dementia and others:

- What gives life meaning for you?
- What is important?
- How do you cope with difficult times?

Observe:

- What makes her happy, calm, upset? What does she like to do?

# How can we help you to live a wonderful life?

- Is faith (religion, spirituality) important to you?
- Has faith been important to you at other times in your life?
- Do you have someone to talk to about religious matters?
- Would you like to explore religious, spiritual matters with someone? (American College of Physicians in D'Souza 2007)
- Do you consider yourself spiritual or religious?
- How important are these beliefs to you and do they influence the way you care for yourself?
- Do you belong to a spiritual community?
- How might health care providers address any needs in this area? (Puchalski et al in Winslow & Whetje-Winslow 2007)



# How do we encourage people to give spiritual care?

- Permission
- Affirmation
- Modeling
- Learning more\*
- Various techniques; spiritual reminiscence, memory boxes etc
- Remind families that while visiting it is important that they make a difference, even if it is forgotten: “making people alive in the moment”

# Enhancing the life of people with dementia: creating moments of joy

- Provide care that can respond to the joy of the moment .
- Communicate sense of acceptance and belonging... “shalom”
- Anyone from cleaner to manager to family to paid caregiver can do this (possibly even doctors)
- Many are already practising spiritual care even if they believe they haven't got the skills.
- Rituals
- Allowing older person to be alone
- Little things make the difference

# Spiritual care as presence

- Functional presence: focus on task
- Partial presence; primary focus on task, some attention to patient
- Full presence: fully-focused on patient psychologically and physically
- Transcendent presence: nurse is open to patient and shares a sense of peacefulness and harmony (Schwartz-Barcott 1996)

# It's about the way we are, not just what we do

## *Virtues of nursing*

- Unconditional positive regard
- Empathy
- Integrity
- Hopefulness
- Truthfulness
- Pride
- Humility

(Robinson, Brown & Kendrick 2003)

# Needs of the family

All of the above: (comfort, identity, inclusion, attachment, love, occupation other than caregiving) ... plus

- Finding a sense of meaning and value to their care
- Coping with grief
- Space to spiritually re-charge, make contact with the transcendent.

*But, each person with dementia and each family is different: at different stages of different journeys*

“As I see it, spiritual needs underlie the psychosocial needs of people---they lie at the very core of what it is to be human.

If we neglect these, especially for people at critical points of their lives and for those who are facing their frailty, dying and death, then we neglect something equally important as failing to provide food.

Spiritual care can no longer be seen as an optional care component.”

E. MacKinlay 2006 p.69

# References

- Byden, C. (1998) *Who will I be when I die?* Pymble: Harper Collins Religious
- D'Souza R (2007) The importance of spirituality in medicine and its application to clinical practice *Medical Journal of Australia* 186 (10) S57-S5
- Goldsmith, M. (2004) *In a Strange land...People with dementia and the local church: a guide and encouragement for ministry* 4M publications, Southwell
- Kitwood, T. (1997) *Dementia re-considered: the person comes first* Open University Press, Buckinghamshire
- MacKinlay, E.(2001) *The spiritual dimension of ageing* London, Jessica Kingsley Publications
- Robinson, S., Kendrick, K., Brown, A. (2003) *Spirituality and the practice of Healthcare* Basingstoke Palgrave Mac Millan
- Saks, J. (2002) in Goldsmith, M. (2004) *In a Strange land...People with dementia and the local church: a guide and encouragement for ministry* 4M publications, Southwell
- Schawtz-Barcott (1996) in *Spirituality and the practice of Healthcare* Robinson, S., Kendrick, K., Brown, A. (2003) Basingstoke Palgrave Mac Millan p.109
- Swinton, J. (2001) *Spirituality in Mental Health Care: Rediscovering a Forgotten Dimension* London: Jessica Kingsley Publishers
- Waldegrave, C. (2009) in *Enhancing Wellbeing in an Ageing 65-84 year old NZers in 2007* Chap. 13, Culture and religion <https://www.ewas.net.nz>
- Winslow G & Whetje-Winslow B, Ethical Boundaries of Spiritual Care *Medical Journal of Australia* 186 (10)S63-S66



# Questions and comments?



YEAR: 1969  
MISSION: APOLLO 11  
TARGET: LUNAR SURFACE  
20/12/2011

Dr. Chris Perkins, The Selwyn Foundation 24th  
August 2011

View from the Apollo 11 spacecraft showing the Earth rising above the Moon's horizon.