

Spirituality in dementia

Delivering Excellence in Dementia Care

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What does spirituality mean?

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

From our ageing and spirituality workshops...

- “ that which is essential to our humanity, embraces the desire for *meaning and purpose*, and has personal, social and *transcendent dimensions*.”

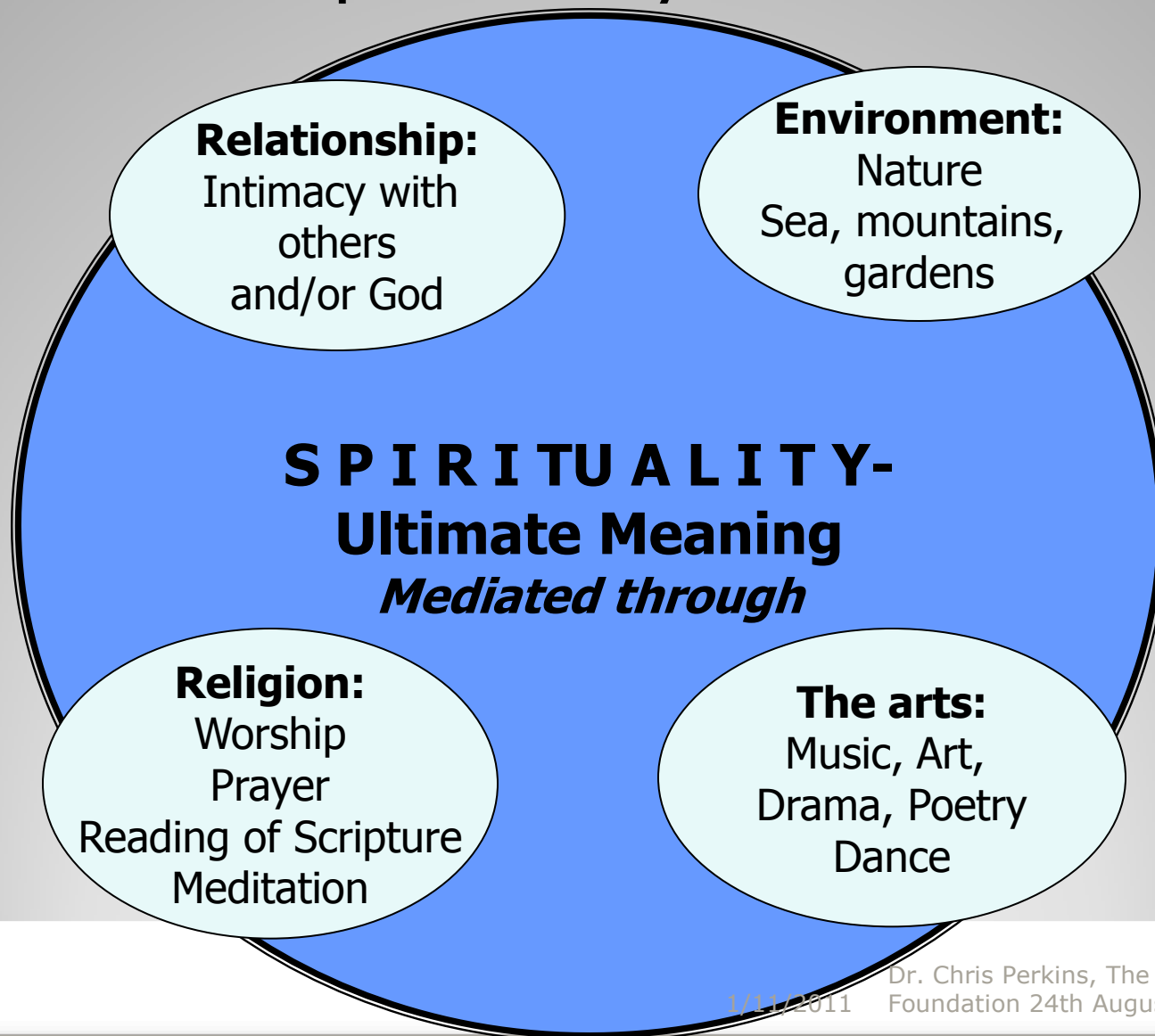
(Allen & Coleman) 2006, 205-206

- “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)

spirituality

How older people express spirituality (Mackinlay 2001)





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

Relationship



**Nature: transcendence
dimensions beyond the self**

The Arts

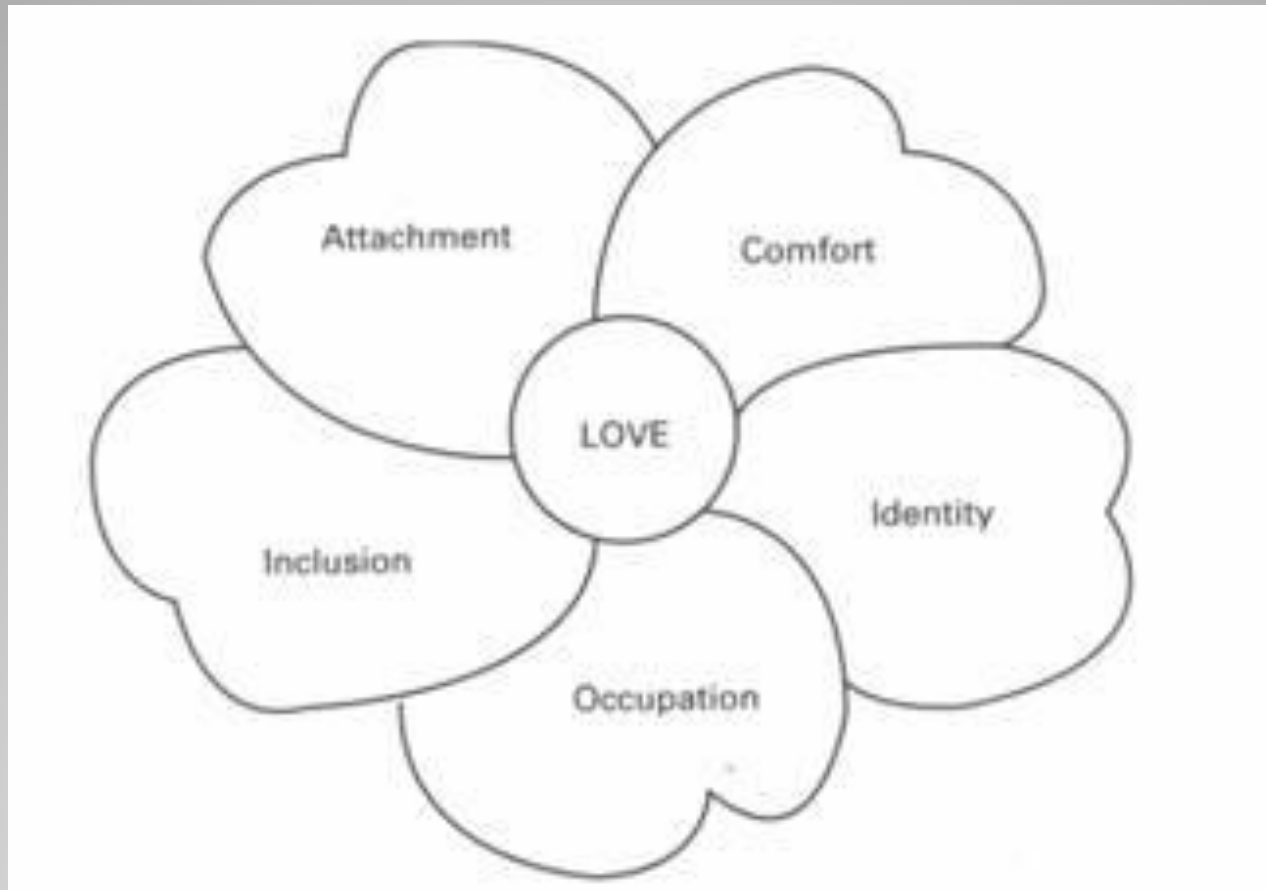


- There is no evidence to show that people lose the capacity to feel per se in the same way they lose the capacity to reason...the arts have a special place to play in allowing people to express themselves non-verbally



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)

- Spirituality is *no different* in dementia: only the brain changes. The intrinsic value of the person is never lost.

(Goldsmith 2004)

- Is it possible that the very deprivation of cognitive capacity can in some people with dementia lead to the growth of spiritual powers?

(Killock 2004)

In dementia

At the centre of our being lies the true self, what identifies us to be truly human, truly unique, and truly the person we were born to be.

This is our spiritual heart, the centre from which we draw meaning in this rush from birth to death, whenever we pause long enough to look beyond our cognition, through our clouded emotions into what lies within

- Bryden 2005 (Dancing with Dementia)

It is the "me" that relates to the beauty of a garden, of the leaves or the flowers, it is the "me" that relates to God, it is my spirit, the essence of me." Bryden (2005)

Spiritual care depends on us being in a “right relationship with ourselves before we can be in an authentic relationship with others.”

(Lawrence & Head 2009)

How can you be spiritually available to people with 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”

John Swinton's hope

- Getting to know the person /resident / patient
- Tendency to focus on the physical (or mental)
- Environment: safety issues
- Low staffing for minimal wages, people with poor English
- Audit compliance, paperwork,
- Perceived lack of skills, lack of support and supervision
- Stepping beyond boundaries (opening a can of worms!)

- PRESSURE OF TIME

Challenges in aged and health 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”

How do we encourage people to give spiritual care?

Ask person with dementia and others:

- What gives life meaning for you?
- What is important?
- How do you cope with difficult times?
- How can we help you to live a wonderful life?

Observe:

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

You find spirituality when you look for it...

Spiritual practices from youth may become more prominent



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.
- Allowing older person to be alone
- Little things make the difference

Rituals

Virtues of nursing

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

(Robinson, Brown & Kendrick 2003)

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

“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

Sometimes I picture myself
like a candle.

I used to be a candle about eight feet tall-
burning bright.

Now every day I lose
a little bit of me.

Someday the candle will be
very small.

But the flame will be
just as bright.



Burning Bright
(Noon, 2003 in Killick 2004)

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References

- 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...
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- (Swinton 2001, Robinson et al 2003)

Spiritual needs

- 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)

Questions