

Spiritual Care and Advanced Dementia

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Dementia (AD in particular) has been called “the theological disease” (Keck, 1996)

- Religious faith (in the Abrahamic traditions) is sometimes defined as “remembering God and being mindful of God in all that I say and do.” Can one hold faith if one can no longer remember God?
- Dementia evokes spiritual questions about meaning.
- Dementia is a “theological disease” because it raises core questions about what it is to be a self, or a creature formed in “the divine image.”

How do we usually think about the self of persons with advanced dementia (severe dementia, late stage dementia)?

Severe Alzheimer's Disease. Cognitive function is severely weakened and yet, paradoxically or because of it, one often sees spirituality blossom. This is seen in the capacity of many PHDs to live totally in the present and to show compassion to others with touch, facial expressions, and other even surprisingly verbal ways that often shock those who witness it. Many PHDs in this stage have no visible fear of death and are always ready to interact completely non-judgmentally and with a smile. One even witnesses PHDs in this stage becoming one with any spiritual song or spiritual ritual that has been part of their history and fabric. (Abhilash Desai, MD)

Personhood understood relationally

Personhood “is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust” (Kitwood, 1997, p. 8).

“In all times and cultures, people have been most frightened of whatever represents the greatest threat to their fundamental identity as a self.”
(Hauerwas)

- ~~Corporality as defining of selfhood~~
- ~~Cognition as defining of selfhood~~
- Then how shall we define selfhood?
- Relationally!

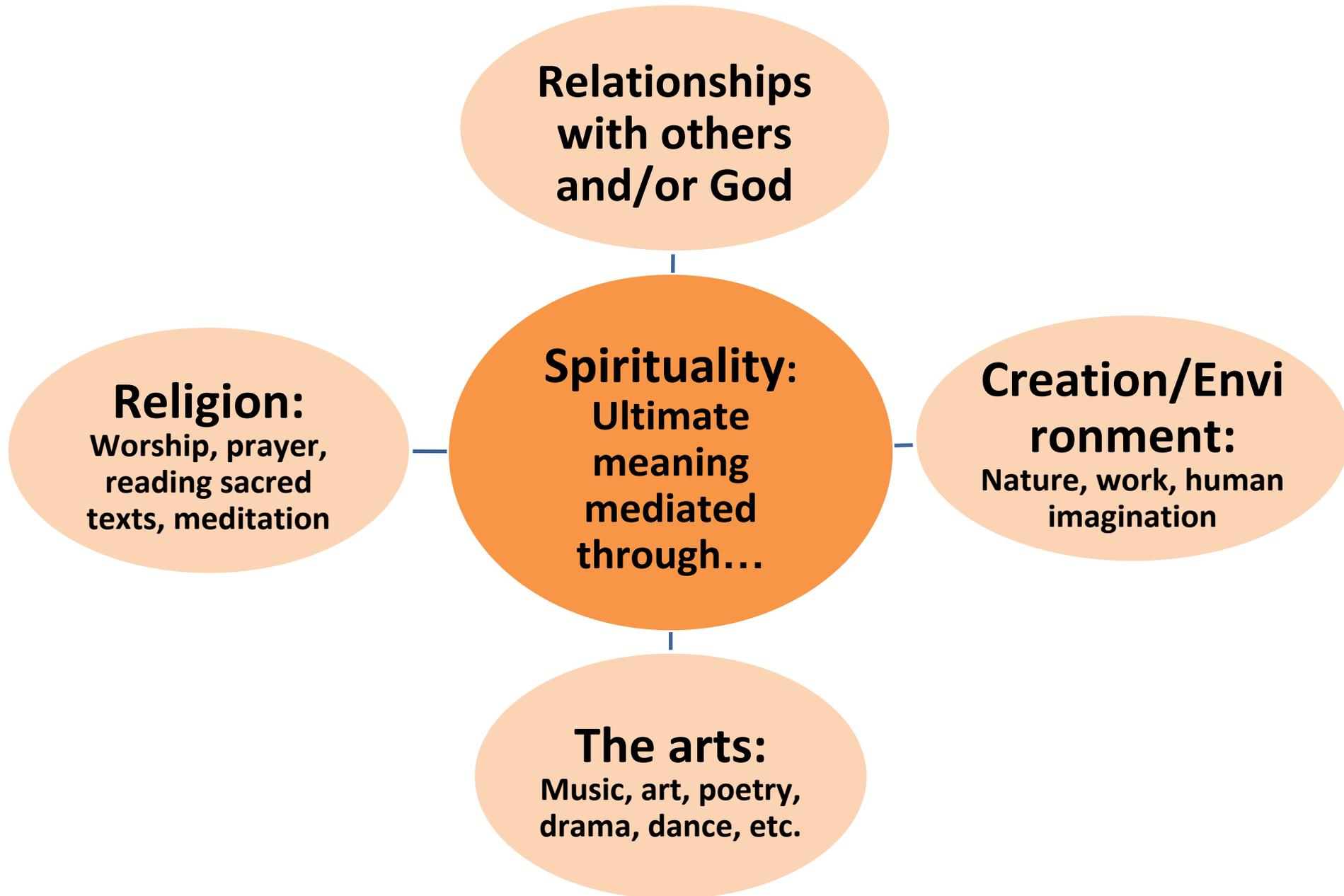
Meister Eckhart

(13th century Christian mystic)

When God laughs at the soul and the soul laughs back at God, the persons of the Trinity are begotten. To speak in hyperbole, when the Father laughs to the Son and the Son laughs back to the Father, that **laughter gives pleasure, that pleasure gives joy, that joy gives love**, and love gives the persons [of the Trinity] of which the Holy Spirit is one.
(Blakney, 1941, p. 245)

What is spirituality?

Elizabeth MacKinlay's Model of Spirituality



What is
religion?



Religions

- Religions provide symbols, stories, and rituals as ways of deepening spiritual connections and making them ultimately meaningful
- Religions are signposts that point people toward meaning that is related to the sacred
- Religions define what is sacred



This way to the
sacred

The
sacred

All religions ask, and try to answer, these questions:

What is the good life?

What is fulfillment?

What is required of you?

How do these questions relate to people living with advanced dementia?

What is the good life?

What is fulfillment?

What is required of you?

**What is
spiritual care?**

**Why should we
care about
spiritual care?**

Spiritual needs of people with advanced dementia

They are the same as the spiritual needs of elders who do not have dementia

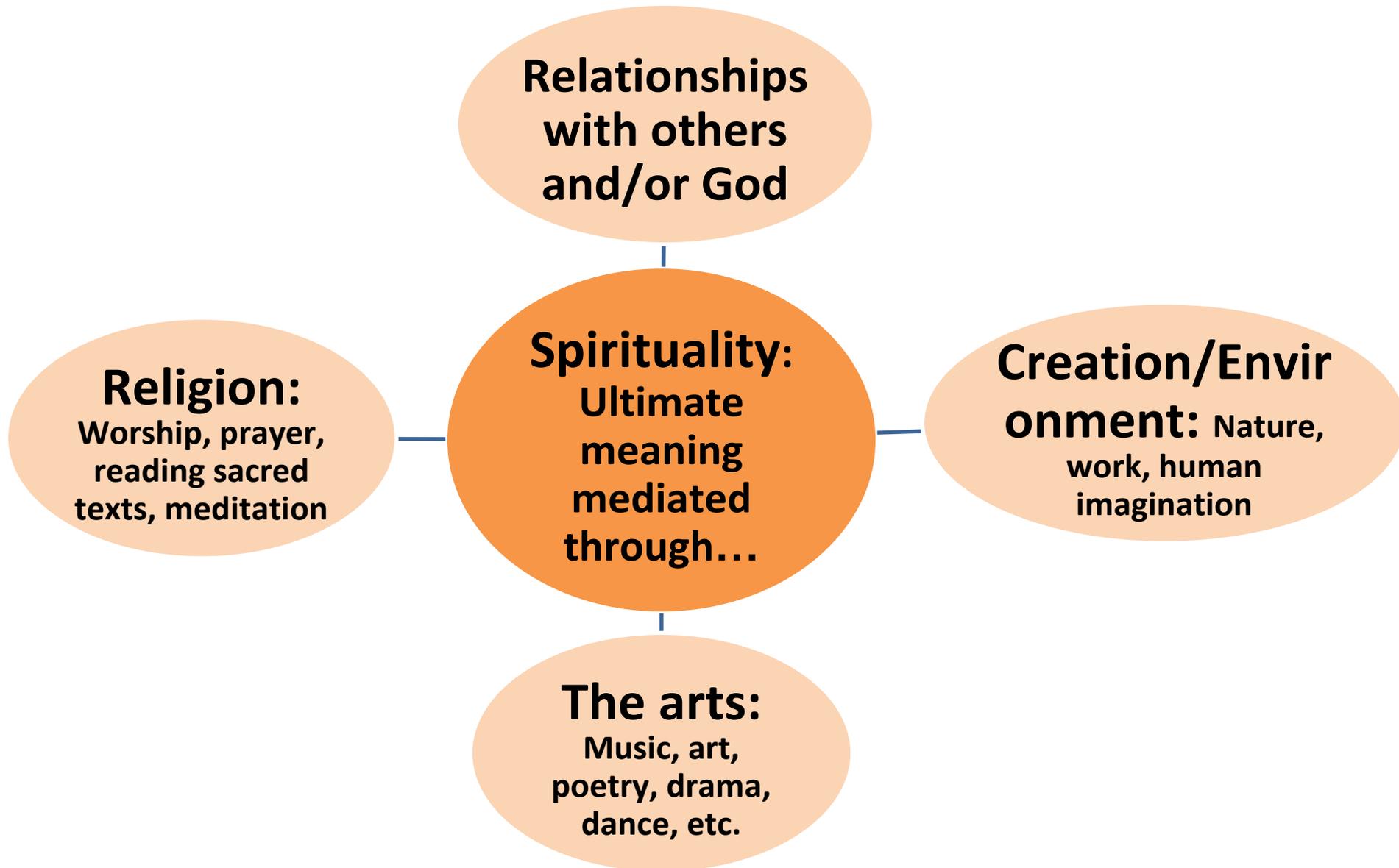
- Acceptance by others and self-acceptance
- Affirmation of value, worth, and dignity
- Guidance and support in times of grief and loss
- Satisfying and meaningful ways to be creative, useful and to care for others

Spiritual needs, cont'd

- Help in dealing with feelings of fear, anger, sadness, contempt, disgust, guilt, shame
- Encouragement and opportunities to experience joy and awe
- Feeling loved

**Who should
engage in
spiritual care in
long-term care
settings?**

How can long-term care staff respond to residents' spiritual needs?



A new model for
retired clergy

Spiritual care is not just one more item to be ticked off a resident's care plan because he or she was given the opportunity to sit through a worship service. It should be woven into the fabric of everyday life in a residential care setting!