



The Spiritual Heart of Dementia Care

**Positioning,
Recognising, Holding
and Loving.**

Cared for who I am...

“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”

Half empty or half full?

- Because our culture so values rationality and productivity, observers easily characterize the life of the person with dementia in the bleakest terms because it lacks sociocultural worth. The experience of the person with irreversible and progressive dementia is clearly tragic, but it need not be interpreted as half empty rather than half full.

(Stephen Post *The Moral Challenge of Alzheimer's*)



The way in
which we
describe
dementia will
determine
what we see

Jimmy's Story



A black and white photograph showing two hands clasped together in a supportive grip. The hands are positioned centrally, with fingers interlaced. The lighting is soft, highlighting the texture of the skin. The background is dark and out of focus. The word "Holding" is written in white serif font in the upper left corner, and a question is written in white serif font in the lower right corner.

Holding

How do you
know who you
are?

The question of the Self

How do you know who you are?

The stories of our lives

- We are the stories we tell about ourselves *and* the stories that others tell about us.
- Backward and forward stories
- Holding one another well

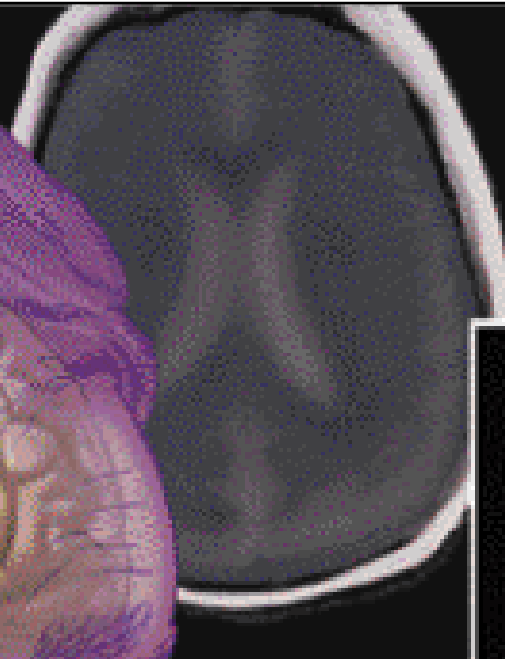
Positioning

What you say is what I am?

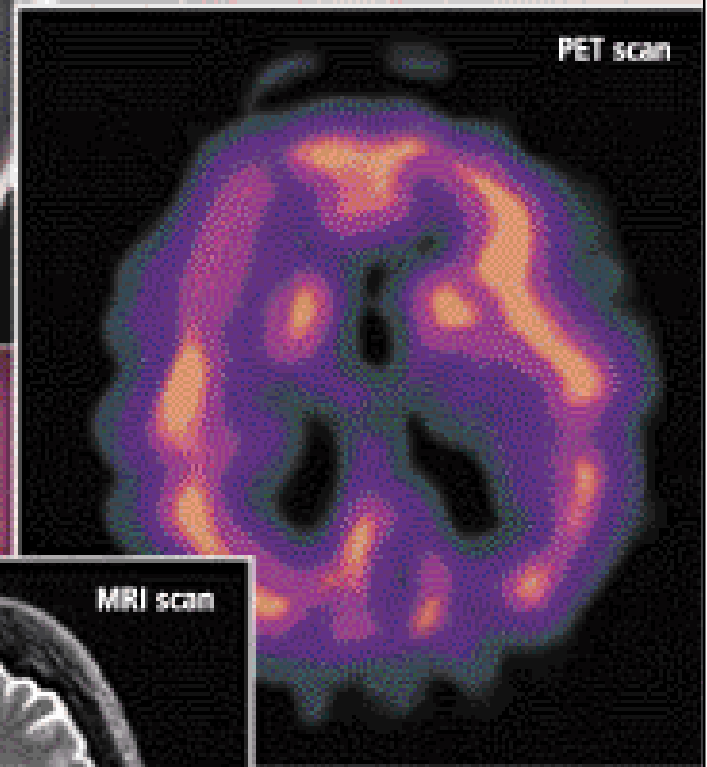
- Standard notions of role are criticised as being overly static and disembodied. Roles describe typical social positions – wife, mother, banker, teacher, student – but fails to identify the particular experience of someone who is ascribed such a role.
- The way in which we position a person within a relationship will determine how we respond to her.

What stories do we tell
about dementia?

A problem of
neurological
decline?



CT scan



PET scan



MRI scan

The medicalisation of dementia

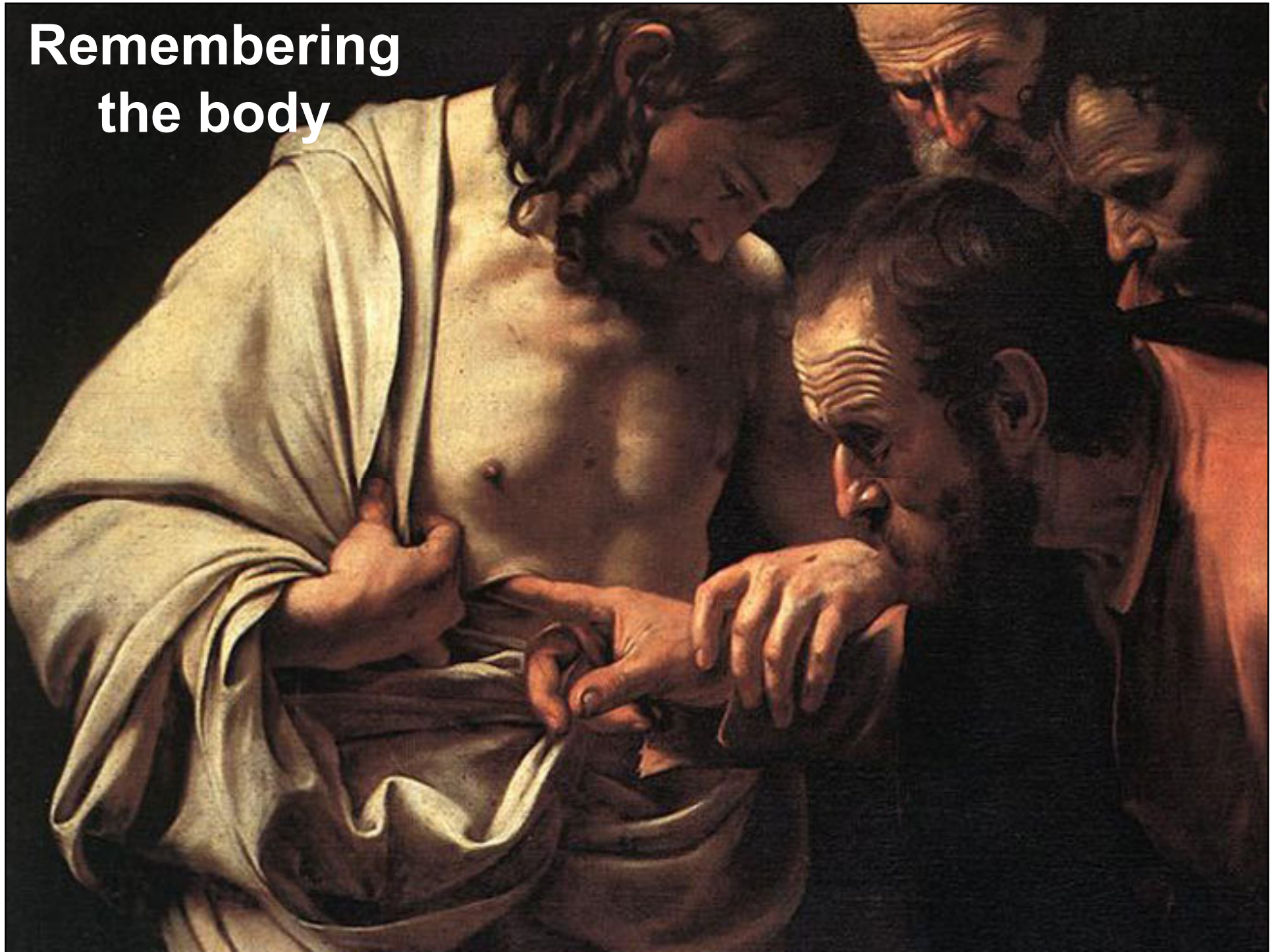
- our understanding of dementia has been constructed by a cluster of discourses, of which the dominant one is grounded in medical science. Within this interpretative framework, the person is totally subsumed to their neurological condition, even to the point where, linguistically, they are frequently referred to as 'dead.'

Tom Kitwood *Dementia Reconsidered*

The problem with the standard account

- It does not take seriously the social nature of dementia
- It does not take spirituality seriously
- It does not take seriously the importance of the body for human personhood

Remembering the body



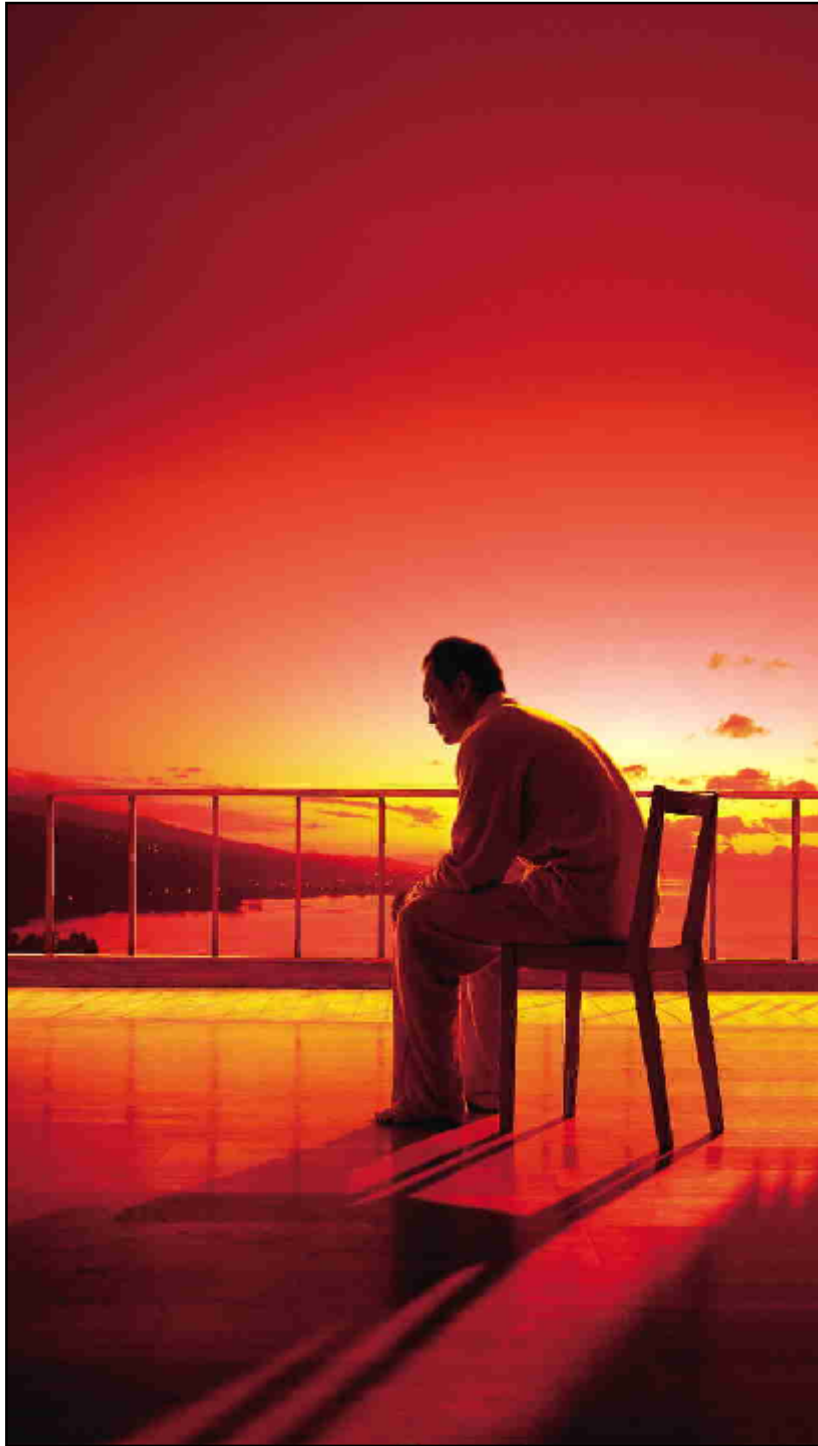
No place like home?

Our bodies remember what it is like to
be at home

Rementia

- Clear examples have been noted of ‘rementing,’ or measurable recovery of powers that had apparently been lost;
- a degree of cognitive decline often ensued, but it was far slower than that which had been typically expected when people with dementia are in long term care.

Sixsmith A, Stilwell J, Copeland J. ‘Rementia’: Challenging the limits of dementia care. *International Journal of Geriatric Psychiatry*. 2004;8(12):993-100.



A Problem of Memory?

Where are our memories?

Our memories are held in the stories
that we tell and that are told about us



May's Story

“Forgetting Whose we are”

Recognising

Forgetting who *you* are.

Does she recognise me?

- Three types of recognising
 - Identification of things
 - Self recognition
 - Recognition by an Other

Does she recognise me?

- “The question concerns my mother’s ability, as a sovereign self, to actively draw intellectual distinctions amongst the objects and people around her. I have come to think, however that also at stake...is whether or not she is granted social and political recognition by others.”

(Janelle S. Taylor (2008) ‘on recognition, caring and dementia.’
Medical Anthropology Quarterly, Vol. 22:4 pp313-335



A
problem
of the
mind?

Once the mind has “gone” the
person no longer exists

Where is your mind?

- “How do you really know [his mind has gone] you don't *really* know for sure do you? You don't really know if those little plaques and tangles are in there, do you? ...how do I know that the poor man isn't hidden somewhere, behind all that confusion, trying to reach out and say, “I love you, Sara””? [weeps]

Gubrium Jaber F. ‘The Social Preservation of Mind: The Alzheimer's Disease Experience.’ *Symbolic Interaction*. Spring 1986, Vol. 9, No. 1, Pages 37–51

The mind is under common ownership!

- The case of psychotherapy
- The mind is both an individual and a social entity.
- A question of faith?

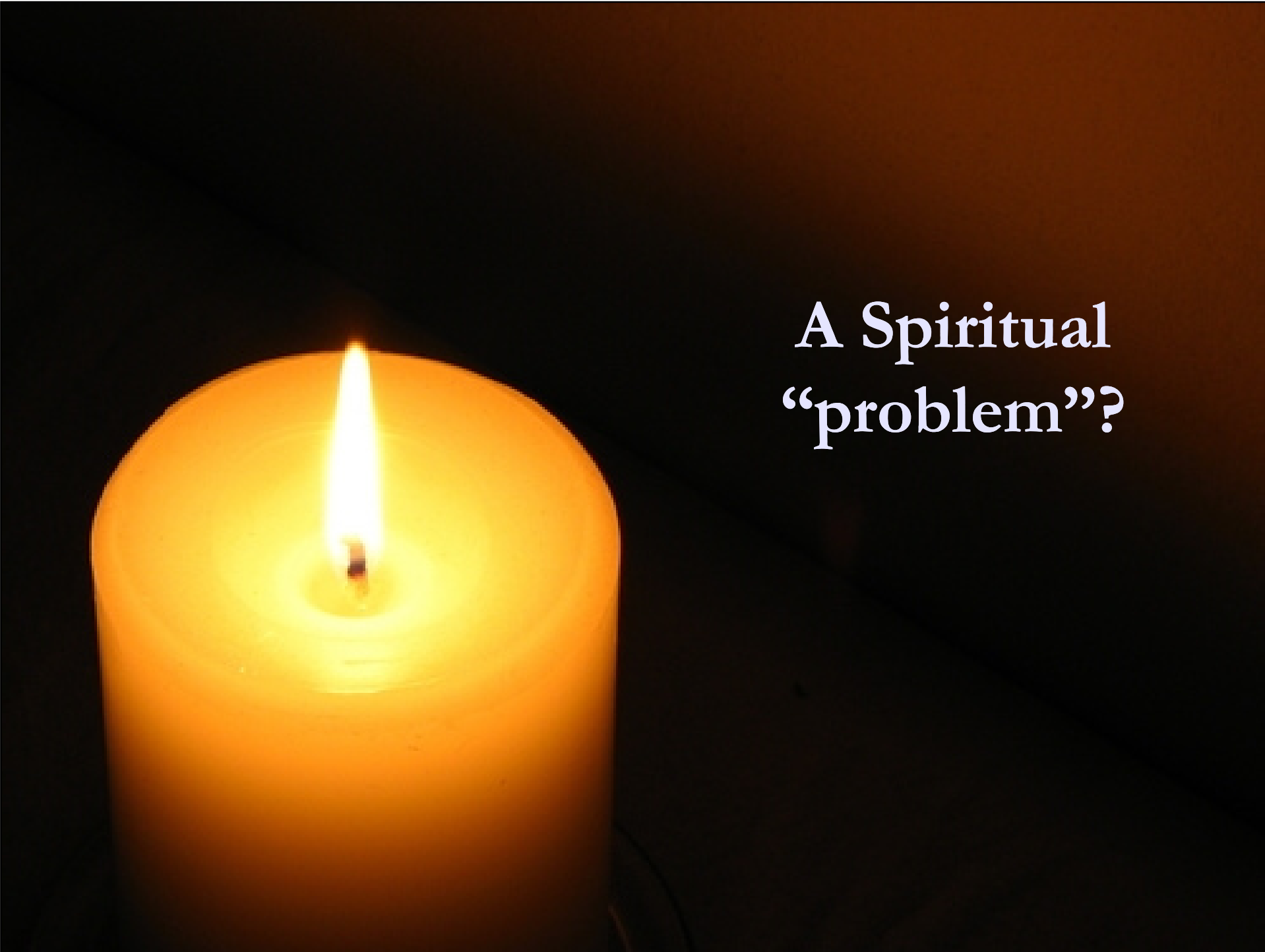
I am because we are...

Alone in a crowd



Where are my friends

- Middle class ... friendships are not generally expected to bear the weight of deep and diffuse obligations to care. More like pleasure crafts than life rafts, they are not built to brave the really rough waters – and these are rough, corrosive, bitter waters indeed. Dementia seems to act as a very powerful solvent on many kinds of social ties. I doubt that many friendships survive its onset.
- (Taylor p. 319)

A lit candle with a flame, set against a dark background. The candle is the central focus, with a bright yellow and orange flame. The background is a gradient of dark brown to black. The text is positioned to the right of the candle.

A Spiritual
“problem”?

Key Spiritual Questions

- Who am I?
- Where do I come from?
- Where am I going to?
 - Why?





Spirituality is
love

Its good that you are here...its
good that you exist!



**Love requires courage...not
fearlessness...courage**

Hope is something that
we do together

KNOW
HOPE

Love Requires Faith

Cared for who I am...

“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”

The spiritual heart of dementia care

Faith, Hope and Love...but
the greatest of these is love