

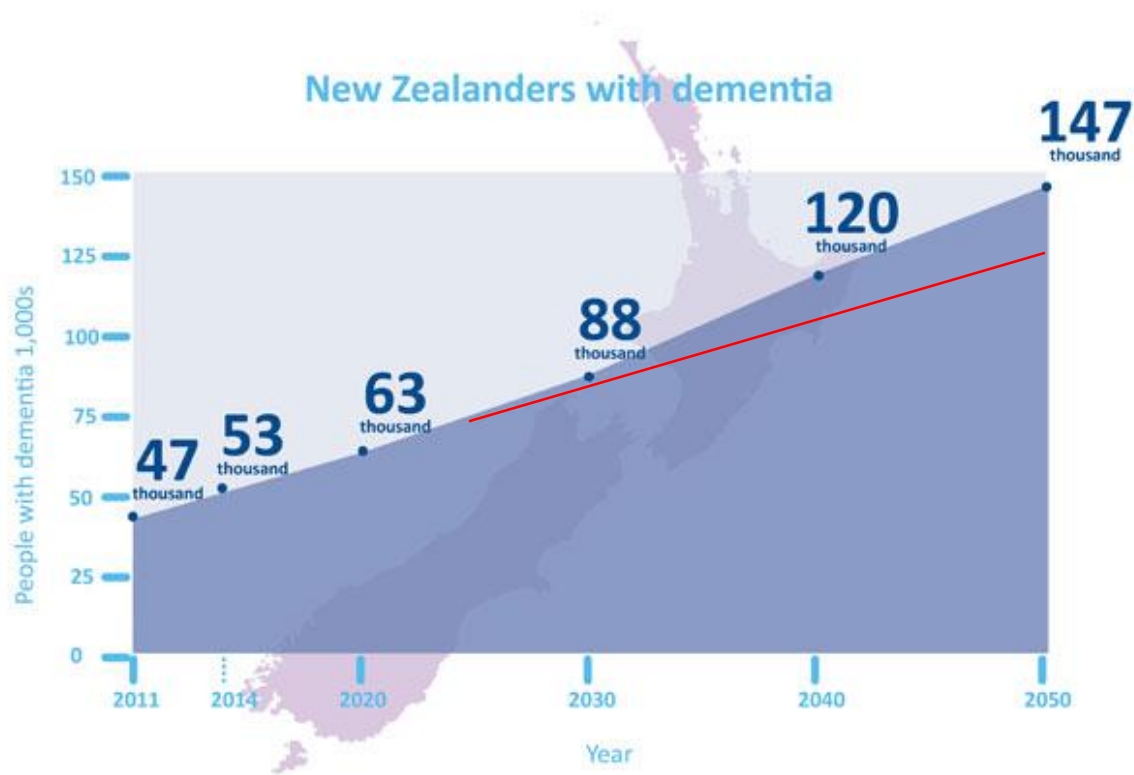


# Spirituality in dementia

Chris Perkins

07/12/2016

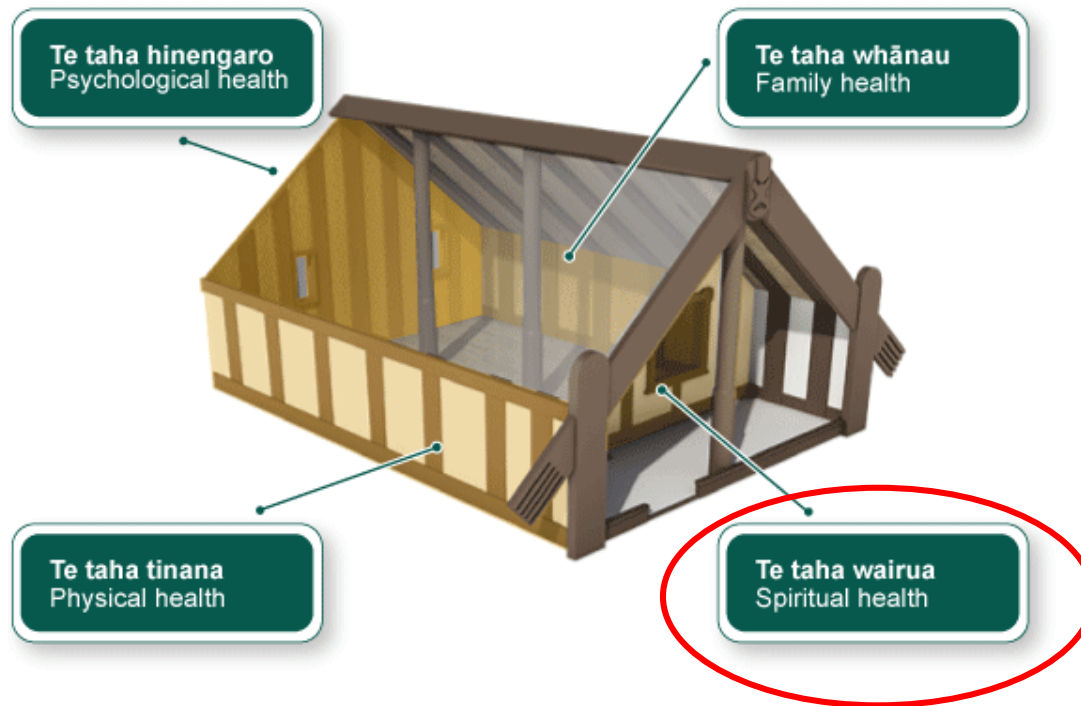
# About dementia



# Person-centred care: psycho-social needs in dementia



# Living well with dementia



# Richard Egan (2009)

“Spirituality means different things to different people. A working definition may include:

- one’s ultimate beliefs and values;
- a sense of meaning and purpose in life;
- a sense of connectedness;
- identity and awareness;
- and for some people, religion”.

# Spirituality

- Spirituality is about what is essential to our humanity, embraces the desire for **meaning and purpose**, and has personal, social and transcendent dimensions (Allen & Coleman 2006)
- That which lies at the core of each person's being, an essential **dimension which brings meaning to life**. Constituted not only by religious practices, but understood more broadly, as relationship with God, however God or **ultimate meaning is perceived by the person**, and in relationship with other people (Elizabeth MacKinlay 2002).

# This study

- Funded by Louisa and Patrick Emmett-Murphy Foundation and The Selwyn Foundation.
- No previous studies of dementia and spirituality in New Zealand
- Qualitative study done to inform quantitative part of study

## **The question:**

**What is meaningful to people with dementia  
severe enough to require specialist care?**

Approved Southern Ethics Committee Sep. 2012 Ethics ref. 12 STH 12

Carried out Nov. 2012- Jan. 2013

On reflections, in my research into spirituality in dementia units I asked the wrong question...

- But got the right answer





# Methods

- **The participants:** 6 people with moderately severe dementia, 5 family members, 7 staff from two D3-level rest homes (1 with religious affiliation, 1 private) → 3-way view
- **Semi-structured questionnaire developed from** MacKinlay & Trevitt (2006)
- **Interviews were audio-taped and I typed transcripts**
- **Analysed:** General Inductive Method (Thomas 2006)

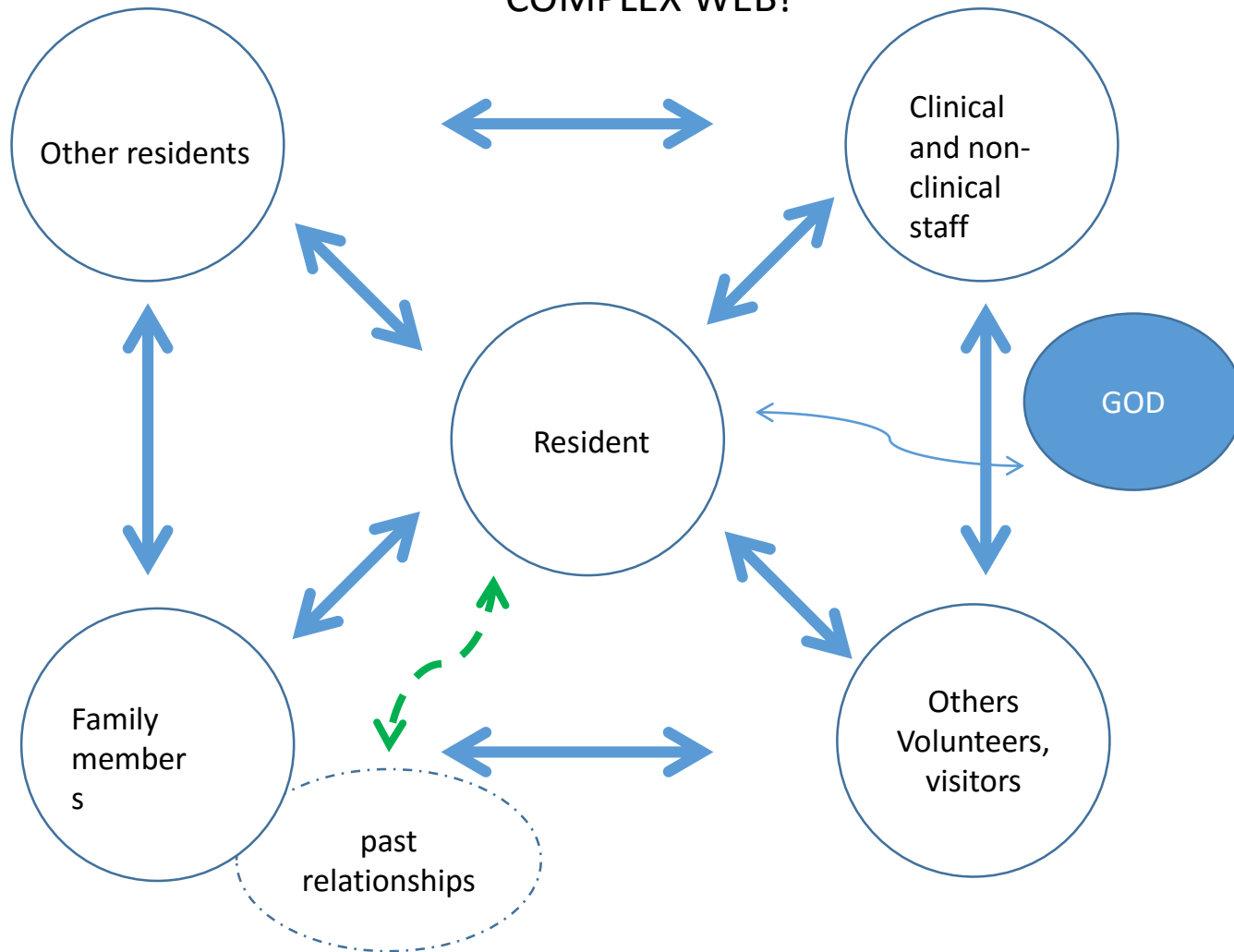
# Themes



- Importance and reciprocity of relationships / community
- Retention of identity
- The progression of dementia

# 1. RELATIONSHIPS

COMPLEX WEB!



# Examples of interactions

- Love
- Annoyance
- Friendship



# Romance

*“And you know, if he gets up in the morning and she’s not up, when she comes into the room, his eyes light up.”*

Caregiver

# Irritation

- *“one resident here, is ... repeating herself...can’t express herself, says “la, la, la” and.. if L’s enjoying the music ... she will turn around and say straight out “Oh, shut up”. That annoys L. because she is enjoying something and someone is distracting, that’s why she gets like that.” (Caregiver)*

# Friendship

*“... there was a lady came here, another Croatian lady came to stay. She made very, very close friends with B because they were like the same, maybe it was the land, like blood and they became immediate friends and she would not leave without B.*

*Anywhere she goes, she just hold her hand and go, just sit, even... nobody could sit on that chair next to N. when B. has gone to the bathroom or somewhere. She'd save the chair... She'll say “this is for my friend, she is coming.” Then they would sit together and go outside and do everything together.”*

Caregiver of N.

## 2. IDENTITY

- *Personality*
- *Life events / habits*
- *Interests*
- *Surroundings*
- *Ethnicity*
- *Humour*
- *Grooming and appearance*
- *Religion*





# Progression of dementia

- *Relationships* (especially verbal communication) with family, staff and other residents became more difficult
- *Physical deterioration* because of other conditions as well as the dementia
- Personality seemed to change in only one case- it got better!
- Humour and interest in religion remained.
- Grooming sometimes became a challenge
- People lost interest in *activities* or the ability sustain them

# Community

*“They watch each other, and they form opinions about their behaviour and... there are judgements going on.”*

*“There are still normal things that play out. Someone might be short-tempered, someone might be tidying up, and want company, want to share a magazine; all those interactions still happen.”*

Staff members

[It is] *“sometimes nice to sit in the lounge with them, a community, they have relationships and chit chat and friendships and the comfort of being in a small group where people are familiar and the routines are familiar and on the medical side, we’re looking after them.”*

Caregiver

# To reiterate...

The important aspects of life for these people with advanced dementia were

- Relationships
- Identity

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- **Meaning:**

Important or worthwhile quality; purpose: *what is meant* by a word, text, concept, or action(life).

- **Purpose:**

The *reason* for which something is done or created or for which something (person) exists.

Where do we come from? What are we? Where are we going? Paul Gauguin





One of the limiting features of Western Christian thought is “its considerable emphasis on rationality; man’s power of reason as the distinguishing mark of humanity.”

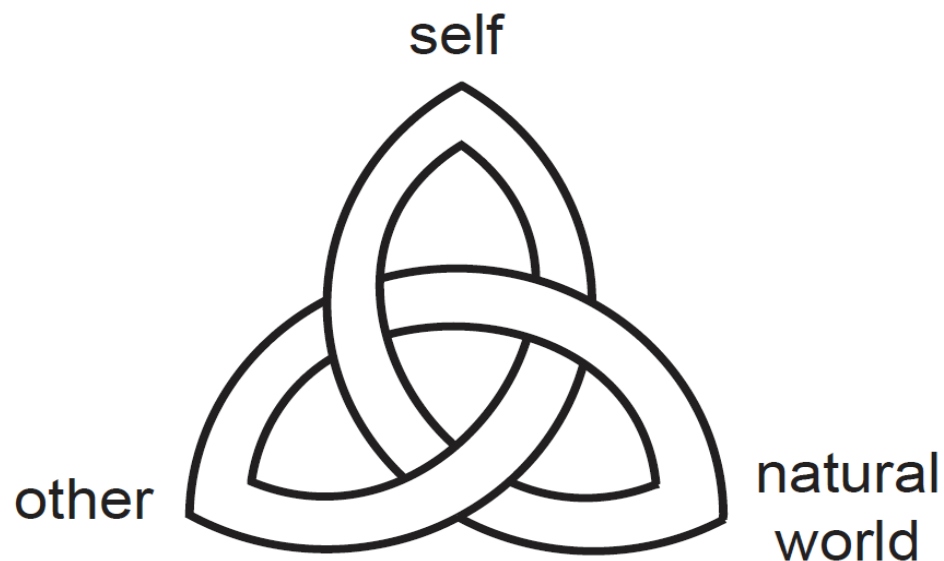
(Allen & Coleman 2006)



# The challenge of finding meaning in dementia

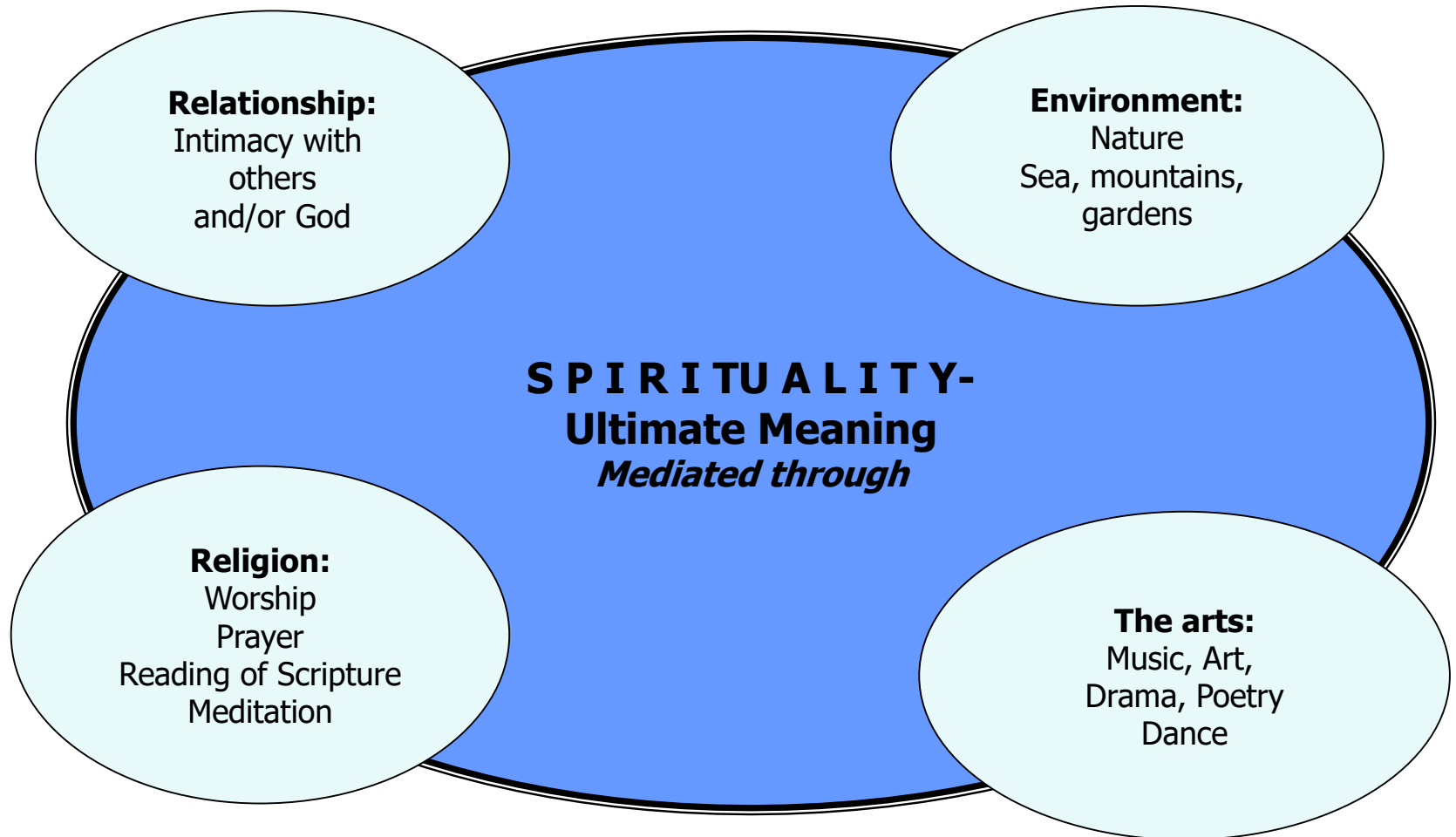
- Dementia is a disorder of cognition (thinking and reasoning)- how can someone consider the meaning and purpose of their lives if they can't *think* coherently?
- Memory is affected. How can people look back and make meaning of their lives if they have *forgotten* much of what they have done?
- How can people who *live in the present* have purpose (which is future orientated)?

# A better way to see spirituality in dementia?



Spirituality as connection-A. Holmes (2010)

*“people with dementia have to be understood in terms of relationships, not because that is all that is left to them, but this is characteristic of all our lives.”*

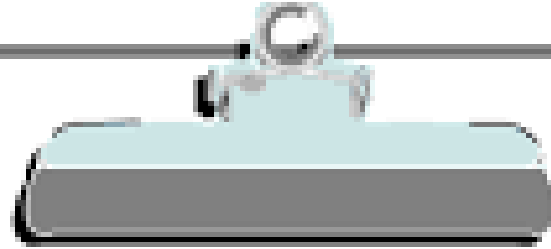


# Ways we access spirituality for ourselves

1. Relationship (connectedness)
2. Arts
3. Nature
4. Religion
- 5. PLACE**

What NZ participants in ageing and spirituality workshops said about accessing spirituality

(Perkins, 2010)



Turangawaewae is a place that we are connected to, that empowers us to stand tall, feel proud and know we belong.



# Turangawaewae: at the heart of spirituality in dementia?



Even when we forget, we are remembered.

We keep our place in the world, in its history and geography. We have our spot in the present between our ancestors who go before us and our descendants who come after us.

We are held in place by our families, our carers, our communities and our country.

We can never lose our place.

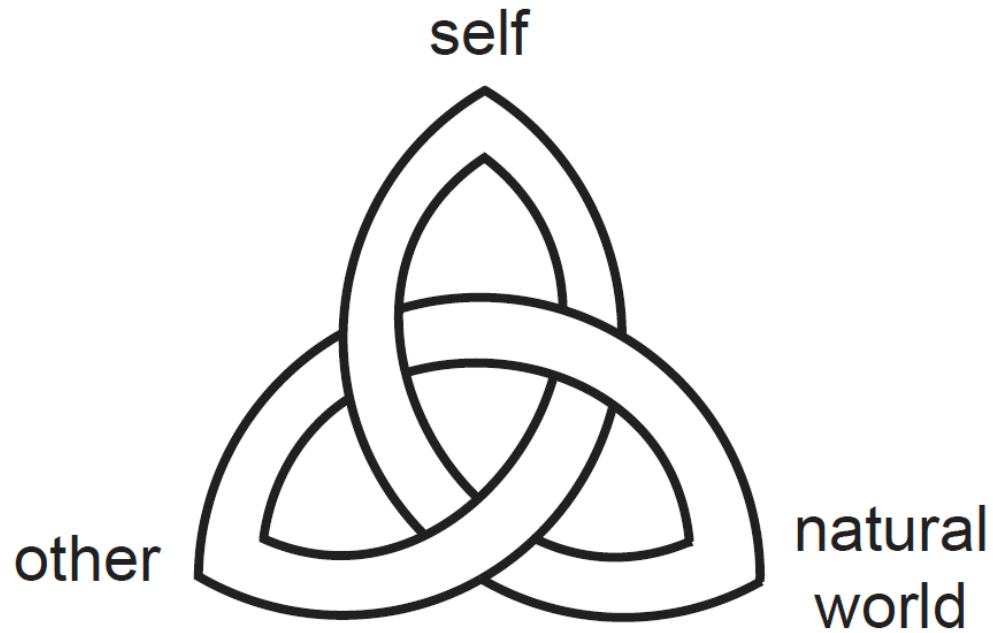


# Spirituality in dementia: what can we do?

Uphold identity:

- *Personality*
- *Life events / habits*
- *Interests*
- *Surroundings*
- *Ethnicity*
- *Humour*
- *Grooming and appearance*
- *Religion*

# Maintain connectedness



# A place to stand

Where people feel  
connected and  
empowered to stand tall,  
feel proud and know they  
belong



# What can we do?

- Balance concerns about risk and safety with the importance of retaining the person's identity. (Consider the risk of eroding the person's identity)
- Balance drive for economy with person's individual needs. (How to do this? More staff? Volunteers? Working differently?)
- Reconsider institutionalised patterns of care. Does it have to be like this?

# Person-centred care: psycho-social needs in dementia



Spiritual as well?

# Questions and comments



The concept of spirituality is about core meaning and connectedness, and it is from this that we respond to all of life. We propose a third view that sees ageing as a “spiritual journey”, with challenges that continue across the later years of life. This is a journey that searches to find meaning in one’s life and, therefore, reason for continued life and hope. Essential elements of spirituality seem to revolve around a relationship with self, others and God, a sense of meaning and purpose, hope, connectedness and beliefs.[7](#)

“I have become very spiritual of late, which I suppose is a natural tendency when one comes face to face with the end of life, or at least the end of life as one knows it” (Lee, 2003, p.71).

Jeanne Lee's personal account of being diagnosed and living with Alzheimer's Disease



# Identity and belonging at Seadrome.

- After lunch each day, a Maori woman would push the tables against the wall. The staff found out that this was because that was the way it was in a Marae..... in time, everyone else started to do the same
- This raised questions for Tina and her partner Pat as to what they could do to make Seadrome more culturally friendly

# Kelston Girls College

- 14 Maori girls came to Seadrome from 1100-1500 on a Wednesdays and did what you'd expect of Maori girls in a residential care setting.....
- Word got out
- Maori families came and took an interest
- And it continued.....Boy the movie...

# Food, music.....

- At Seadrome, they will have a hangi (traditional recipes) and the appropriate cultural inclusions- Waiata, prayers etc
- These events are for Maori only
- Some Maori with dementia can talk ok, others cannot. When it comes time for someone to talk who cannot, they sing a Waiata
- Seadrome sees Maori as a blue print for others...they have a powhiri for all new guests