

# END OF LIFE ISSUES FOR OLDER PEOPLE: *FROM THE STATISTICAL TO THE ESOTERIC*

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Albany

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# Summary

- Older people dying in NZ
- Palliative and end-of-life arrangements
- Holistic care
- The psychologist's job

# Top 10 causes of death for NZers >65:

- heart disease
- cancer
- respiratory
- endocrine
- mental\* - 2300 NZers die p.a. from Alzheimer's disease
- digestive
- nervous
- unintentional injury
- genitourinary
- musculoskeletal (IPRU Otago University)

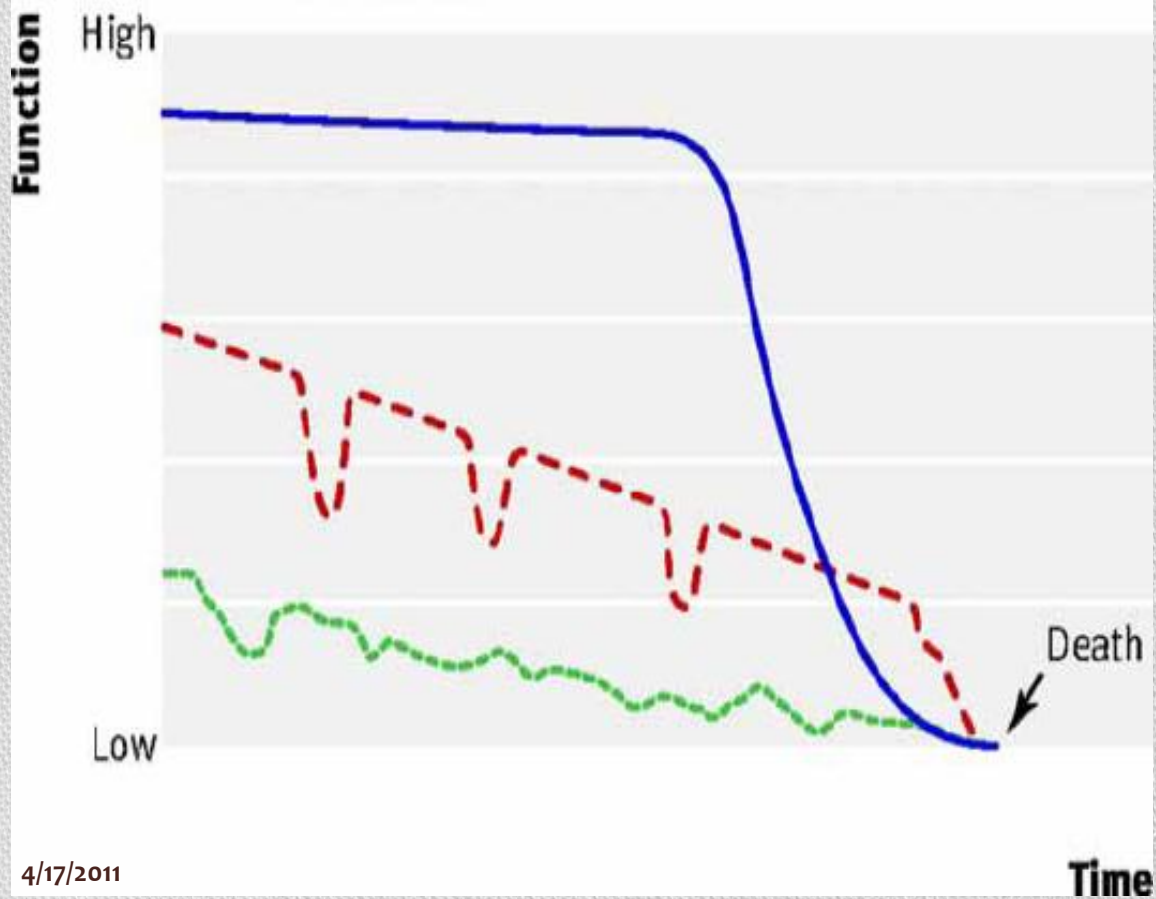
# World-wide

Chronic diseases such as heart failure, stroke, cancer, chronic respiratory diseases and dementia are the leading causes of mortality across the world, representing 60% of all deaths and 43% of the global burden of disease.

(M. Gott 2011 Presentation to postgraduate students Auckland University)

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

- Cancer (n=5)
- - - Organ failure (n=6)
- · - · - Physical and cognitive frailty (n=7)
- Other (n=2)



# Prognosis of frailty

- symptomatic long term disease
  - decline in function
  - abbreviated survival
- coexisting needs
  - medical
  - social
  - psychological
  - spiritual
- discussion about
  - goals of care
    - Advanced Care Planning

# Where NZers die (MOH in Press per Gott, M. 2011)

- 34% hospital
- 31% residential care
- 22% private residence
- 6% hospice
- 7% other

# Dying at home

- In US 90% prefer to die at home but despite this, 60-80% die in institutional settings (Lyness 2004)
- By 2030 only 1:10 (in NZ) will die at home (MOH in press)
  - Family away and tendency to institutionalisation
- Can't assume death at home is the preferred option e.g. don't want to be alone, concern about carer burden or don't want family doing intimate cares
- In UK 20,000-50,000 people die annually of cold-related illness (Gott, M. 2011)
- Also, what is home? Especially when hospital technology and personnel come in to make it possible to care for someone (See Hale, B. 2010)

# Palliative care

“...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of **early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.**”

(WHO 2002)

# Palliative care (WHO):

- provides *relief from pain and other distressing symptoms*;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- *integrates the psychological and spiritual* aspects of patient care;
- *offers a support system* to help patients live as actively as possible until death; *offers a support system to help the family cope* during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including *bereavement counselling*, if indicated;
- *will enhance quality of life*, and may also positively influence the course of illness;
- is applicable *early in the course of illness*, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and *manage distressing clinical complications*

## A palliative *approach*:

- “... an integral part of **standard clinical practice** by any health professional who is not part of a specialist palliative care team.”

(MOH 2009 iv)

- the goal being to effectively manage symptoms of disease, promoting comfort and function while addressing psychological, spiritual and social needs

(p.37 Australian Palliative care guidelines for ARCF)

# *Specialist palliative care*

- *Provision of specialist palliative care* i.e. a palliative care team, hospice, clinicians with specialist palliative care training.

# End-of-life care

*End-of-life or terminal care:* Last few days or weeks of life *Liverpool Care Pathway ...* provides a holistic and planned approach

[www.lcpnz.org.nz](http://www.lcpnz.org.nz)

# Liverpool Care Pathway

(Ellershaw & Wilkinson 2003)

“The LCP is an evidence-based, integrated care pathway ... to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best practice care to dying patients and their families/whânau in *the last days and hours of life*, irrespective of diagnosis or care setting.

The eighteen 'goals of care' in the LCP are measurable and facilitate audit and benchmarking of end-of-life care.”

# Some goals of care - e.g...

- Goal 3.1: The patient is given the opportunity to discuss what is important to them at this time e.g. their wishes, feelings, faith, beliefs, values.
- Goal 4.1: The patient has medication prescribed on a 'prn' basis for all of the following 5 symptoms which may develop in the last hours or days of life.

Achieved? Variance?

# Issues in palliative care of older people

- Hospices more focused on younger / middle-aged people, mainly cancer patients.
- OP have reduced access to services e.g. in UK if aged >85 3X less likely to receive in-patient hospice care than people <85 (Addington-Hall et al 1998).
- OP near end of life seen as drain on hospital resources (great efforts made to keep them out of acute hospitals- they might benefit from admission)
- Poor treatment in hospital
- Geriatric services have focus on “positive ageing” and ignore inevitability of dying

# Issues in residential care

- Death is a common part of ARC life and staff often feel that they are experts in terminal care of very old people (they may be). They can be reluctant to call in additional help such as the specialized palliative care team (Phillips 2006).
- The Auckland District Health Board Draft Palliative Care Strategy notes hostility from some ARC staff to palliative care teams. (ADHB 2009)
- Hospice care seen to be aimed at symptom relief- not care of the whole person
- Neglect of residential care by (psycho)geriatric services
- Terminal care of older people usually left to GPs who have variable expertise and may not be readily available

# GPs and residential aged care

“Where locum services are the only medical resource for palliative care patients in the community – at home or in residential care – there is a high likelihood that carers will choose to send the person to hospital” (ADHBDPCS Sec.3.7).

This is not just a local problem. Phillips et al (2006) report problems with GPs unable to provide timely treatment.

They write of doctors

- “missing in action” in ARC,
- uninterested in older people’s needs, and
- unaware of the availability and usefulness of palliative teams.

# Dying in residential care

- Currently ARCFs have no financial incentive to keep acutely unwell or dying older people at home as this would require additional nursing staff and payment for extra GP visits.
- One of the advantages of the LCP is that appropriate medication is prescribed in advance and can be given as necessary by nursing staff without calling in a doctor (Taylor & Randall 2007).

# Your role?

Palliative care:

**“standard clinical practice”**

Holistic care:

**“early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”**

# Holistic care

You don't have to *provide* all the care, but you need to

- recognise symptoms- physical, social, spiritual
- know who to refer to for symptom relief
- maybe advocate for proper assessment and treatment

The presence of symptoms may make psychological intervention impossible or require modification of your approach

## e.g. symptoms...

- 96% of non-cancer patients >65 were distressed by pain in the last 3 months of life; only 28% had pain relieved some or all of the time (Burt et al 2010)
- 542 people >60 with advanced heart failure. Over half experienced breathlessness and/or fatigue daily. One third showed evidence of depression (Gott et al 2006)
- Delirium
- Dementia

# Prognosis

- Don't assume that because you know they are dying that they do
- Prognosis is often not specifically discussed- many GPs find it too hard– especially true of heart failure and COPD (in cancer, patients assume the worst)
- Health professionals over-estimate how much people understand about their illness and prognosis
- Some people want to discuss prognosis, some want to ignore it
- Not understanding prognosis may be the reason they want to go to hospital every time symptoms get worse- they don't know they are dying

(M. Gott 24.3.11)

And sometimes others specifically try to keep the truth from the patient-

“What tortured Ivan Illich most was the pretence, the lie- which for some reason they all kept up- that he was merely ill and not dying, and he need only stay quiet and carry out the doctor’s orders and then some great change for the better would result”

Tolstoy- The Death of Ivan Illich

## And a modern version-

“I know that something's up, I mean they used to be checking my blood pressure and temperature and taking blood samples and doing all sorts of tests. Now they do nothing and during the ward round they look at me and smile and say nowt, oh I know what's going on alright.” (Costello 2001 p.64)

# Who gets referred?

- Possibly depressed
- Excessive symptoms e.g. breathlessness ?panic, pain
- Recurrent ED visits
- Not following instructions, treatment refusal
- Capacity issues
- + PWD and BPSD who are dying
- Delirious, paranormal phenomena, ?psychosis
- Others?

“People die the way they live”

Anon.

# “The inner journey” (Barbato 2002)

- **Fear:** Dying is very scary; human contact and trust give courage. Be there, listen, be honest.
- **Depression:** tolerate tears, including your own
- **Guilt:** and shame- need someone to trust with confessions
- **Hope :** small hopes replace the big one
- **Denial:** all use this to some degree- varies
- **Anger:** the closer you are, the more likely the target – often misdirected
- **Joy:** moments of “joy, happiness, awe, excitement, wonder” Don’t forget to laugh

# Approaches (Lo et al 2002)

- Ask open-ended questions / ask patient to say more
- Acknowledge and normalise the patient's concerns
- Use empathic comments
- Ask about patient's emotions
- Use "wish" statements
- Clarify the patient's concerns, beliefs and needs and follow hints about spiritual or religious issues
- Identify common goals for care and reach agreement on clinical decisions
- Mobilize sources of support for the patient

# Tips (for visitors, Barbato 2002)

- Listening is more important than speaking
- Be aware of how you feel
- Body language--eye contact, come near, touch
- Be real and authentic
- Don't be afraid of silences
- If you say something you wish you had not, say so.
- Avoid false claims, such as “you look better...”
- Relate to the person as you have in the past.

“ ...the pauses between the notes– ah there is where the artistry lies”

Artur Schnabel

“Don’t just do something. Sit there”

# Dementia: challenges at the end of life

- communication problems
  - expressing symptoms e.g pain restlessness agitation
  - understanding prognosis
- delirium
  - hypoxia dehydration infection
  - retention constipation restraints
  - pain drugs
- medications
  - more susceptible to SE and toxicity
  - start low go slow
  - administration

# Barriers to support of dying people (Yalom 2008)

- Deny presence or relevance of death anxiety especially in older people
- Claim it is anxiety about something else something we have more control over
- Feel perplexed or despairing about mortality
- Risk of igniting our own pain/ fears

# Feeling their pain-

“Your pain is the breaking of the shell  
that encloses your understanding”

Kahlil Gibran *The Prophet*

**Death as our failure- “nothing more we can do...”**

**“At the heart of modern medicine is a conflict about the place and meaning of death in human life”** Daniel Callahan

Health system is oriented towards cure, may overlook need for care- forget that good death is as important.

# Barriers to support of dying people by health professionals

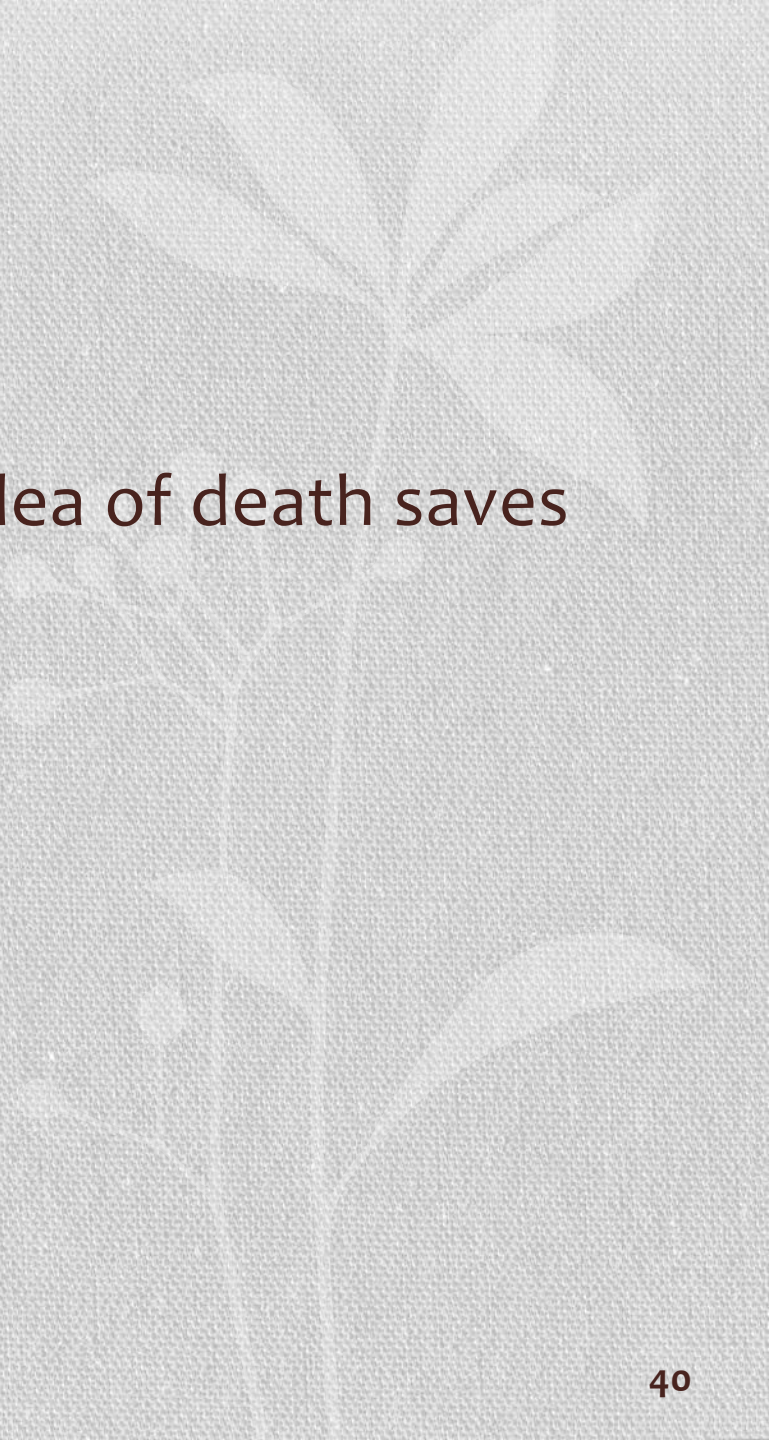
- Fear of causing / aggravating distress → premature reassurance How much do they know? What do they think is happening? How can we possibly reassure them?
- Belief you lack expertise
- Perceived lack of time (? Outcome measure)- this is not about 6-8 sessions of CBT
- Going beyond the physician's expertise and role or imposing the physician's religious beliefs on the patient (Lo et al 2002, p. 751)

- “How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole- a litmus test for health and social care services”

End of Life Care Strategy Department of Health UK. July 2008

# Stages of death acceptance (Yalom 2008)

- *Staring at the sun*: stage of initial awakening. Confrontation- “death awareness may serve as an awakening experience, a profoundly useful catalyst for life changes.” (p.30)
- *Walking towards the sun*: Exploration of various pathways for meaningful living. Awareness of our finitude gives us a greater sense of urgency and focus on what really matters.
- *Gazing into the sunset*: Getting ready for the final exit. Can now stare death in the face without regret and fear



“Death destroys a man, but the idea of death saves him.”

E.M. Forster 1910 (p 171)

# Summary

- Older people die of chronic illnesses,
- Neither palliative nor geriatric services are well-equipped to care for dying older people
- Holistic care is the responsibility of all health professionals
- Even at the end- psychologists can help

“ you can be absolutely brilliant without knowing what is going on.”

Woody Allen

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- Palliative care in dementia is recommended in the UK (National Council for Palliative Care 2008) and elsewhere (MacPhee & Bickell 2007). Some local palliative care teams actively assist in the management of advanced dementia. Most residents of ARCFs have some cognitive impairment- only 32% of residents in Boyd et al's study (2009) had no noticeable memory defect and only 37% were orientated to time. Provision of good palliative care in dementia is vital in ARCFs.

# Where people die

- Proportion of older New Zealanders dying in ARC? Of all deaths in April 2006, 32% were in residential care (MOH figures accessed 2010). This compares with 18% in the UK and 24% the USA (Phillips et al 2006) but includes people under 65.
- In Auckland, 12.4% people stayed in ARC less than 3 months and 35% less than 1 year (Boyd et al 2009). Presumably death ended their stay. The average length of stay in ARC is now 2.5 years, down from 3.0 years in 1998 (Boyd et al 2009).
- 28% of people over 85 live in ARC (Kiata et al 2005).

## The NZ Palliative Care Strategy (2001)

“affirms life and regards dying as a normal process and aims neither to hasten nor to postpone death”.

- A needs-based approach that provides care for *all* people with life-limiting illnesses, based on the person rather than the disease is recommended (Murtagh et al., 2004, Hudson & O'Connor 2007). The ADHBDPCS notes “good palliative care is based on need rather than diagnosis” (1.2.2) and is delivered along the disease trajectory (ADHB p.25). The authors also note that symptoms for cancer and non-cancer patients can be similar.

- The *New Zealand Palliative Care Strategy* (MOH 2001) calls for total and active care across the continuum of illness. It emphasises Maori constructions of self and wellbeing aiming to integrate physical (tinana), social (whanau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whanau to attain an acceptable quality of life. This is the *whare tapa wha* model. Durie (1998) describes the four-sided house of health. All four walls, physical, mental, family/social and spiritual must be in place for optimal wellbeing.

- Different cultures think differently about death. A colleague talking to older rural Maori about palliative care was told “we don’t do end-of-life; our wairua (spirit) carries on.” She suspects that for Maori acceptance of death comes too readily, resulting in premature and unnecessarily distressing deaths. (Williams, 2010).

- “We need to re-evaluate the way we provide care. In particular, we need to acknowledge that many residents are close to the end of their lives, and better support for those people and their families through proper end-of-life planning.”

(Editor NZ Nursing Journal 2010)

- “Residential care settings are dependent on the declining general practice workforce for timely assessment and treatment of medical events, and transfer to acute hospitals often occurs unnecessarily. Such transfer is a huge physical and psychological disruption for an elderly person and the admission and subsequent care increase the burden on strained hospital services” (Carryer, 2006).

# Positive existential therapy

- “instinctual aversion toward death– the spoiler of all things we hold dear and the terminator of all our dreams and aspirations.”
- “The problem with death denial is that it is doomed to fail”
- The main objective is to reduce death anxiety by confronting death, which may result in positive life change
- Awaken sense of meaning and responsibility , because such awakening will embolden and enrich our lives, no matter what.

( Wong 2009)

“ Everyone is destined to experience both the exhilaration of life and the fear of mortality.”