TASMANIAN HEALTH SERVICE

SPECIALIST PALLIATIVE CARE SERVICE

UTAS

FACULTY OF HEALTH SCIENCE

School of Medicine

Death, dying, loss and grief: why is it so difficult?

Professor Michael Ashby

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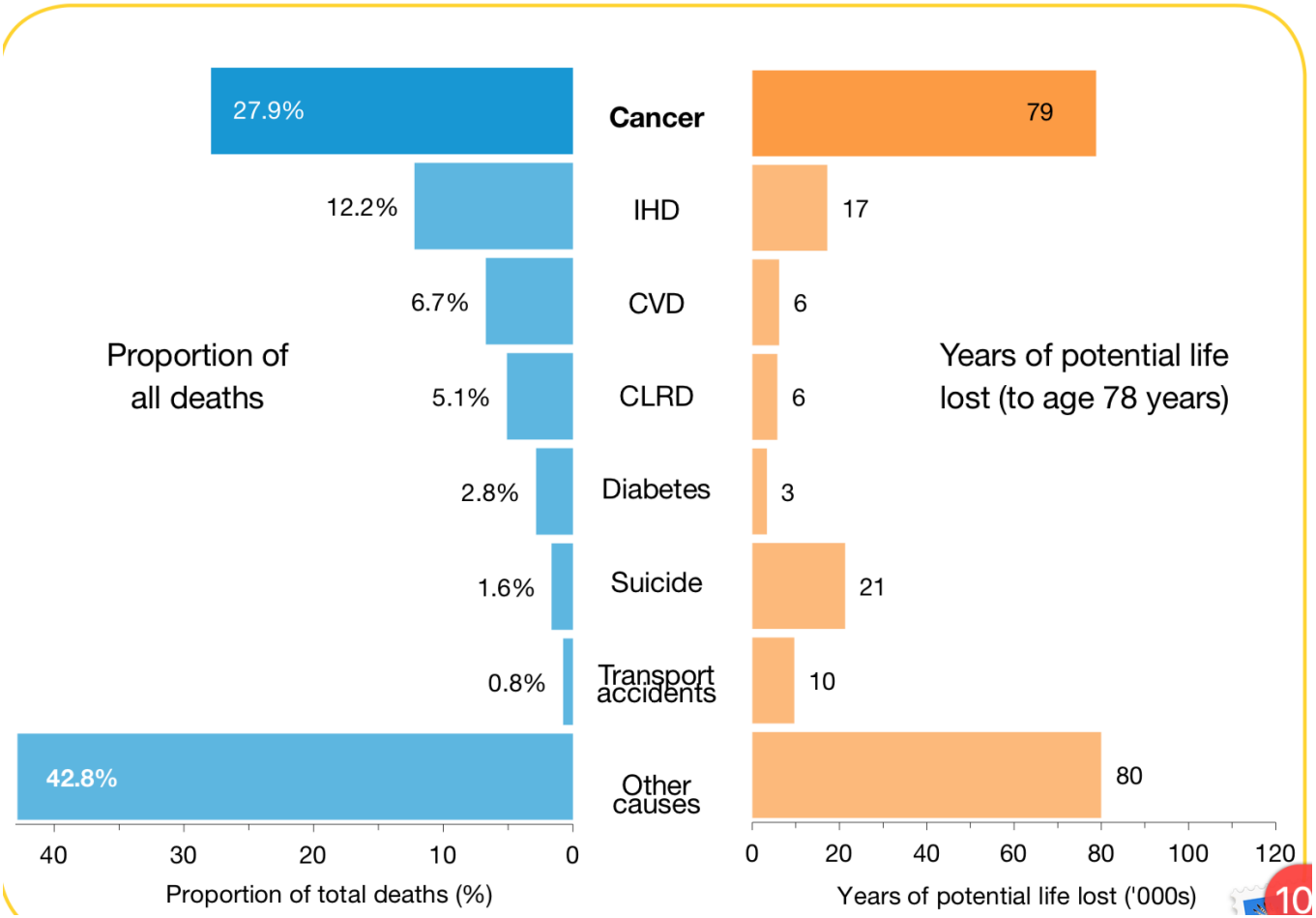
Social Workers

- “Make things happen”!

MA

- Clinical Director
  Cancer, Chronic Disease & Sub-Acute Care Stream | THS-South
- Palliative Care Specialist |Royal Hobart Hospital & Repatriation Centre
- Professor of Medical Ethics and Death Studies School of Medicine, University of Tasmania
- Joint Editor-in-Chief | Journal of Bioethical Enquiry
- Member of Board, ACGB
- Trained in Clinical (Radiation) Oncology in UK, France and Australia
- Start ups and leadership roles in Palliative Medicine: Adelaide, Monash and Melbourne Universities since 1989
- Hobart since 2007

Cancer Council Vic 2016



Main messages

- Most of us don't want to die, and our society prefers positivity
- It is natural to avoid death and dying, and not to prepare for it
- We also have a dark fascination with it, and sometimes welcome it!
- Given the nature of the journeys we face as an ageing population, planning and social action are a good idea
- Specialist palliative care is necessary, so is health promotion focused on death, dying, loss and grief
- Hospice/palliative care can be seen as a social movement (Weber)
- Medical and nursing care are essential but should not overtake the social, spiritual and emotional dimensions of living and dying
- Death and dying is everybody's business: our community and the health sector need to be supported and empowered to play their part in palliative care

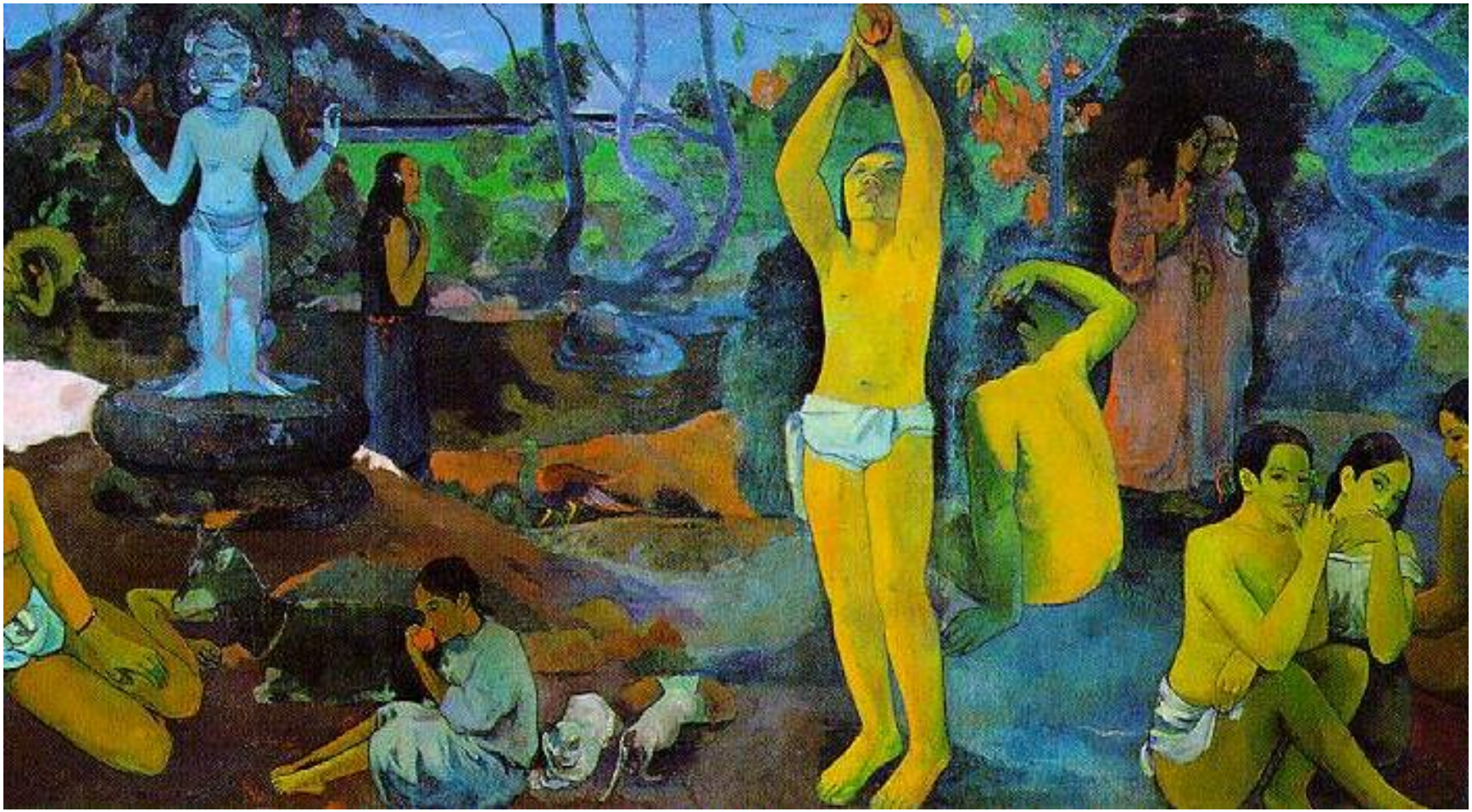
Barriers to improvement of decision-making and care at the end of life

- Not primarily medical
- Arise from social, ethical, religious and political considerations of death and dying
- Deeply embedded in history, culture and politics

Features of modern societies that may generate death denial

- Emphasis on achievement of human potential and individualism
- Geared to success, happiness and achievement
- Positive thinking approach to life
- Talk of death or loss seen as ‘negative’
- Long lives and high expectations
- Doing rather than being
- Decline of formal religion

Paul Gauguin: D'où Venons Nous / Que Sommes Nous / Où Allons Nous? 1897

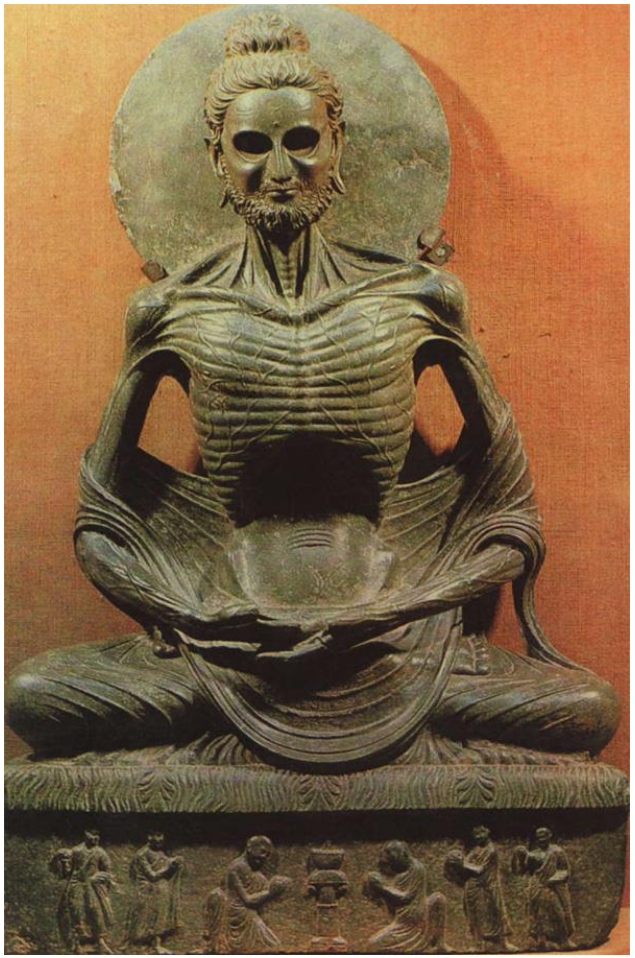


Existential questions

- Meaning and purpose of life
- Bonds and relationships
- Regrets
- Afterlife: religious, spiritual, reincarnation, electronic
- Fate of the body
- Nature of funerals and memorials
- Legacy

10. Hans Holbein the younger, *Sir Brian Tuke*, oil on canvas.

Momento mori



Francois Mitterand (1916-1996)

- Diagnosed with prostate cancer soon after election to his first 7 year term of president of France: for 14 years press never broke the story
- Opened first 1990 EAPC meeting in Paris
- Confided to Marie de Hennezel: "We are all aboard an aeroplane which will end up one day by crashing into a mountain. Most of the passengers forget this fact. I think about it every day, but perhaps this is because I am beginning to see the mountain out of the window."

Introduction of ‘La Mort Intime’

- "Never before has our relationship with death been so impoverished as in these times of spiritual aridity, when men are so eager to exist that they evade the mystery of death. Is there not a portion of eternity in man, something which death brings to birth. . . elsewhere?”
- http://archive.thetablet.co.uk/article/13th-january-1996/4/francois-mitterrand-an-agnostic-mystic

Three attitudinal barriers to deployment of palliative care

- You cannot initiate talk of death as patients and families do not want this and you run the risk of precipitating it if you do (“don’t talk about death it will kill him”).
- You have to do everything to maintain and prolong life otherwise you are causing death (“you can never give up on a patient”).
- Use of opioids and sedatives in palliative care can contribute to the cause of death

Daniel Callahan

‘Medicine can give us a longer life and a slower death. It can also keep us alive when we might be better off dead’

MJA 2005;183: 230-1

“We cannot control the fact of death, but we can have some influence on the manner of our dying. Medicine can make a wonderful contribution to quality of life until death; and it can make it miserable. This choice is ours.”

Ashby, Kellehear and Stoffell.

Three Rubicons of death (unless sudden)

1. The childhood realisation that “I” die (around 9, loss of childhood ‘innocence’)
2. Diagnosis of fatal condition (or first relapse)
3. Last days of life: point of no return, you would die even if the condition could be miraculously cured

49 BC, Julius Caesar crosses the river back into Italy and thus violates the law of imperium: *ālea iacta est*

Murray-Parkes

“ one of the main differences between man and other species is our cognitive ability to recognise that we shall die. This has not prevented most cultures and individuals from finding ways to disbelieve it.” Colin Murray-Parkes

Terror Management Theory

- Social psychology construct
- Psychological conflict between self preservation instinct and knowledge that death is inevitable,
- This conflict generates terror
- Managed by cultural values or symbolic systems that provide life with meaning and value
- Sheldon Solomon, Skidmore College, NY
- https://www.skidmore.edu/psychology/faculty/solomon.php

THE SHADOW SIDE

- Fascination with death and violence (Eg TV crime and murder stories, forensic pathology)
- Self destructive impulses and behaviours
- Death tourism
- Desire for death
- Vicarious grief
- Eros and thanatos tension, see MONA imagery

Pain ‘pathways’

- Import pain of clients into ourselves
- Add and conflate it with our own ‘baggage’
- Transmit and recycle it within our teams and organisations
- Circuit overload
- Pandora’s Box of troubles
- Ventilation, processing and evacuation
- Supervision
- Survivor guilt: thank God it is not me (but it will be one day)
- Plumber: water always finds its own level

Death now

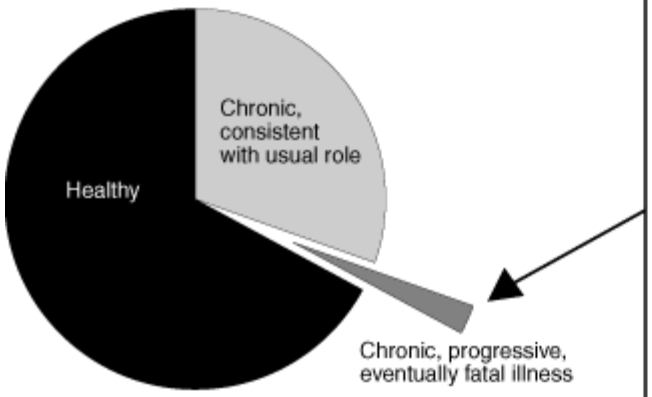
- It is new territory for human beings to have such long life expectation, and such good quality of life
- This new demographic longevity is associated with strong individualism and lessening of social bonds, and a culture of death avoidance
- Absence of a social ‘space’ for ageing and dying as natural processes, ‘healthy’ ageing always presented in a positivistic framing
- However, no halcyon days when all was well and easy: mortality is and will remain the ultimate challenge: we cannot go back to the future

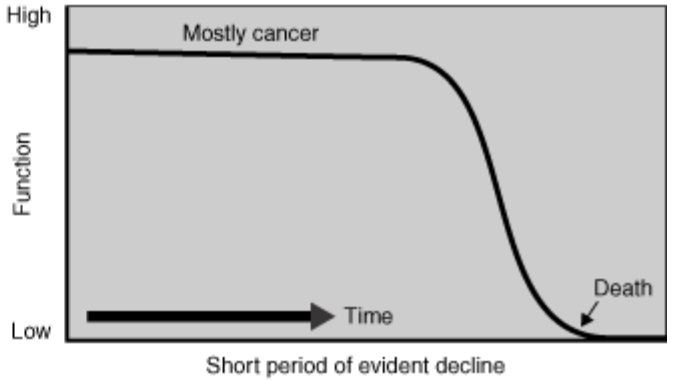
Pathways to death

- Most of us living longer, but taking longer to die
- Up to two years at the end of life with:
  - Physical deterioration and disability
  - Increasing symptom burden
  - Increasing dependence
- Dementia incidence rising dramatically (3rd commonest cause of death and 140% rise in certifications in a decade, (those who lack capacity get more ‘aggressive’ treatment)
- More decision points (few ‘zero’ options)

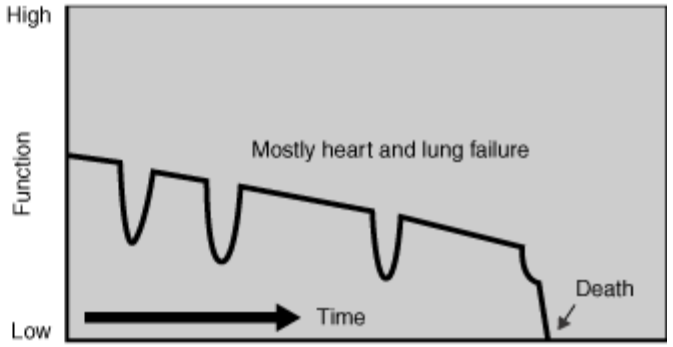
Source : J Lynn, D M Adamson. RAND Health White Paper: Living Well at the End of Life. 2003

Illness trajectories

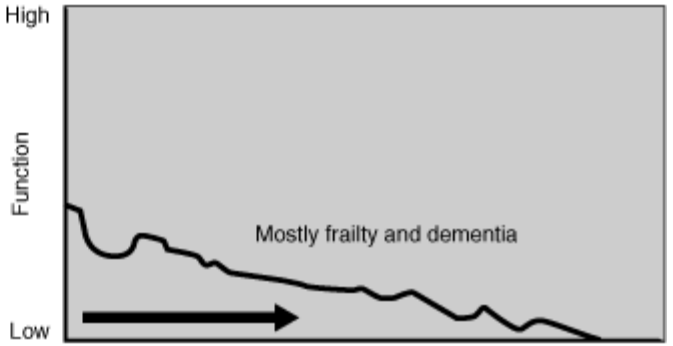




Short period of evident decline



Long-term limitations with intermittent serious episodes



Prolonged dwindling

Adapted from: Lynn J, Adamson DM. Living well at the end of life; adapting health care to serious chronic illness in old age. Arlington, VA, Rand Health, 2003

Dementia as fatal process

Bioethical Inquiry (2019) 16:143–146
https://doi.org/10.1007/s11673-019-09921-5

EDITORIAL

Dementia: Unwelcome change has arrived and we are not ready!

Michael Ashby

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Dementia has crept up on us, rather like D.W. Winnicott's idea of the unwelcome change that we dread in the future, not realizing that it has already happened. Our own ageing is something we only see when it has arrived, through a veil of denial, as the artist Lucien Freud found when he said that he looked in the mirror every morning, misinterpreted the information that he received, and that is where his troubles started. As we age our body demands our attention, as the ego, will and life forces on one hand, and our physical capacity on the other, are increasingly mismatched. The darker side of cognitive decline has moved from being the butt of jokes around a bit of "senile" memory loss, to being one of the major challenges of the new century: a downside of (mostly) welcomed greater collective longevity than ever before in human history, bringing with it, the sting in the tail, the "epidemic" of dementia. According to the World Health Organisation, more than 50 million people now live with dementia worldwide – nearly 60% of whom live in low and middle income countries – and every year there are nearly ten million new cases[1]. Coming from nowhere in the charts of death causation, dementia is now either the leading contributory cause of death, or close to it. Far more than memory loss, it is actually a remorseless process of global physical and mental decline that can cause death in its own right.. Deaths due to dementia worldwide more than doubled between 2000 and 2016, making it the fifth leading cause of all global deaths in 2016 (compared to 14th in 2000) (World Health Organisation 2018). In some higher income countries it has become a leading cause of death. In Australia, for example, deaths from the leading cause, heart disease, have decreased over the past decade, while numbers of deaths from dementia, now the second leading cause of death, have increased by 68% (Australian Bureau of Statistics 2018). It is the leading cause of death for Australian women. Being played out over years, and often unrecognized for several in the early stages, dementia is making enormous demands on patients, families, carers, health systems, and entire societies (for good information, for example in the Australian context, see https://www.utas.edu.au/wicking). The ceiling of future care demand is not known, but the 'area

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[1] The World Health Organisation has a range of informat
resources on dementia, see https://www.who.int/st
health/neurology/dementia/en/

Dementia global challenge

- 5th commonest cause of death (WHO, 14th in 2000)
- Second commonest cause in Australia, first for women
- 68% increase documented by ABS (time frame?)

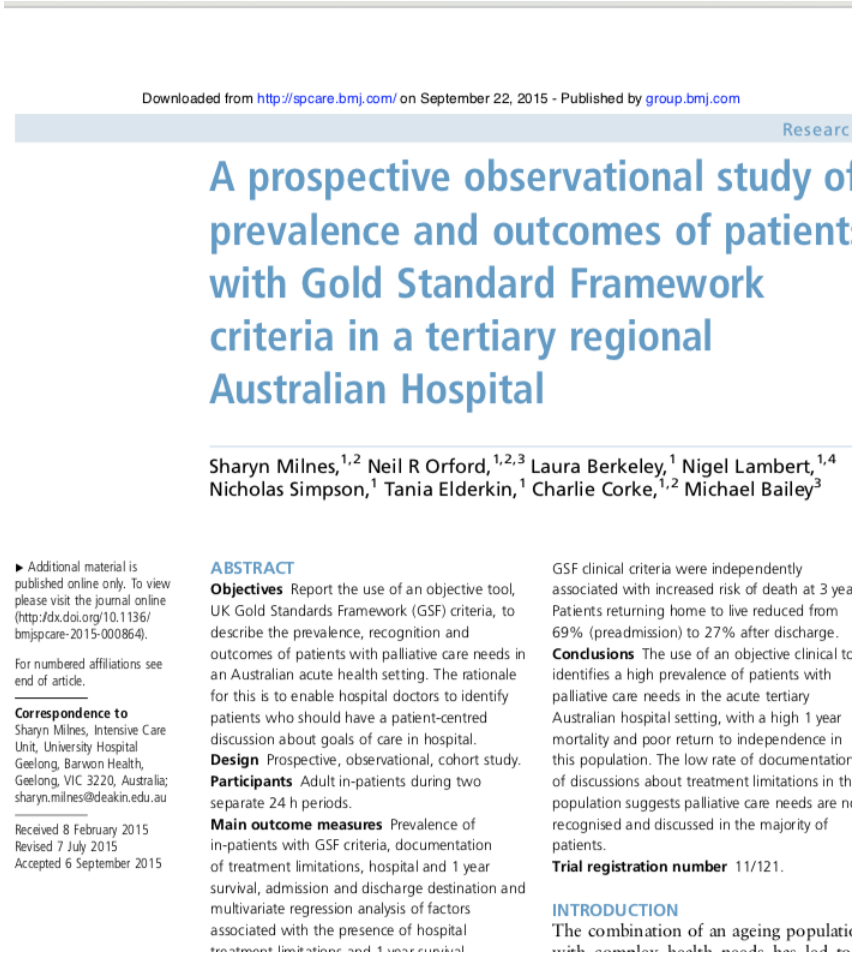
Frailty of old age

- Muscle wasting
- Neural degeneration: cerebellum and balance
- Falls
- Hip fractures
- Will falls and hip fracture become leading cause of death in the future?
- Hip your Achilles heel not your heart?!
- Falls are a marker of global decline rather than an accident (ACHS please note!)
- Liberty v safety
- Careful but adequate sedation IS needed for behaviour management, especially as death approaches

The Hospital

- Repository of our collective fear of death: the true ‘Pandora’s Box’
- We want life saving treatments for reversible injury and illness
- Ethics and technical capacity drives medical intervention and ‘omnipotence’
- Difficulty of responding to dying

GSF Study Geelong



A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian Hospital

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For numbered affiliations see end of article.

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ABSTRACT

Objectives Report the use of an objective tool, UK Gold Standards Framework (GSF) criteria, to describe the prevalence, recognition and outcomes of patients with palliative care needs in an Australian acute health setting. The rationale for this is to enable hospital doctors to identify patients who should have a patient-centred discussion about goals of care in hospital.

Design Prospective, observational, cohort study.

Participants Adult in-patients during two separate 24 h periods.

Main outcome measures Prevalence of in-patients with GSF criteria, documentation of treatment limitations, hospital and 1 year survival, admission and discharge destination and multivariate regression analysis of factors associated with the presence of hospital

GSF clinical criteria were independently associated with increased risk of death at 3 yea Patients returning home to live reduced from 69% (preadmission) to 27% after discharge.

Conclusions The use of an objective clinical tc identifies a high prevalence of patients with palliative care needs in the acute tertiary Australian hospital setting, with a high 1 year mortality and poor return to independence in this population. The low rate of documentatior of discussions about treatment limitations in th population suggests palliative care needs are n recognised and discussed in the majority of patients.

Trial registration number 11/121.

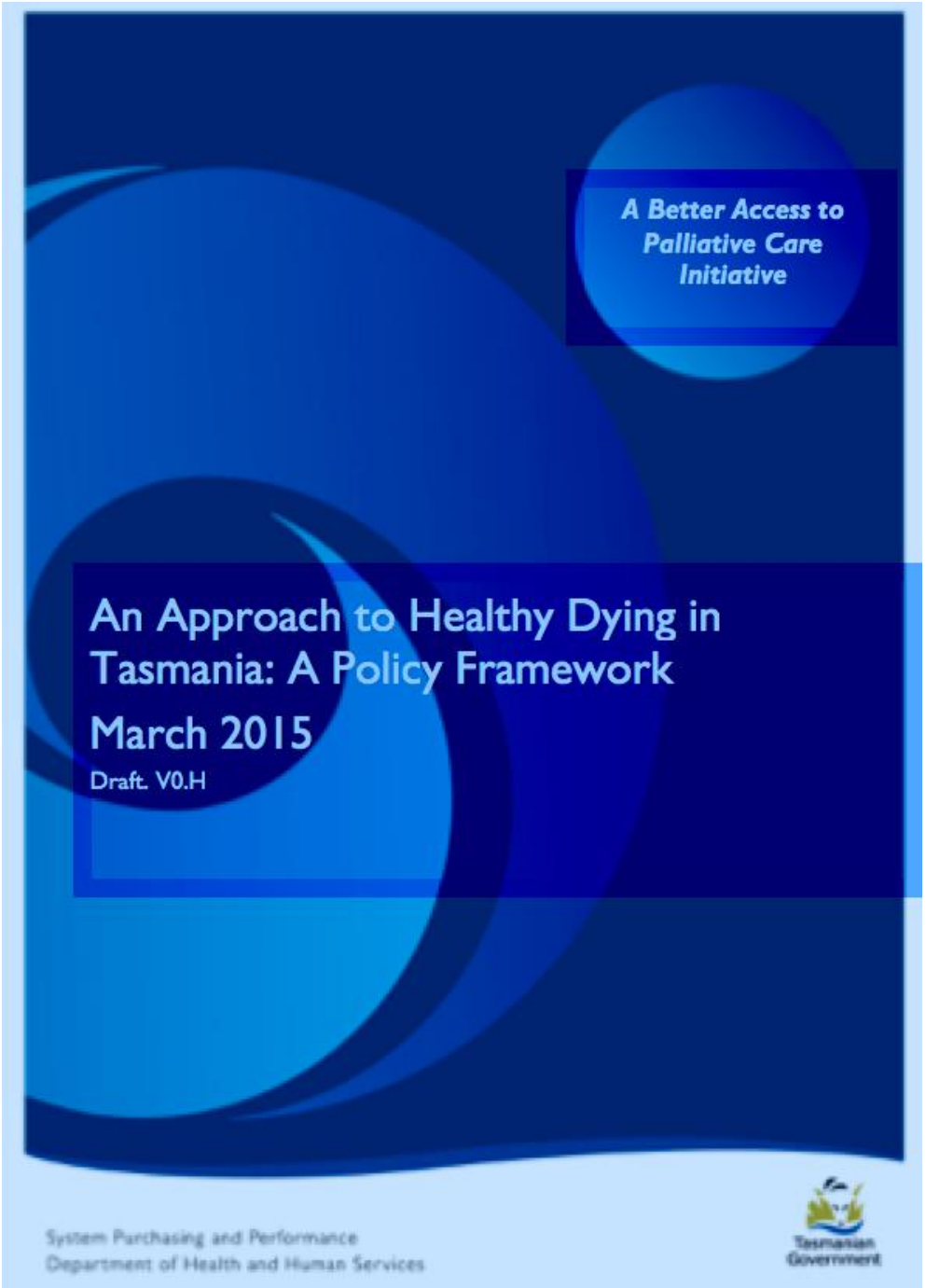
INTRODUCTION

The combination of an ageing populatic

- 27% meet at least one of the GSF criteria
- Frailty, organ failure, nursing home origin
- 50% dead at one year
- 70% dead at 3 years

Communication about dying

- Find out what assessment patient/family make of their situation, never start by information giving
- Open questions
- How do you see the future?
- What are your hopes/fears?
- Fight and Flight: learning shut down
- Non-linear: oscillation (Dual Process Model, Stroebe and Schut, 1995)
- That which patients cannot tell us, they make us feel (Michael Carroll)


A Better Access to Palliative Care Initiative
An Approach to Healthy Dying in Tasmania: A Policy Framework
March 2015
Draft. V0.H
System Purchasing and Performance
Department of Health and Human Services
Tasmanian Government

Goals of Health-Promoting Palliative Care

- Provide education & information for health, death & dying
- Provide both personal & social supports
- Encourage interpersonal reorientation towards a ‘natural’ death
- Encourage reorientation of palliative care services towards public health ideas of prevention, harm reduction & community participation
- Combat death-denying health policies & attitudes

(See Kellehear A. Health Promoting Palliative Care, Melbourne: OUP, 1999)

El-ahrairah comes for Hazel at the end of his long and happy life.

'It seemed to Hazel that he would not be needing his body any more, so he left it lying on the edge of the ditch, but stopped for a moment to watch his rabbits.....

"You needn't worry about them," said his companion. "They'll be all right, and thousands like them. If you'll come along, I'll show you what I mean."

He reached the top of the bank in a single, powerful leap. Hazel followed; and together they slipped away ....'

Rudolf Steiner 1861-1925

- Mind
- Body
- Spirit

- Head
- Hands
- Heart