

The value of health & The value of death

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Community Participation in
Palliative Care and Long Term Care

Overview

1

To explore what **health** means in the context of **death, dying, and grief**

2

To understand the **core** messages from the **Lancet Commission on the Value of Death**

3

Consider **tensions** and **opportunities** for **palliative care** in the future



What is health?



April 7, 1948

Health is a state of complete physical, mental and social wellbeing, and not just the absence of disease or infirmity

CONSTITUTION OF THE WORLD HEALTH ORGANIZATION

THE STATES parties to this Constitution declare, in conformity with the Charter of the United Nations, that the following principles are basic to the happiness, harmonious relations and security of all peoples:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest co-operation of individuals and States.

The achievement of any State in the promotion and protection of health is of value to all.

Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

ADOPTING THESE PRINCIPLES, and for the purposes of co-operation among themselves and with others to promote and protect the health of all peoples, the contracting parties agree to the present Constitution and hereby establish the World Health Organization as a specialized agency within the terms of Article 57 of the Charter of the United Nations.

A radical reconceptualization (2007)

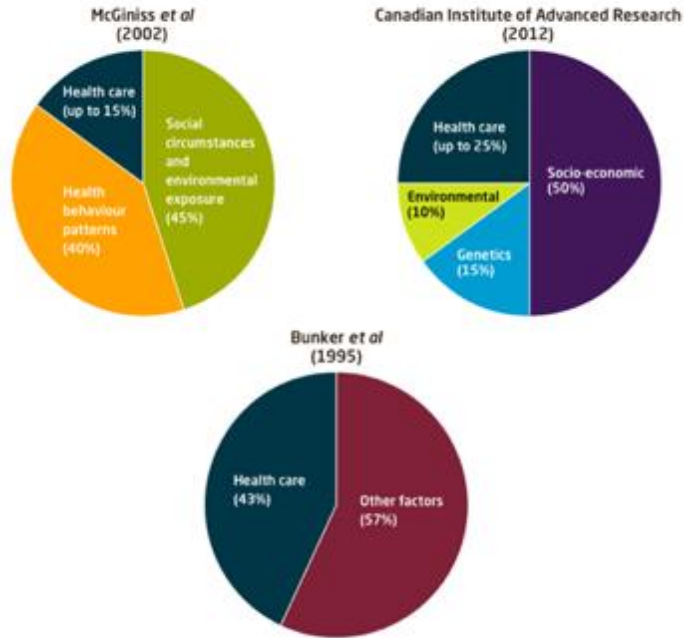


“Health is the capacity of an individual or community to adapt and self manage in the face of physical, mental and social challenges”

A high-angle photograph of a child in a yellow shirt and dark pants standing on a sidewalk, drawing colorful chalk art. The sidewalk is divided into sections, each featuring a different drawing: a crescent moon and stars, a rainbow, a smiling sun, the word 'LOVE' in large letters, and a yellow house. The child is currently drawing a pink heart. The background shows lush green plants and a garden bed.

How is health created?

Figure 1 Estimates of the relative contribution of factors to our health



Source: The King's Fund 2013



1. Health services contribute only 15-25% health outcomes



Examples from my practice



“... the conditions in which people are born, grow, work, live, and age...”



Social determinants of health



The social and structural
determinants of health

Wider determinants of health equity



Health & Health
Services



Health & Income
Security and Social
Protection



Health & Living
Conditions



Health & Social and
Human Capital



Health & Employment
and Working Conditions



REGIONAL OFFICE FOR

**World Health
Organization**

Europe



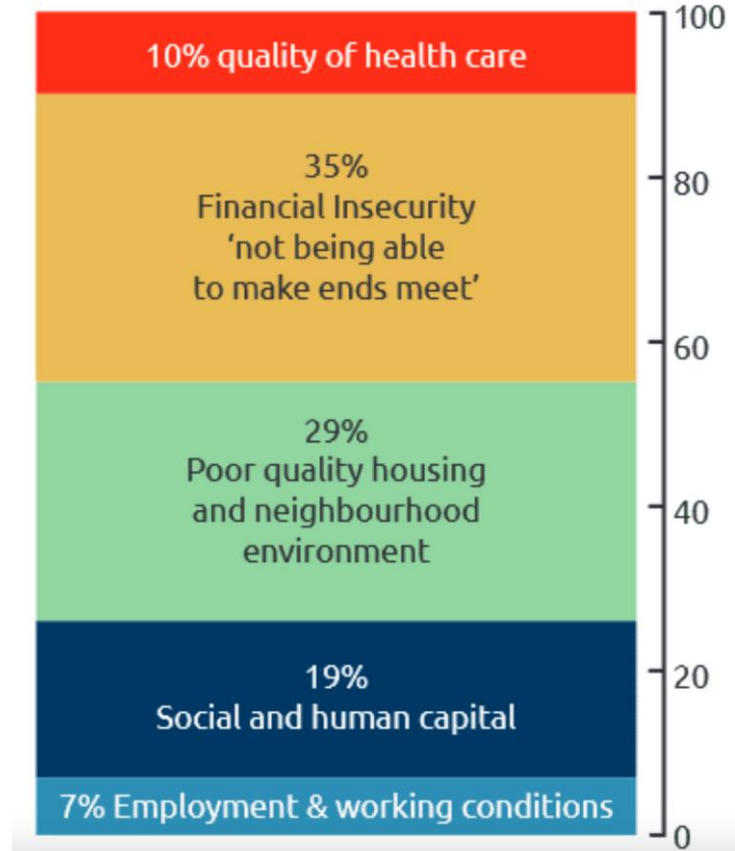
Healthy, prosperous lives for all:

the European Health Equity Status Report



7%

Wider determinants of palliative care?





2. Health is a collective phenomenon

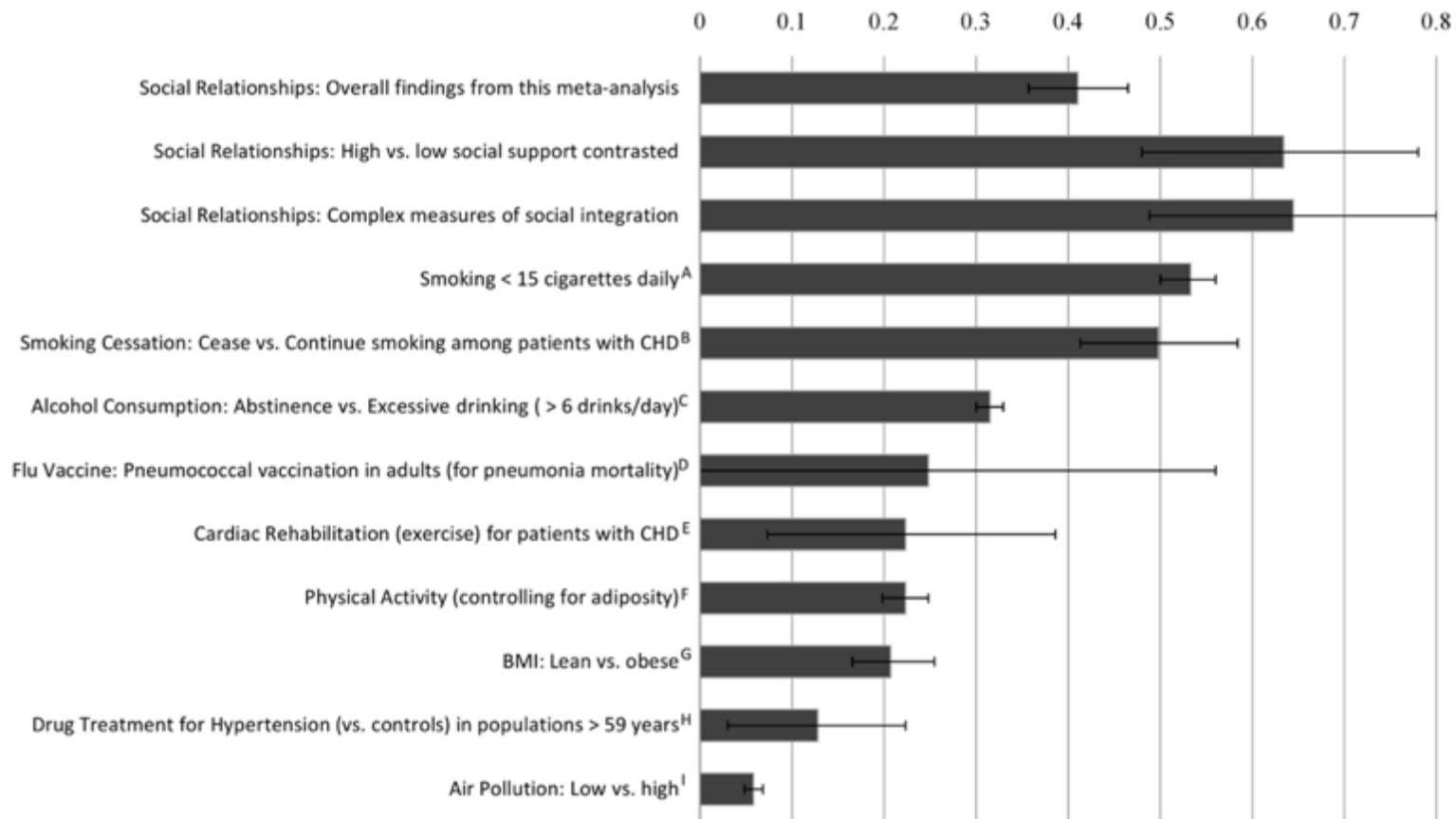
 OPEN ACCESS  PEER-REVIEWED

RESEARCH ARTICLE

Social Relationships and Mortality Risk: A Meta-analytic Review

Julianne Holt-Lunstad  , Timothy B. Smith , J. Bradley Layton

Published: July 27, 2010 • <https://doi.org/10.1371/journal.pmed.1000316>





3. Death, dying and grieving are a part of health and wellbeing



The diagram illustrates the Life Course approach. At the top, two horizontal bars represent the goals: "Sustainable communities and places" and "Healthy Standard of Living". Below these, four boxes represent key areas: "Early Years", "Skills Development", "Employment and Work", and "Prevention". The central part of the diagram is a large green area labeled "Life Course", which is shaped like a wedge that expands from left to right, indicating the accumulation of effects over time. Below this, a horizontal bar represents "Life course stages", divided into six segments: "Prenatal", "Pre-School", "School", "Training", "Employment", and "Retirement". A curved arrow points from the "Retirement" stage back to the "Prenatal" stage, suggesting a continuous cycle. A red circle highlights the "Retirement" stage.

An aerial, grayscale photograph of a winding road that snakes through a dense forest. The road is dark and contrasts with the lighter, textured ground and foliage. The text is overlaid in the center of the image.

What does this mean for
health in death, dying, and
grieving?



The social and structural
determinants of **dying**?

The *Lancet* Commission on the Value of Death (2022)



The *Lancet* Value of Death Commission: bringing death back into life

(Sallnow et al. 2022)

- Explored contemporary death, dying, and grieving
- Global perspective, commissioners from across the world
- Looked beyond palliative care and healthcare services
- Structural issues such as gender, race and power considered alongside relationships, communities, healthcare services, philosophy, consumerism and economics
- Took a systems approach
- Critical perspectives, but also hopeful and intentional



The *Lancet* Commission on the Value of Death:
bringing death back into life

- **Dying in the 21st century is a paradox** – overtreated and undertreated.
- Death, dying, and grieving today have become **unbalanced**.
- Links with the **climate crisis** – the delusion that we are in **control of**, not part of, **nature**.
- **Rebalancing** death and dying depends on changes across “**death systems**.”
- **Disadvantaged** and **powerless** **suffer most** from the current imbalance in death systems.
- Five principles of “**realistic utopia**” – a **new vision of how death and dying could be**.
- The challenge of transforming how people die and grieve today has been **recognised and responded to by many around the world** but concerted action is needed
- **Radical changes across all death systems** are a **collective responsibility**.



Taking a systems approach

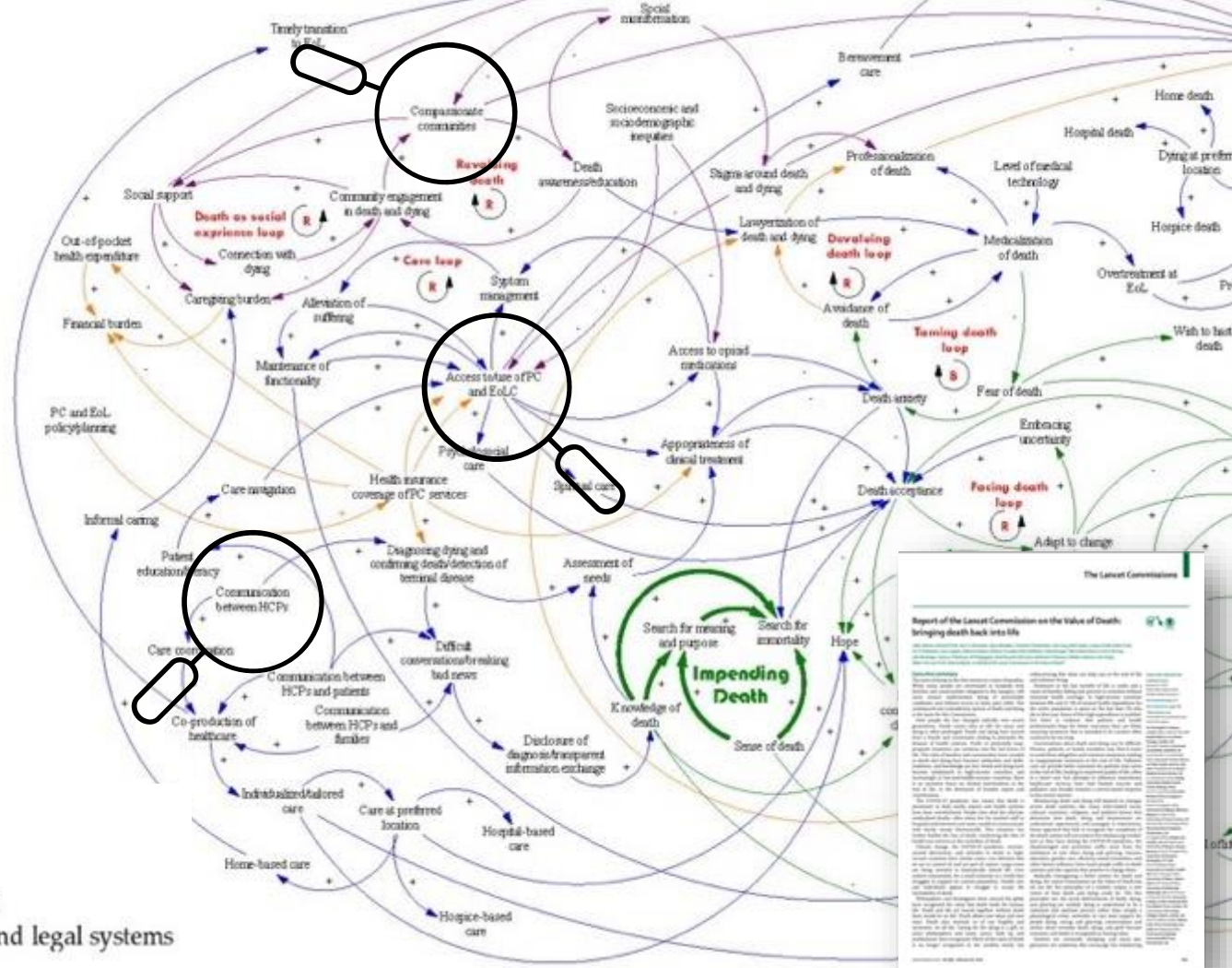
“There is no such thing as a single-issue struggle because we do not lead single-issue lives.”

Audre Lorde

“the many inter-related social, cultural, economic, religious, and political factors that determine how death, dying, and bereavement are understood, experienced, and managed.”

Legend

Human system
Health system
Sociocultural system
Political, economic, and legal systems



A new vision: the realistic utopia

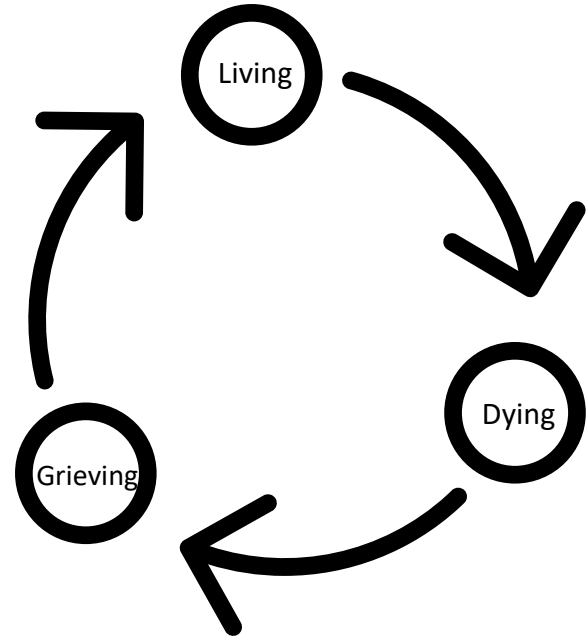
- A radically different vision of future society
- Whilst radical, it is also achievable
- Profound rather than incremental change
- Based on shared vision and principles

• *[A realistic utopia] "joins reasonableness and justice with conditions enabling citizens to realize their fundamental interests."*

- John Rawls (1993)

The realistic utopia of the Commission

1. The social and structural determinants of death, dying, and grieving are tackled



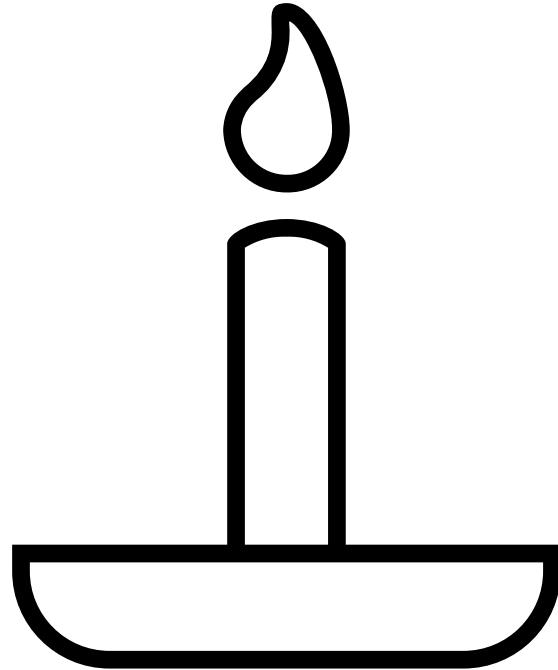
The realistic utopia of the Commission

1. The social and structural determinants of death, dying, and grieving are tackled



The realistic utopia of the Commission

2. Dying is understood to be a
relational and spiritual process rather
than simply a physiological event



CARING
COMMUNITY
KÖLN

The Groundswell Project Australia



good life
good death
good grief



Pallium Canada

**COMPASSIONATE
BRUGGE**
VERLIES-VERBINDEN-VERSTERKEN



**Compassionate
Communities UK**



PHPCI
Public Health Palliative Care International

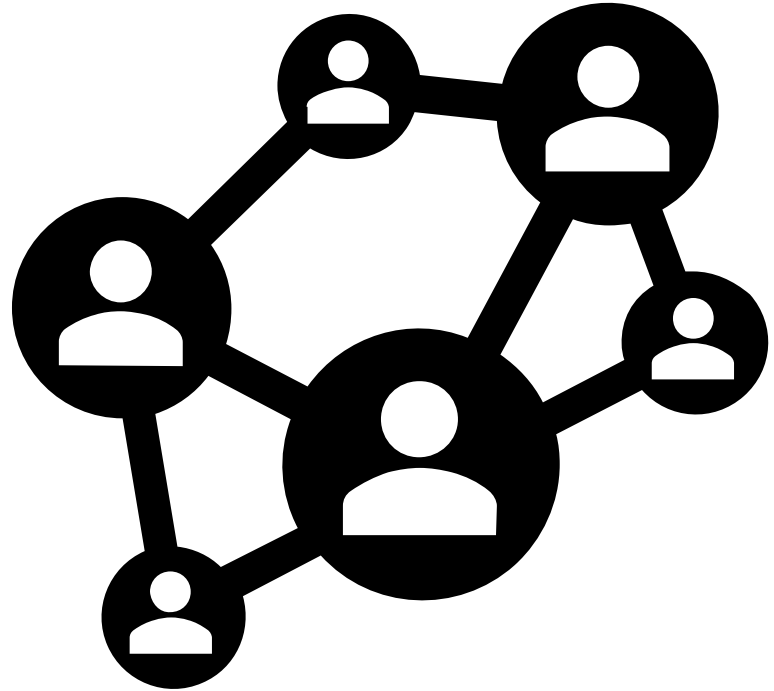


Studio DöBra Toolbox
Using arts to support conversations between children and older adults about dying, death and loss.



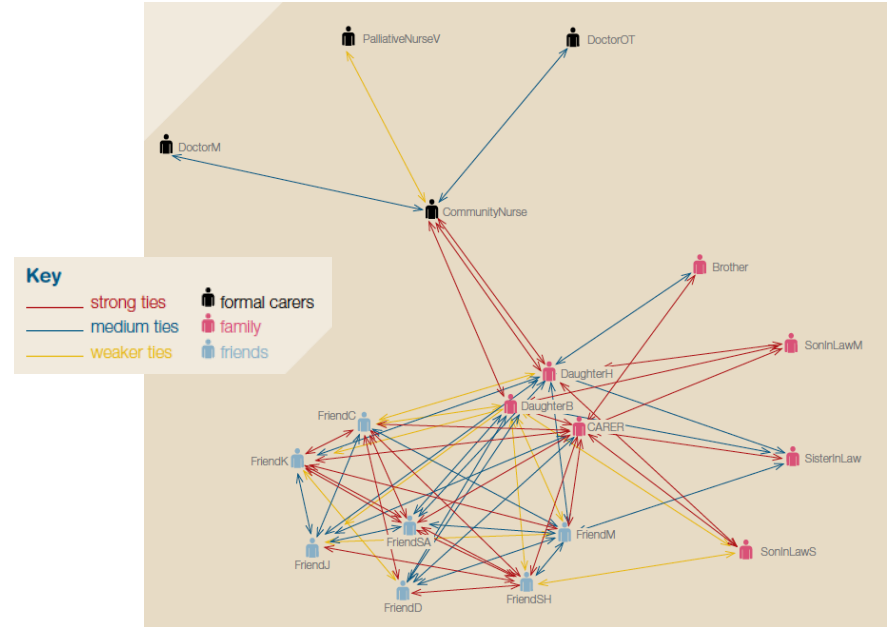
The realistic utopia of the Commission

3. Networks of care lead support for
people dying, caring, and grieving



The realistic utopia of the Commission

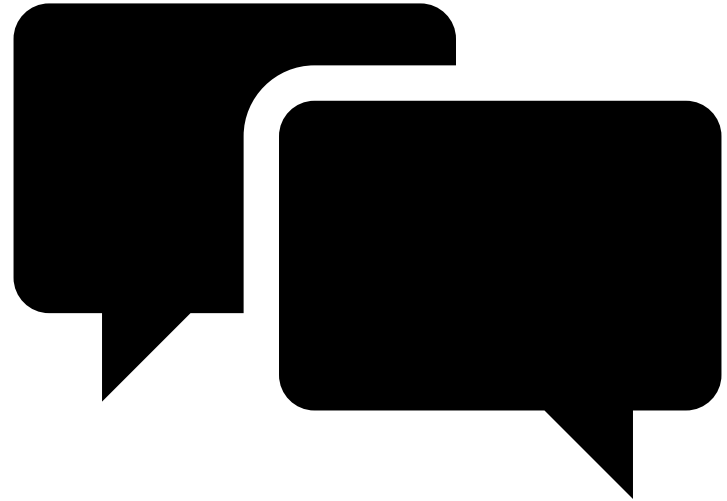
3. Networks of care lead support for people dying, caring, and grieving



End of Life at Home: Co-Creating an Ecology of Care (Horsfall et al. 2015)

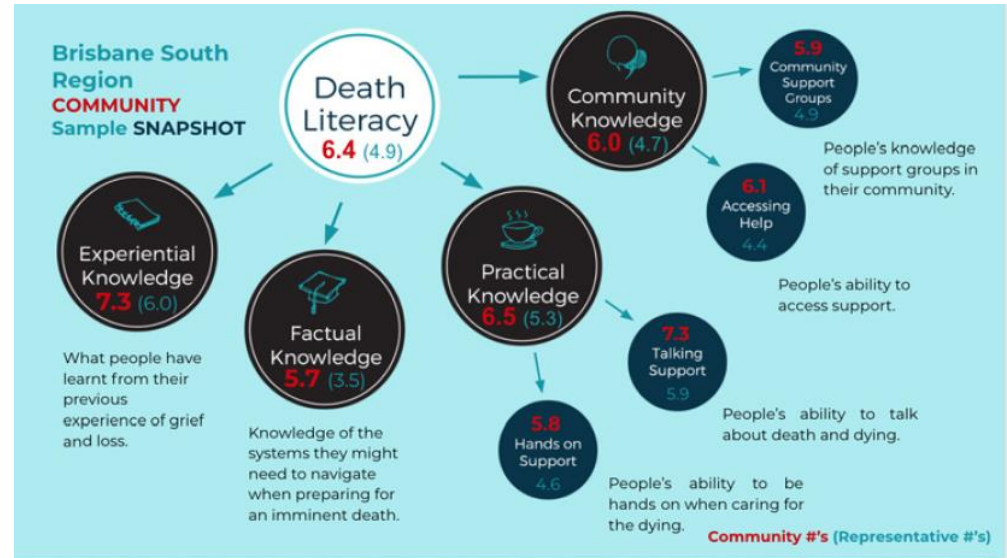
The realistic utopia of the Commission

4. Conversations and stories about everyday death, dying, and grief become common



The realistic utopia of the Commission

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The realistic utopia of the Commission

5. Death is recognized as having value



The realistic utopia of the Commission

5. Death is recognized as having value



Death is a part of health and wellbeing, not just its failure

Implications for palliative care



EU Policy Brief: Innovative palliative care for people with cancer (2024)

- **Collective findings** of 22 EU funded studies
- Workshops, expert opinion, rounds of review
- To highlight both:
 - **urgent needs** in palliative care in cancer
 - the **power** of palliative care in cancer
- To identify **clear actions** for practitioners, policy makers, researchers, public
- To **set priorities** for future research and funding



Tensions for palliative care



In summary

1

Integration of palliative care requires a consideration of **wider death systems**

2

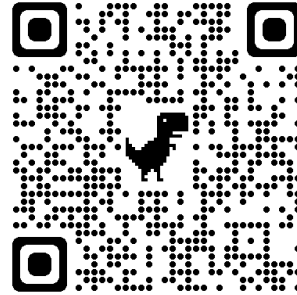
Change requires **more than** health service innovation – **social determinants** of dying well

3

Death & dying are a **part of health** and wellbeing, not only their **failure**

Final thoughts

- How much do we understand about death, dying and grieving systems?
- What wider actors are needed to lead sustainable change?
- How do we build death literacy?
- Is it possible for society to value death?



To find out more visit
www.valueofdeath.org

"Death and dying must be recognised as not only normal, but valuable. Care of the dying and grieving must be rebalanced..."

— The Lancet Commission on the Value of Death

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The best science for better lives