

The *Lancet* Value of Death Commission:

**Bringing death back into life in the 21st
century**



life experience

death experience

The impetus for a commission on death

Death, dying and grief are core, universal human concerns

How people die has changed significantly over recent generations

Some changes have been for the better – people die later in life and many have access to pain and symptom relief as they die

Some changes have been for the worse – dying is prolonged, more people die in hospital, families and communities feel unprepared

Did You Know?

100% of Canadians will die



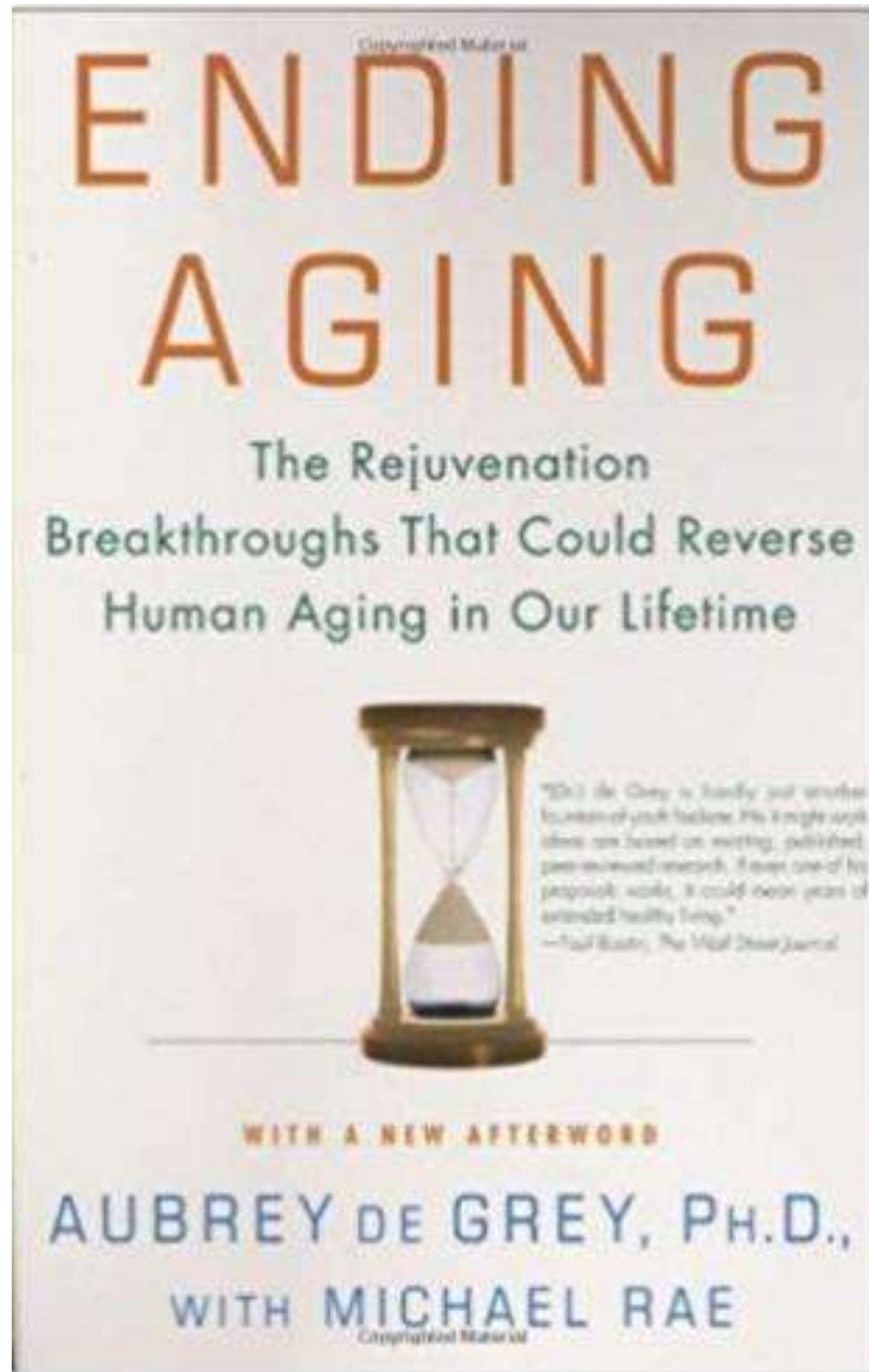
8 out of 10 Canadians have never heard of Advance Care Planning

IMMORTALITY

The Quest to Live Forever and
How it Drives Civilisation



Stephen Cave



COMMENT | VOLUME 392, ISSUE 10155, P1291-1293, OCTOBER 13, 2018

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Lancet Commission on the Value of Death

Richard Smith for the Lancet Commission on the Value of Death

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Check for updates

PlumX Metrics

Without death every birth would be a tragedy. “We die so that others may live, we grow old so that others may be young”, writes the poet

Supplementary Material

Recommend this journal
to your librarian

Formed in 2018. 30 people representing twelve countries
China, India, Ireland, Japan, Malawi, Mexico, Netherlands, Norway, Singapore, Sudan, UK, USA
Healthcare professionals, carers, authors, social scientists, researchers, philosophers, economists,
religious commentators
Began by exploring the medicalization of death but expanded
Builds on work from Lancet Commission on Palliative Care and Pain Relief (2017)
Considered stopping as a result of the pandemic but reflected now more relevant than ever

The approach of the Commission

- Global in perspective
- Commissioners across disciplines and countries
- Uses a systems approach to understand challenges
- Looks beyond palliative care and healthcare services
- Structural issues such as gender, race and power considered alongside healthcare services, philosophy, consumerism and economics

Death and dying in the 21st century

- Global mortality and life expectancy trends in recent decades appear to be a success story, **BUT**:
 - Disproportionate progress
 - within and across countries
 - for specific population groups
 - Reversals in places with previous gains
 - Healthy life expectancy not kept pace
 - Shifts in burden of disease from communicable to non-communicable
- Millions experiencing **serious health-related suffering**

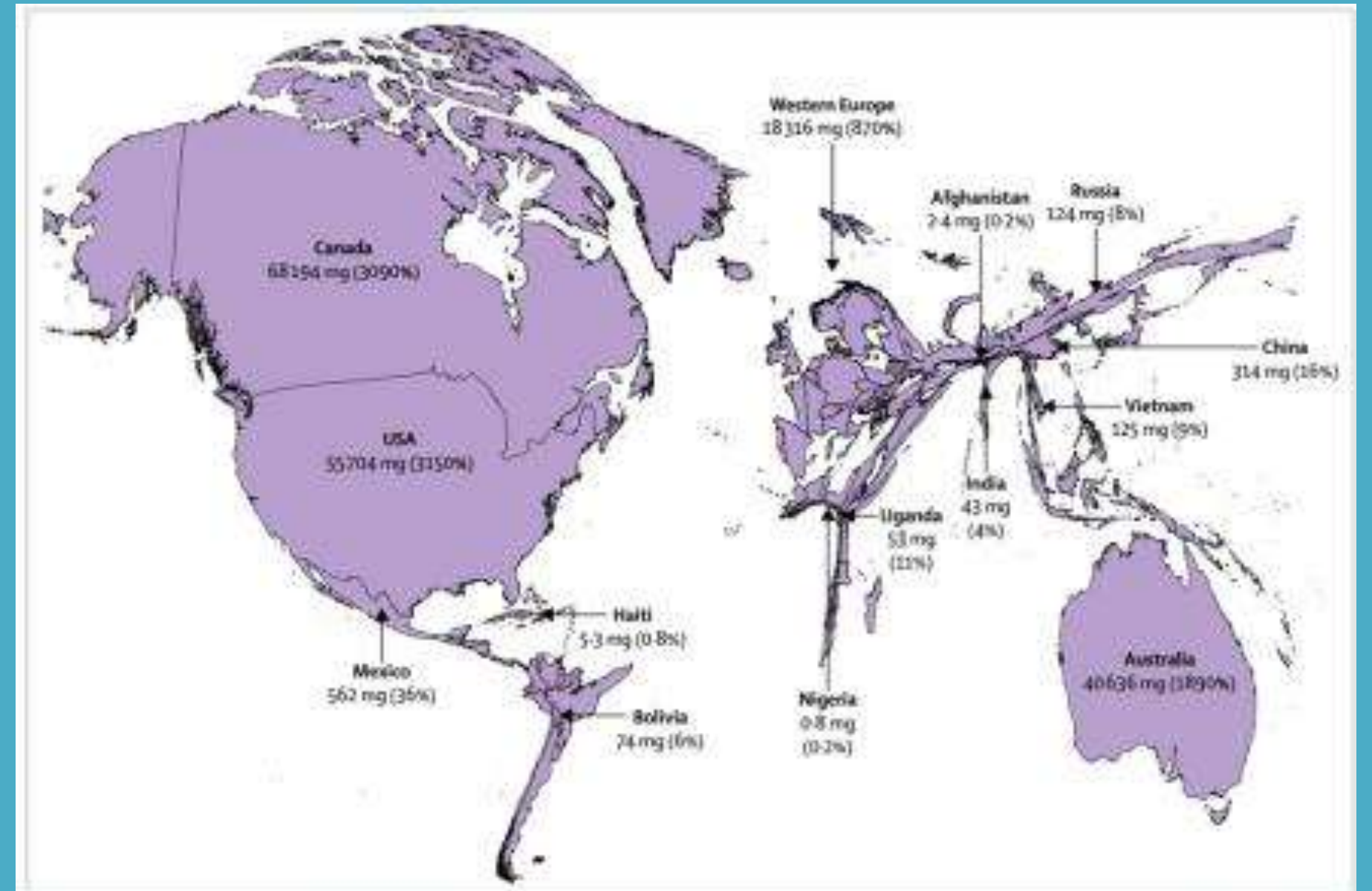


Figure 1: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010-13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering
Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. See additional online material for methods.

A central paradox in contemporary dying

	Before 1950	1950	2019
Level of medical technology	Low	Increasing	High and increasing
Detection of terminal disease	Poor	Improving	High
Definition of death	Simple	Still simple	Complex
Deaths from acute disease (mostly rapid)	High	Still high	Low
Deaths from injuries (mostly rapid)	High	Still high	Lower
Deaths from chronic disease (mostly slow)	Low	Increasing	The majority
Length of dying	Short	Still mostly short	Long
Passivity in response to a person dying	Common	Decreasing	Gone in western medicine
Involvement of doctors in dying	Low	Increasing	High
Number of doctors in UK per 100 000 people	Fewer than 26	26	280
Familiarity with death among the population	High	Still high	Low
Activities to manage death (death awareness campaigns, advance care planning, assisted dying, etc)	Low	Low	High
Community involvement in death and dying	High	Falling	Low
Meaning in death and dying	Mostly supplied through faith and faith organisations	Faith and faith organisations still have an important role	Inadequately supplied by multiple organisations, including the health system

Table 3: The changing nature of death and dying (adapted from Lofland)⁴⁷

event-centred care?

- Treat each **event** as a discrete reversible episode without considering trajectory



RESCUE

The importance of death systems



*MANAGING
SUFFERING &
UNCERTAINTY*



Death systems

“the physical and symbolic networks through which an individual's relationship to mortality is mediated”

Robert Kastenbaum (1977)

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bringing death back into life

Rationale for thinking about death systems

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Current approaches only consider:

- Linear thinking
- Reductionist reasoning
- Static options

Fragmented approaches can lead to:

- Inefficiencies
- Unintended consequences
- Inequities

Death system: framework

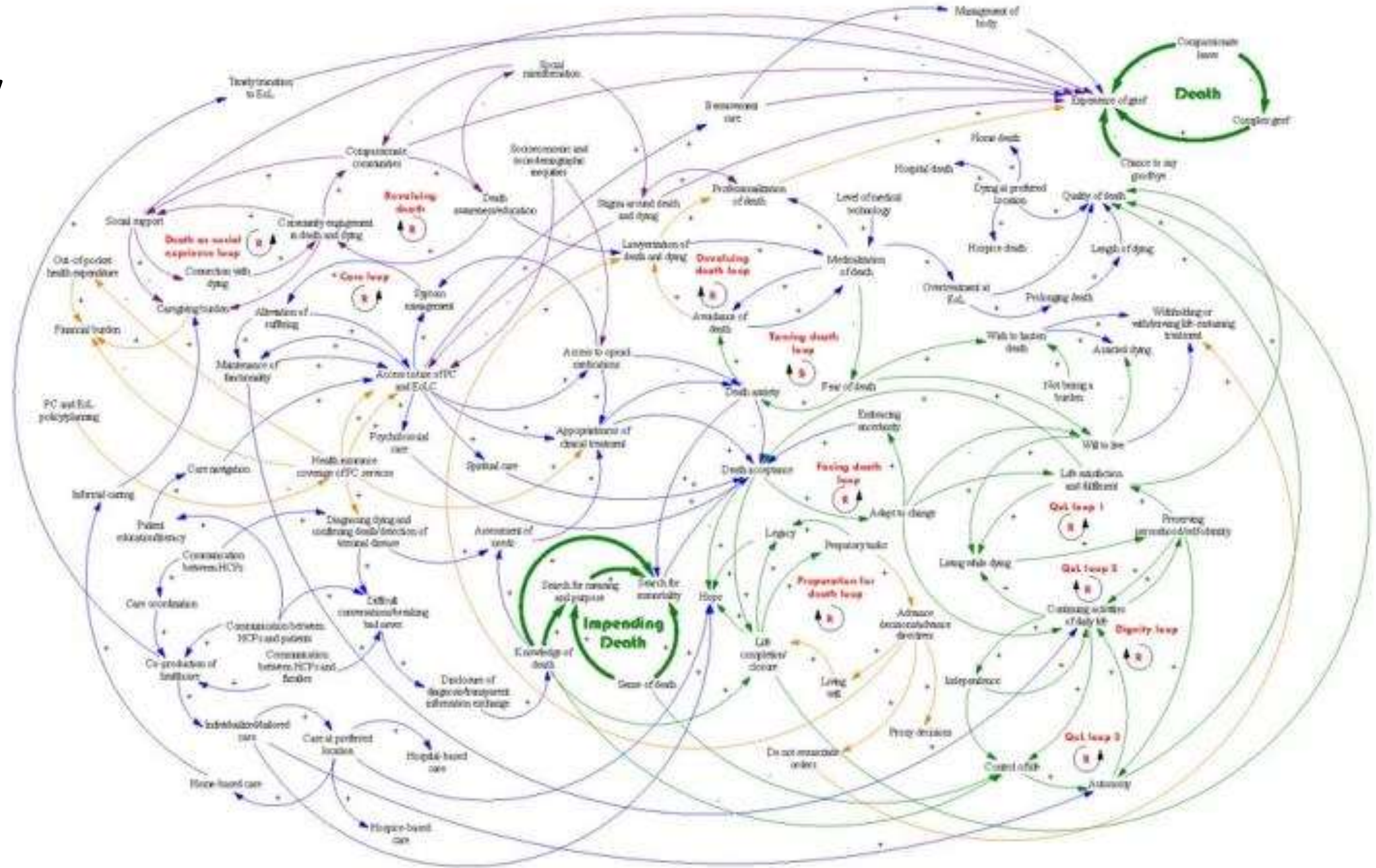
Death systems:

- Provide means for death and dying to be **understood and managed**
- Define **meaning of death** in **culture or community**
- Determine **where** and **how people die and mourn**
- Encompass **components** – e.g., places, symbols
- Have **functions** – e.g., warn and predict death, care for dying, making sense of death
- Exhibit **‘dynamic complexity’**

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Dynamic complexity of the end-of-life care system

- Patient experience mapped through the death trajectory
- Rebalancing the death system requires integrated healthcare, legal, and societal approaches



Leverage points of transforming death systems

- Alter mindsets on **reality of death**
- Change goals to improve **experience of death**
- Practice the power to **self-organize structures** and **mobilize a movement**
- Modify rules to **support, recognize, and facilitate death**
- Change how information is held and it flows to be **open** and to **educate all**

Key messages from the report

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

The realistic utopia and recommendations

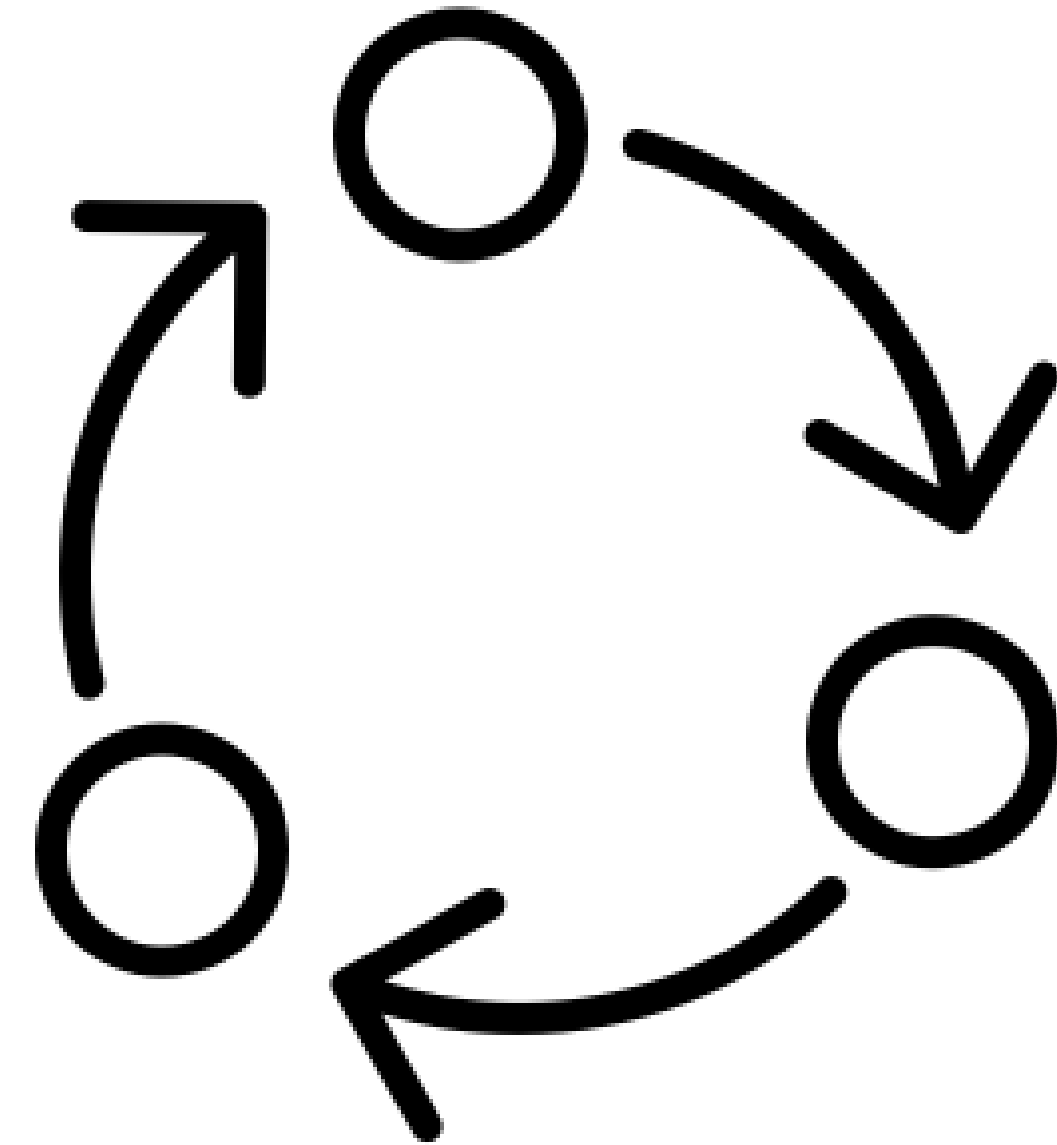


A realistic utopia

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

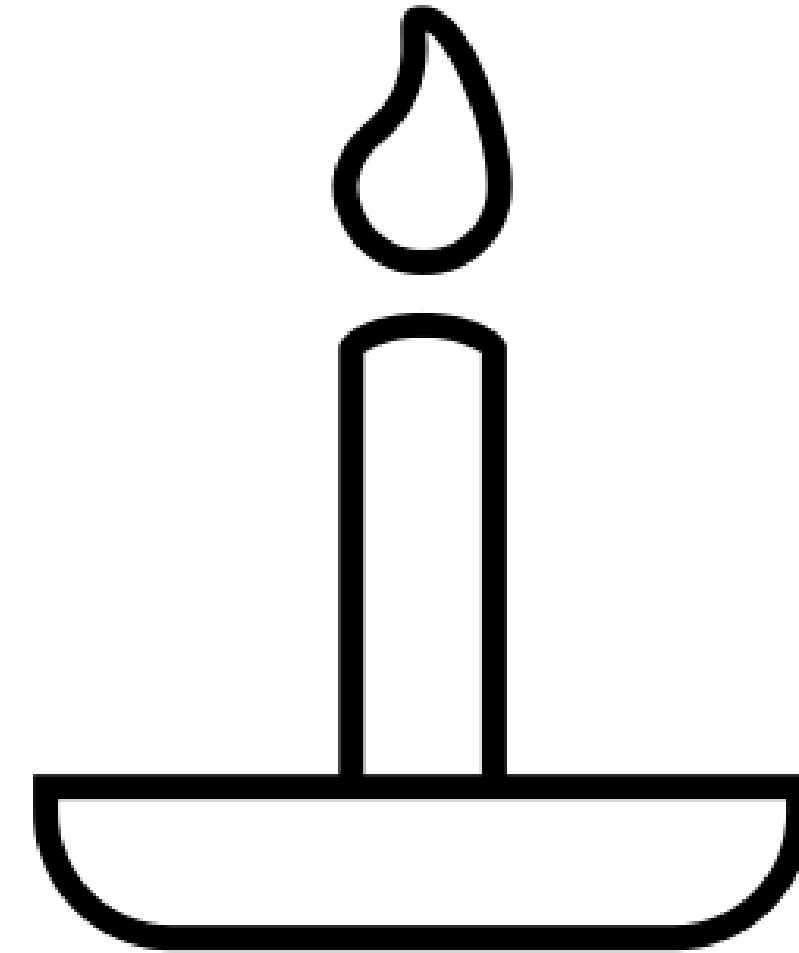
The realistic utopia of the Commission

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



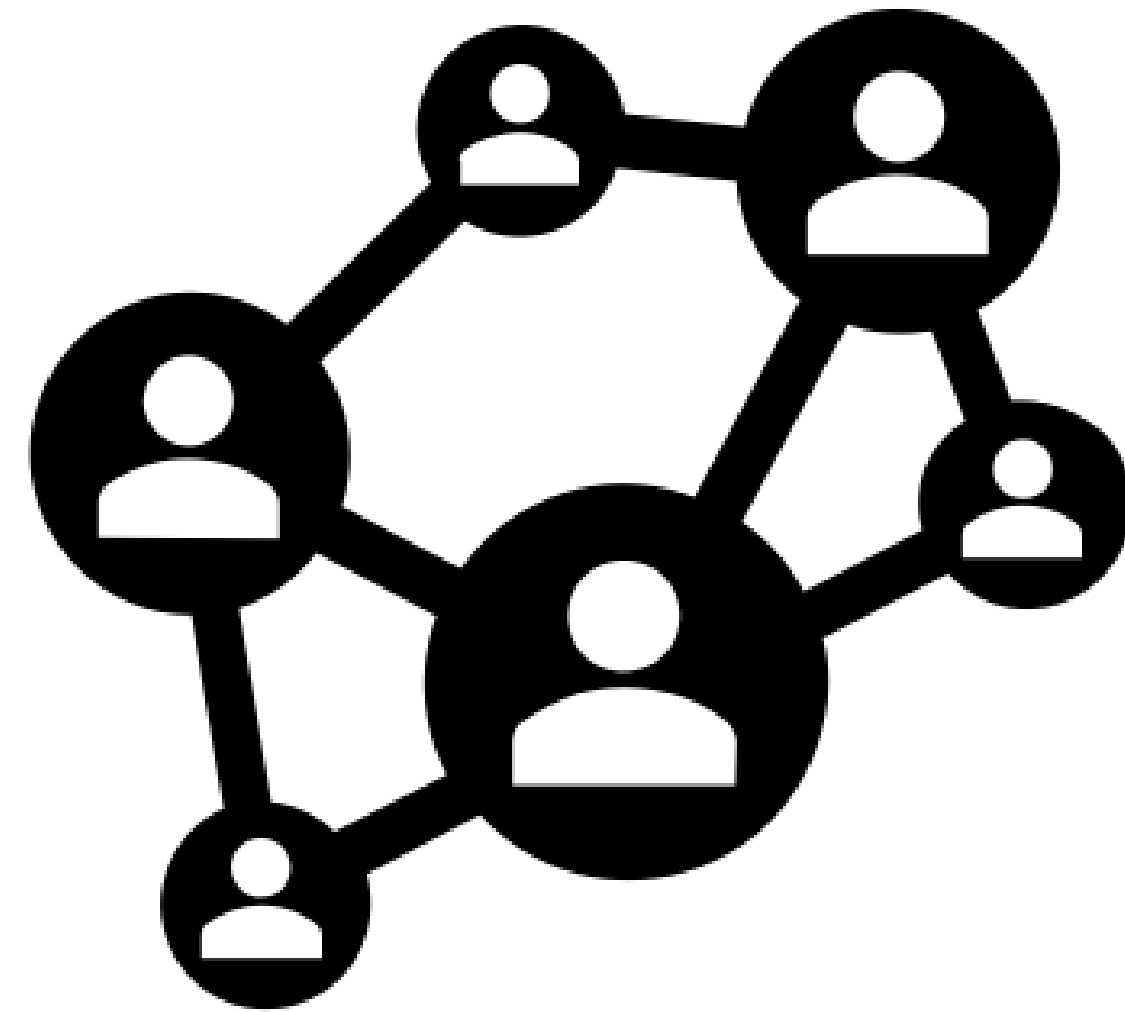
The realistic utopia of the Commission

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



The realistic utopia of the Commission

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



The realistic utopia of the Commission

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



The realistic utopia of the Commission

5. Death is recognized as having value



Selected recommendations

- **For all:**
 - **Relationships** should be placed at the centre of efforts to improve end of life experiences
 - **Partnership** approach is important – care of the dying and grieving should not rest solely with health services nor communities
 - **Death literacy** must be developed for all

Selected recommendations

For civil society:

- Models of **community action** in death, dying and grieving should exist for all communities
- **Stories and experiences** of death, dying and grieving should be through communities
- The importance of **rituals, traditions and supports** at these times should be understood and preserved

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Selected recommendations

For health and social care systems:

- **All health and social care professionals** should be competent in caring for the dying and bereaved
- The **management of suffering** should be a goal alongside extension of life
- **Specialist palliative care** should focus on education, research, building capacity of general health-care workers, and extending reach and equity in access to the palliative-care approach rather than just delivering specialist services.
- People are increasingly likely to die in care homes, so efforts to **improve the experience of living, dying, and grieving in care homes**, and adequate resourcing, must be a priority.

8760 hours

Selected recommendations

For researchers and funders:

- Funders should invest in programmes that experiment with **rebalancing** death and dying, **beyond healthcare interventions**
- Research efforts should explore and understand **over treatment** at the end of life

Selected recommendations

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For governments and policy makers:

- Families and communities should not be impoverished by **out-of-pocket expenditure** at the end of life, governments should find ways to support this
- All countries should have **clear guidelines on withholding and withdrawing** treatments
- **Plans, policies and strategies** about health, social care and wellbeing should include considerations of death, dying and grieving

Next steps

- The launch of the report is the beginning not the end of this work
- Series of diverse events throughout 2022
- We intend this to stimulate experimentation and innovation in death systems globally
- Encourage all to embed the realistic utopia and implement the recommendations locally
- We wish to collaborate with partners across the globe to transform death systems

- For more information:
 - <https://www.thelancet.com/commissions/value-of-death>
 - Follow the conversation on Twitter - @VoDCommission and #ValueofDeath

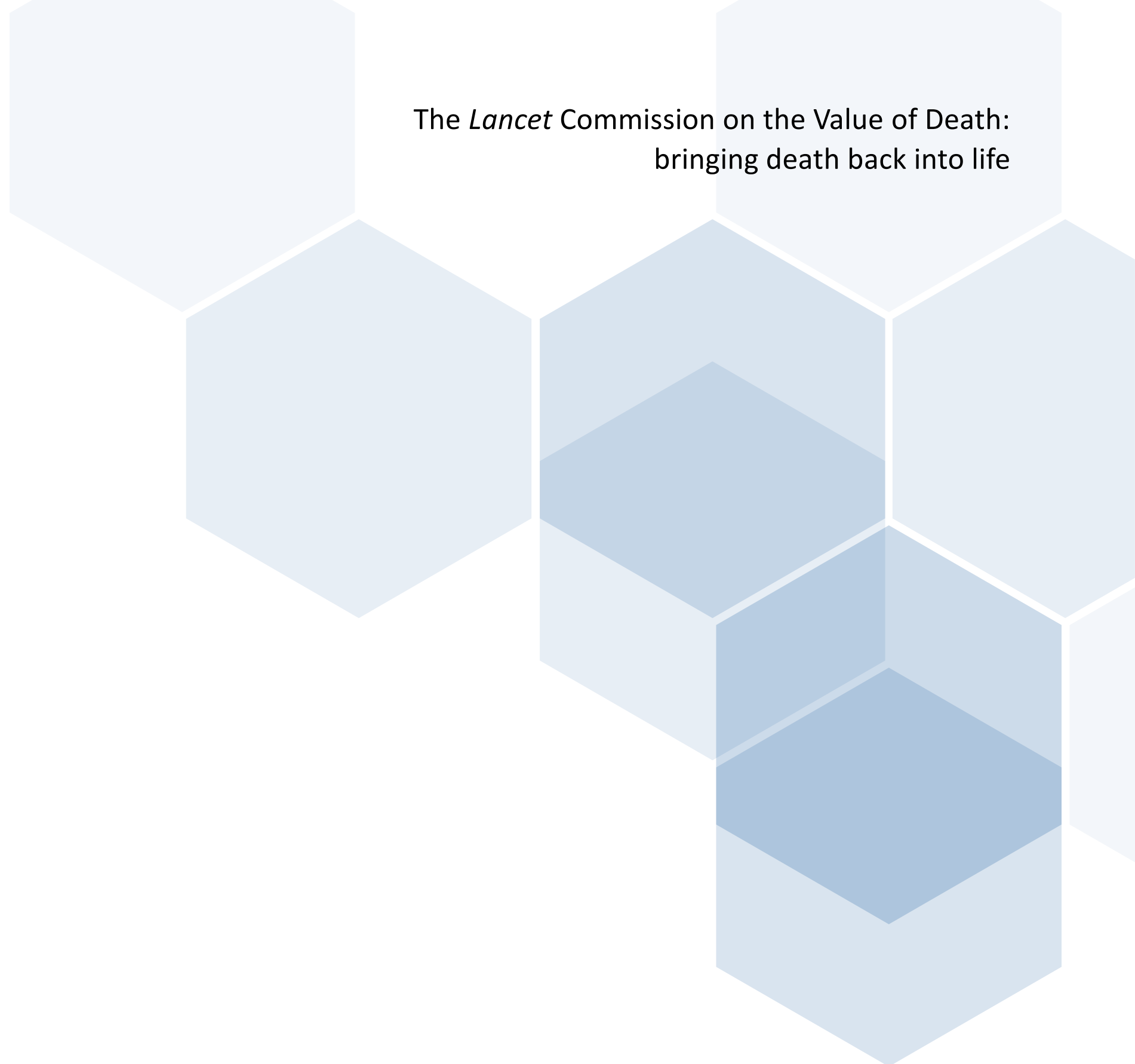
Death and dying must be recognized as not only normal, but valuable.

Care of the dying and grieving must be rebalanced, and we call on all throughout society to respond to this challenge

“The future is already here, just not very evenly distributed”.

William Gibson

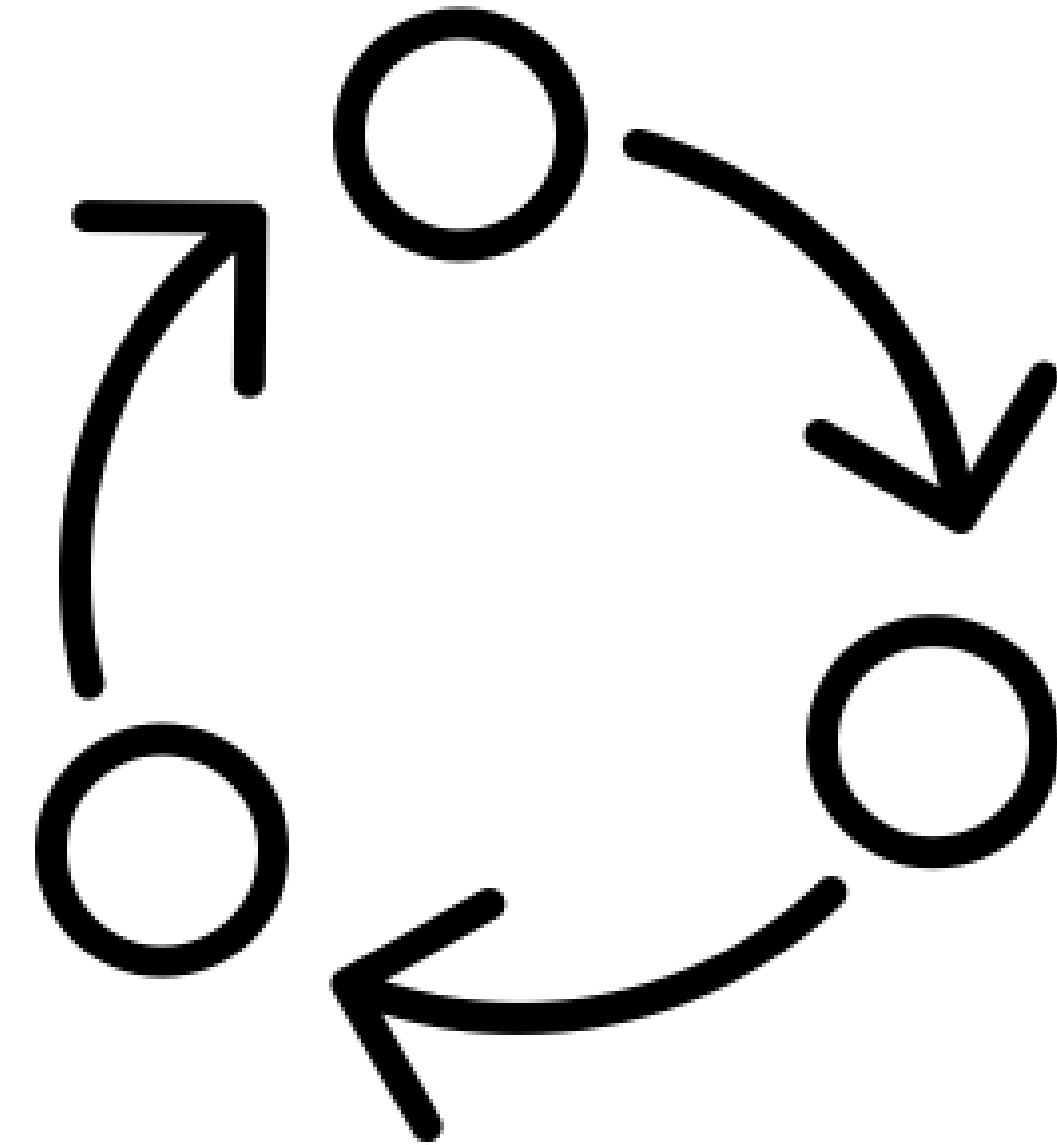




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The realistic utopia of the Commission

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



certain

**family structures
are
changing**

certain

**loneliness is
increasing**



WHO CARES? PROFESSIONAL CARERS

Average care worker salary in London = £10 per hour

Average garbage collector salary in London = £14 per hour



WHO CARES? FAMILY CAREGIVERS

The **Female Face** of Family Caregiving

NOVEMBER 2018

Caregiving is a major part of life for millions of women, with women of color and immigrants taking on a disproportionate amount of both paid and unpaid family caregiving.

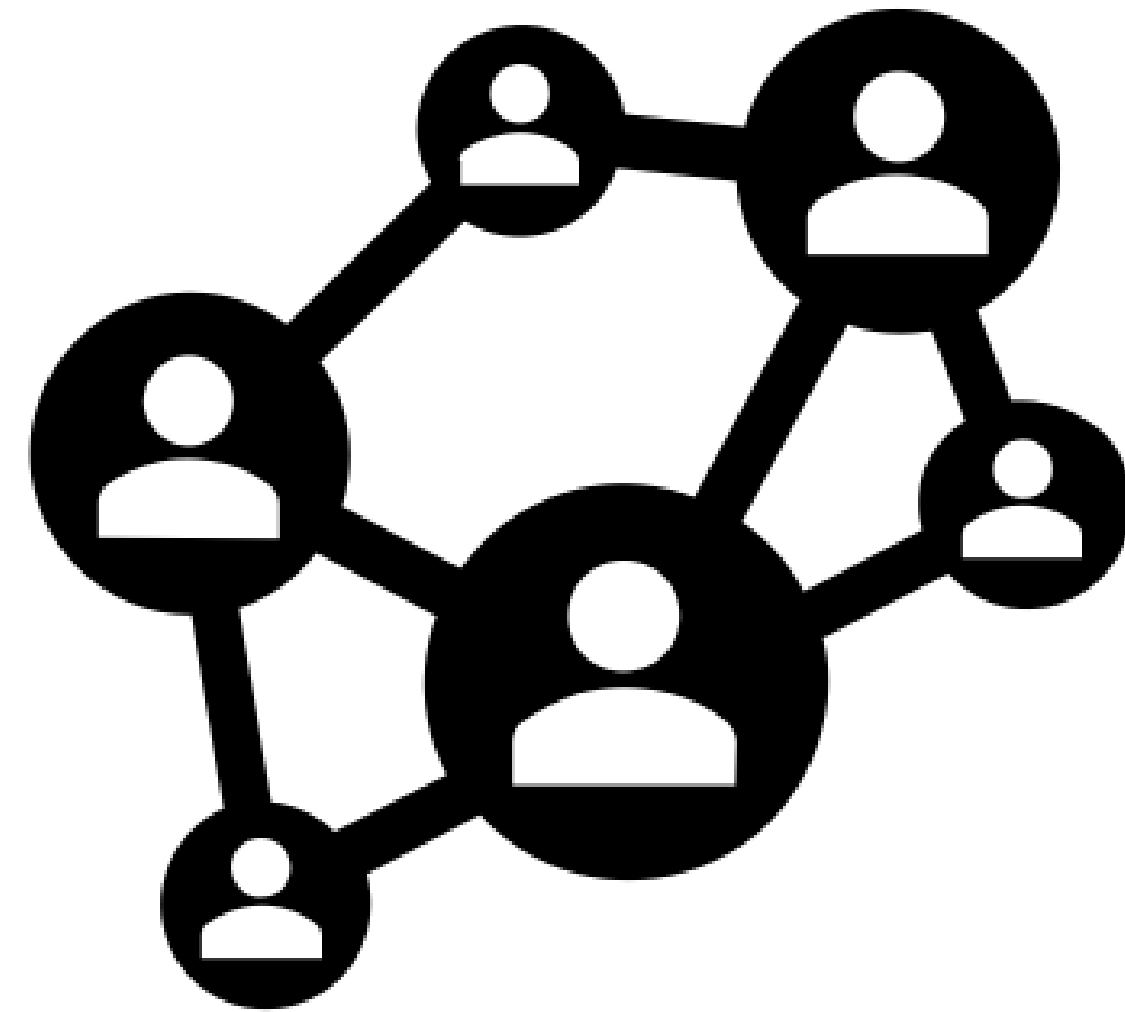
Carers Allowance – the only benefit is £62
(equivalent to 6 hours pay)



. "My home is not a nice place to live, she said, let alone a nice place to die."

The realistic utopia of the Commission

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

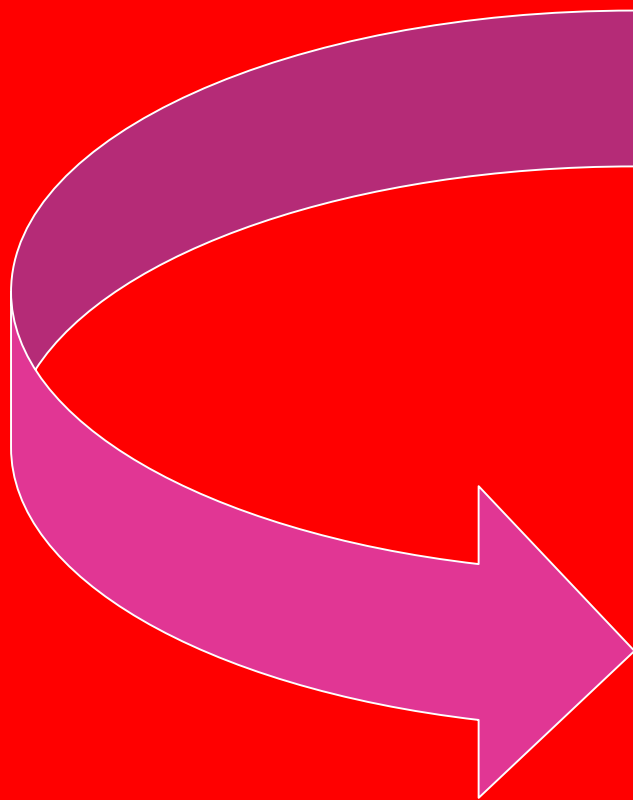


ask about networks.....

**what would it take to
support you to be cared
for at home..... and what
can your family, friends
and community bring to
that?**



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Compassionate Neighbours - Reciprocity

from Compassionate Neighbours

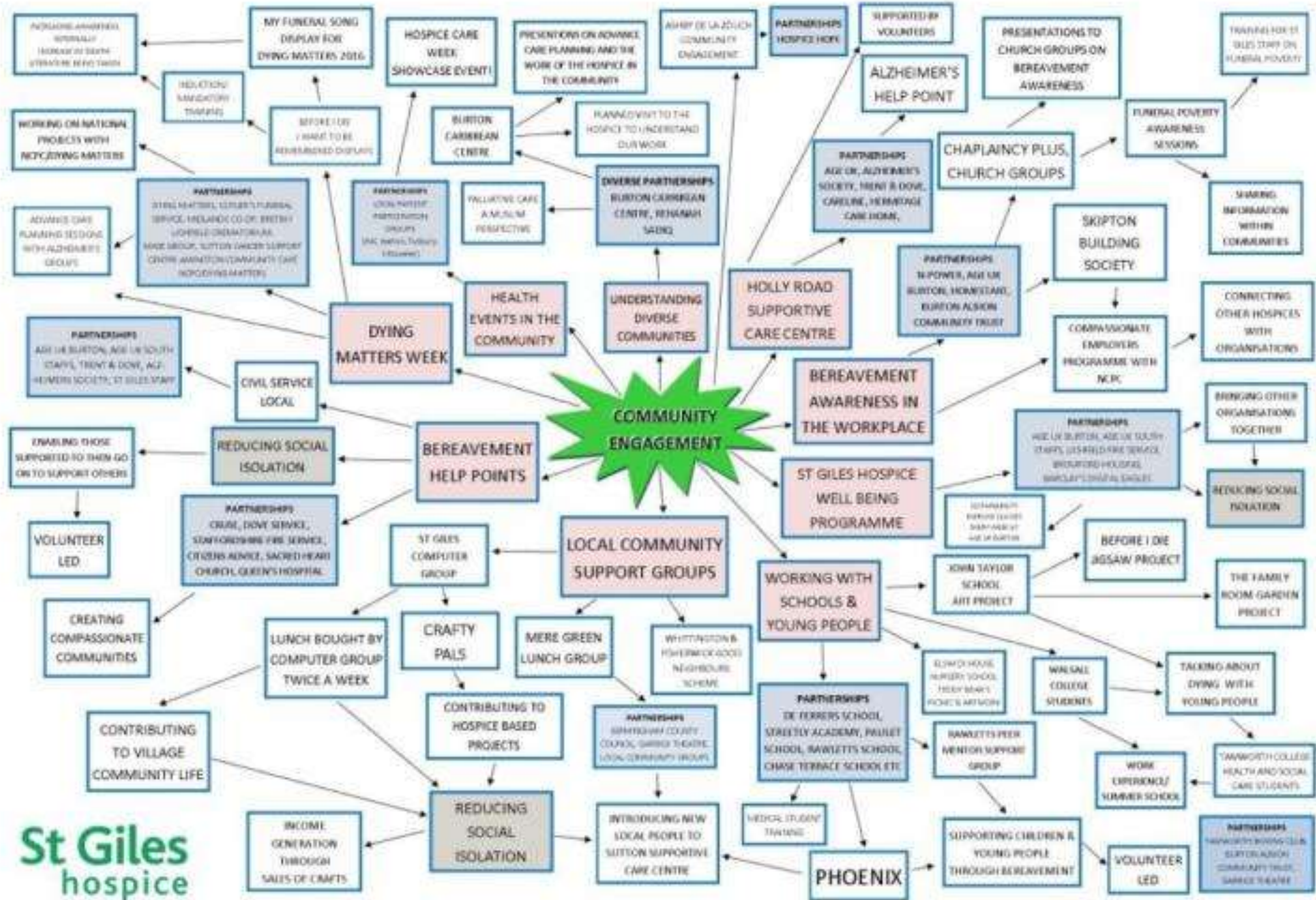


Reciprocity

“It has changed him a lot and changed me too”

Kito

Relationships as mutual and reciprocal

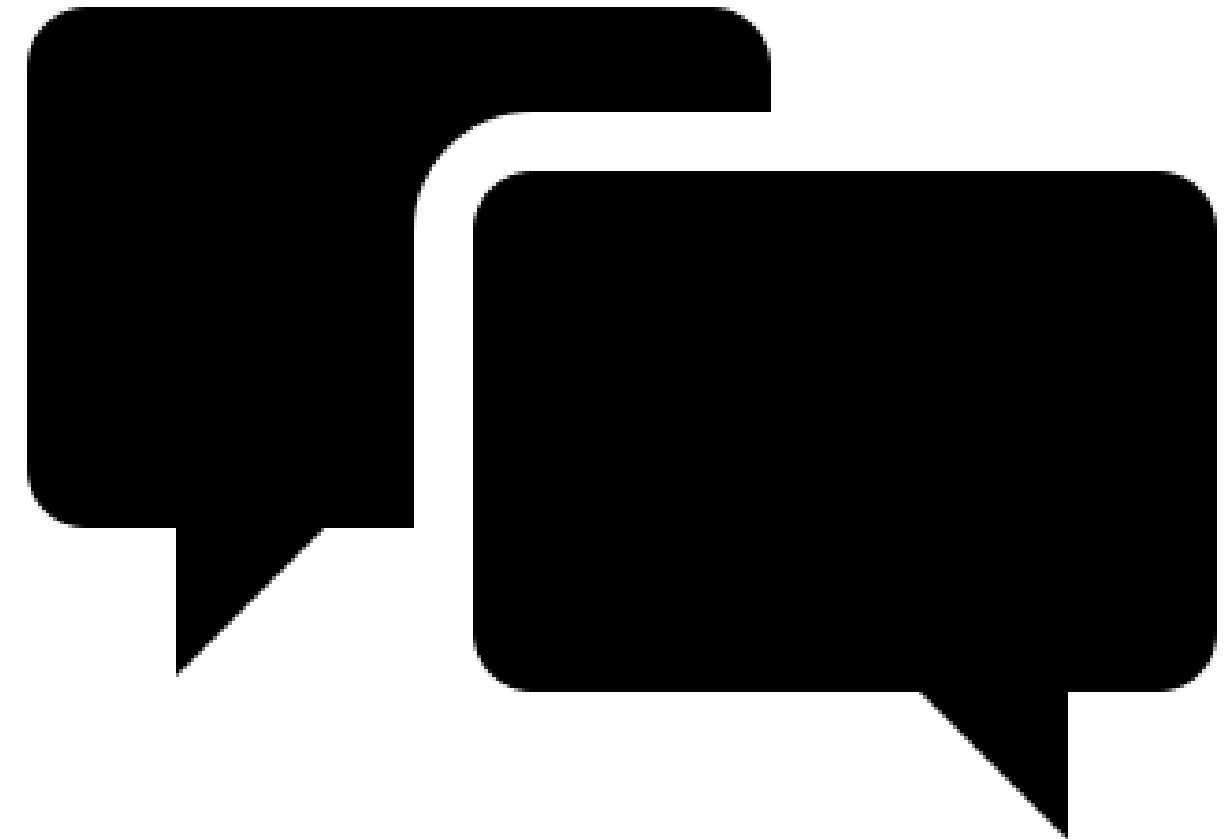


who is going to come
and live with me ?



The realistic utopia of the Commission

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



goals of care conversations

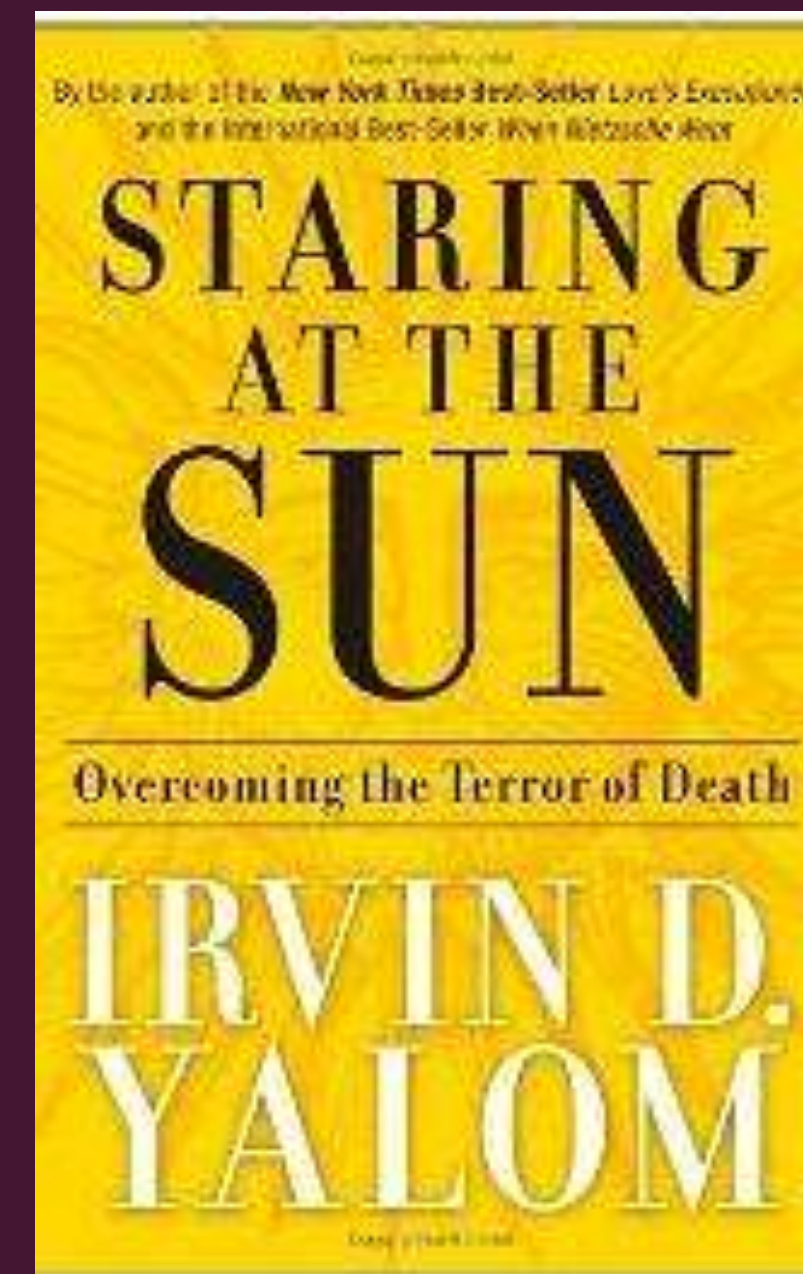
**what matters to
you if time is
short?**



www.dyingtoknowday.org



people are anxious
about dying





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Dr Kieran Sweeney

**A hesitation
to be brave.....**