

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

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Specialist Palliative Physician



# CONFLICTS OF INTEREST DECLARATION

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CONGRÈS  
INTERNATIONAL  
DE SOINS PALLIATIFS  
MCGILL

MCGILL  
INTERNATIONAL  
PALLIATIVE CARE  
CONGRESS

I have an affiliation with a not-for-profit organization, Harlington Hospice for 2.5 years

# LEARNING OBJECTIVES

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CONGRÈS  
INTERNATIONAL  
DE SOINS PALLIATIFS  
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PALLIATIVE CARE  
CONGRESS

At the conclusion of this presentation, participants will be able to:

- Consider several principles of the ‘realistic utopia’ in more depth
- Appreciate gender as a key social determinant of dying
- Understand the concept of networks of care
- Consider how ‘death has value’ – a cornerstone of the Lancet Commission

# lost words of dying

suffering

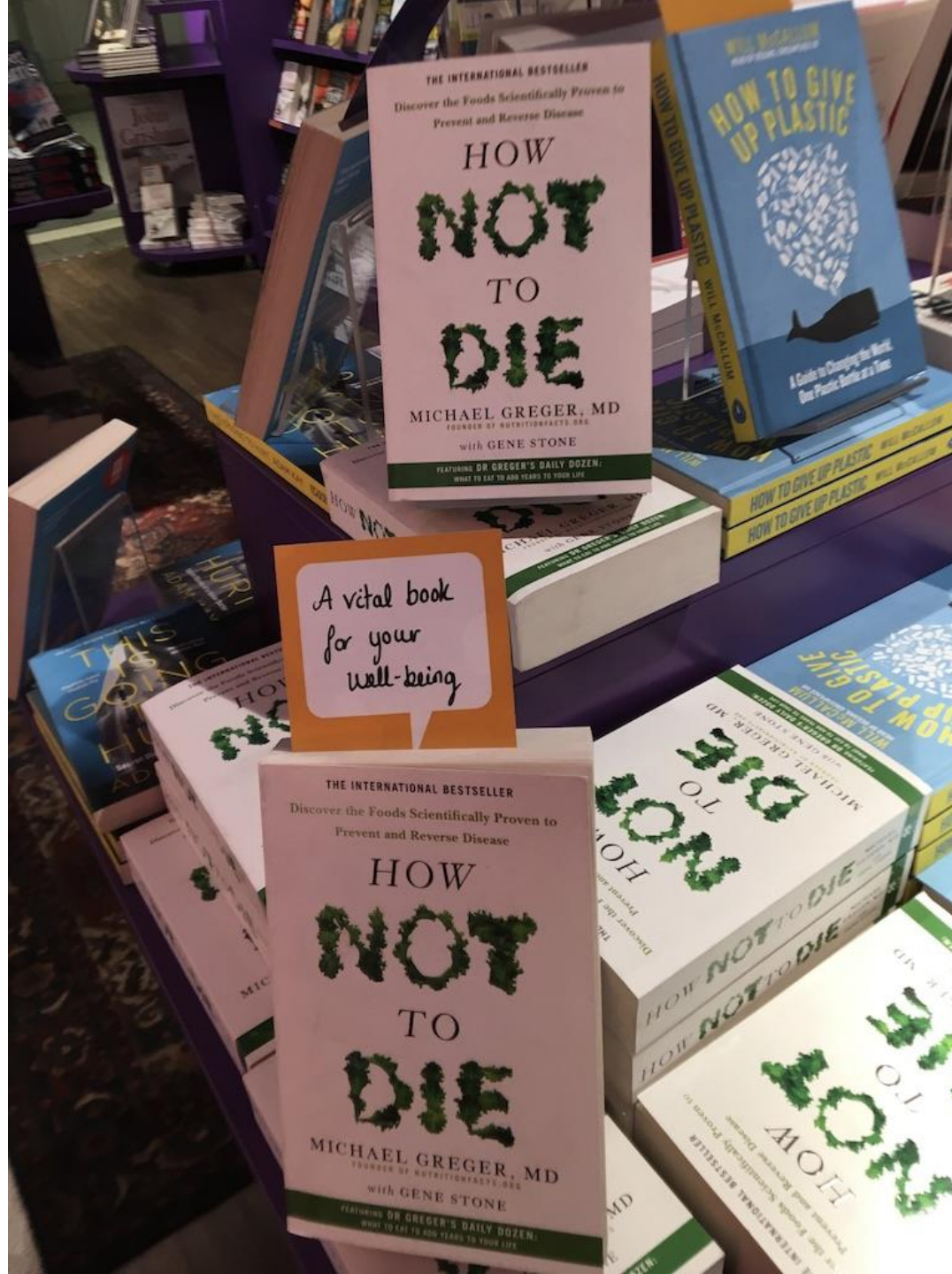
healing

died

vigil

consolation

presence



	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)<sup>47</sup>

*certain*

**medicine is doing too  
much.....**

# event-centred care?

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



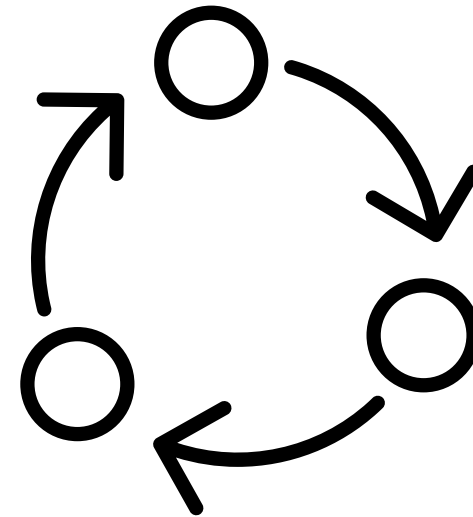


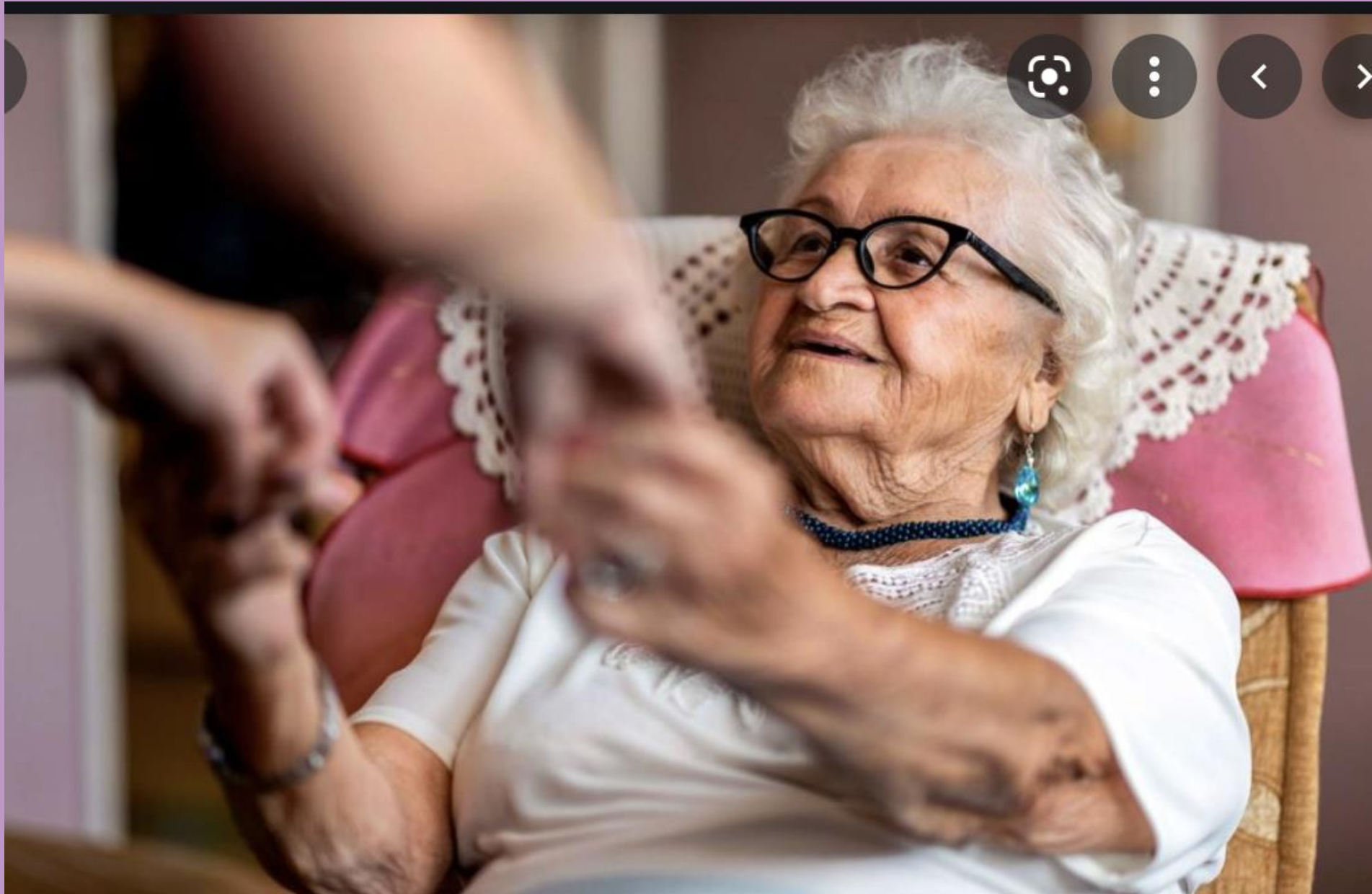
*MANAGING  
SUFFERING &  
UNCERTAINTY*



# The realistic utopia of the Commission

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





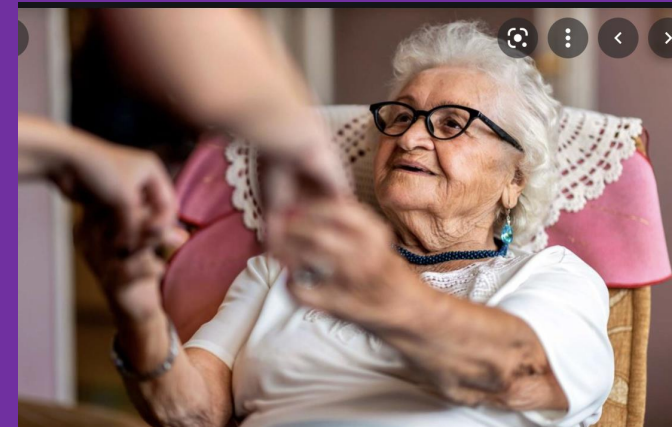
# SIGNIFICANT EVIDENCE THAT GENDER INFLUENCES :

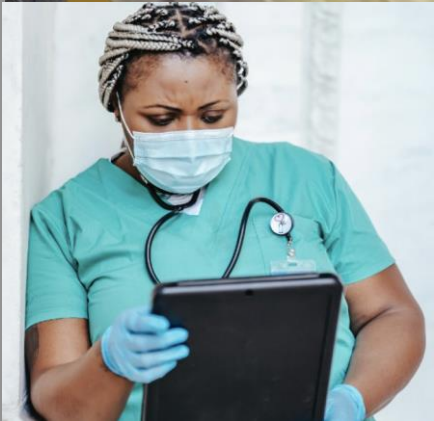
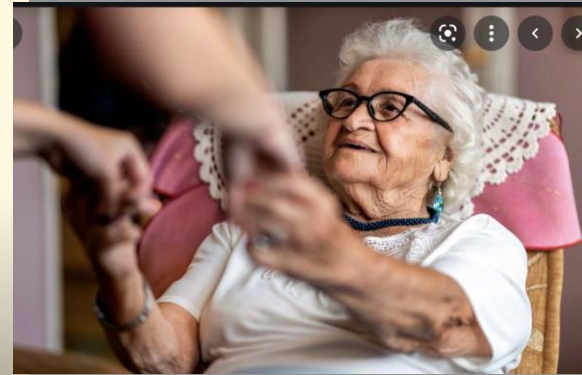
WHO CARES FOR YOU ?

EXPERIENCE OF CARE

PLACE OF CARE

END OF LIFE CHOICES AND INTERVENTIONS







# Gender and palliative care: a call to arms

Merryn Gott, Tessa Morgan  and Lisa Williams

2020 Vol 14

## THE LANCET

COMMENT | VOLUME 386, ISSUE 9999, P1112-1114, SEPTEMBER 19, 2015

### Making women count

Richard Horton • Audrey Ceschia

Published: June 04, 2015 • DOI: [https://doi.org/10.1016/S0140-6736\(15\)60964-3](https://doi.org/10.1016/S0140-6736(15)60964-3)

Lancet Commission on Women and Health 2015



# WHO CARES? PROFESSIONAL CARERS

64% doctors in US are male, 36% female

78% doctors in Japan are male, 22% female

9% nurses in US are male, 91% female

3% nurses in Japan are male, 97% female



**power**





**DOCTORS** →  
&  
← **OTHERS**

NOTICE  
ALL CONCERNED  
CCHW&RI  
PLEASE SHOW YOUR ID CARD  
FOR DISCOUNT  
BY ORDER  
MANAGEMENT, CCWH&RI

# WHO CARES? PROFESSIONAL CARERS

Average care worker in London = £10 per hour

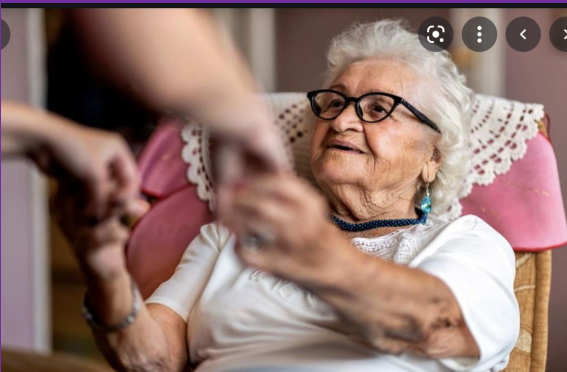
Average garbage collector in London = £14 per hour



# WHO CARES? FAMILY CAREGIVERS

In the US- 75% of all caregivers are women

Cuba and Venezuela - this figure rises to 81%



# WHO CARES ?



Caring for the Older Person with Love in Taiwan

## Who takes care of the elderly? Findings from rural South Africa

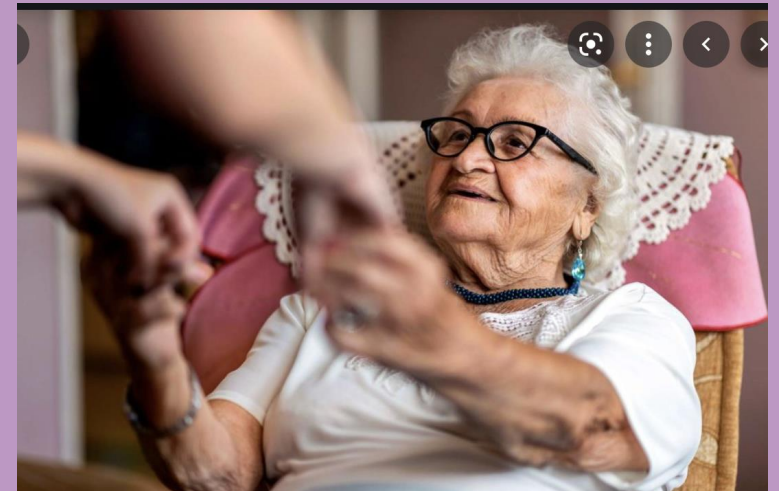
October 17, 2019 9.31am BST



# WHO CARES? FAMILY CAREGIVERS

Carers Allowance in the UK – is £62 per week

(equivalent to 6 hours pay)



# WHO CARES? FAMILY CAREGIVERS

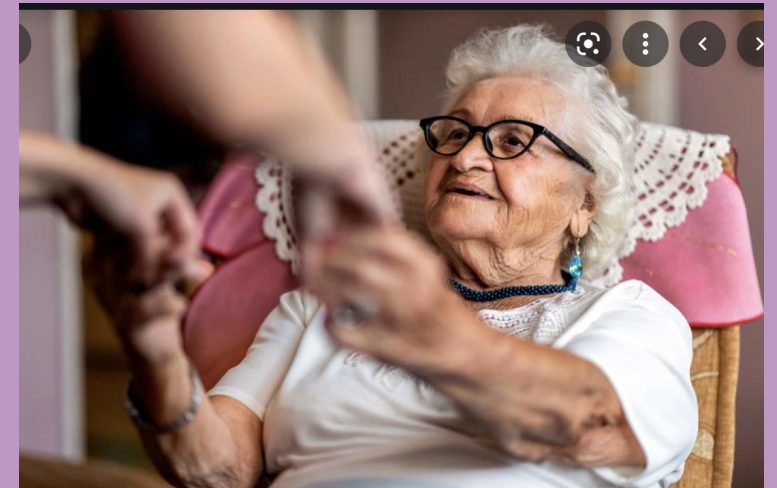
AARP PUBLIC POLICY INSTITUTE

NOVEMBER 2019

**Insight on the Issues**

## **Valuing the Invaluable: 2019 Update** *Charting a Path Forward*

Susan C. Reinhard, Lynn Friss Feinberg, Ari Houser, Rita Choula, and Molly Evans  
AARP Public Policy Institute



\$470 billion in 2017 in the US

£77 billion ++ in the UK

'the success of the global economy rests on women's unpaid work and on the environment ....

yet both are systematically ignored and undervalued by conventional economic measures'

Marilyn Waring

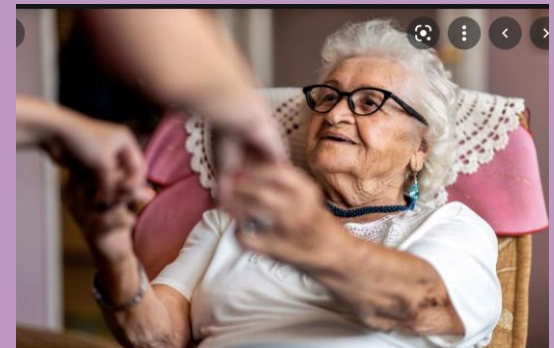
# COVID CRISIS.....

55%



of unpaid carers feel overwhelmed  
and are worried that they are going  
to burnout in the coming weeks

**Carers UK 2020**

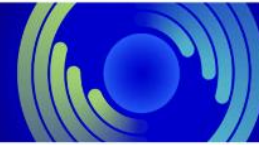




# COVID CRISIS.....



TACKLING CORONAVIRUS (COVID-19)  
CONTRIBUTING TO A GLOBAL EFFORT



OECD Policy Responses to Coronavirus (COVID-19)

## **Caregiving in Crisis: Gender inequality in paid and unpaid work during COVID-19**

13 December 2021

# EXPERIENCE OF CARE

More women globally have chronic kidney disease – but fewer offered dialysis

Carrero & Hecking 2018  
Nature Reviews Nephrology

# EXPERIENCE OF CARE

Women wait **65** minutes before receiving a pain killer for acute abdominal pain in the Emergency Dept compared to only 49 minutes for men.

Chen & Shofer 2008  
Acad Emerg Med



# WHERE DO PEOPLE DIE?

Home death assumed as a quality marker of a good ending

# WHERE DO PEOPLE DIE?

More women die in care homes

Low pay, low status, invisible....

Reflects not just ageism, but sexism.



# CARE CHOICES AT THE END OF LIFE?

women are less likely to choose life extending treatment than men

Miesfeldt: J Pall Med 2008

men are likely to receive aggressive, non-beneficial, treatment near death

Sharma : Cancer 2015

# POVERTY, GENDER AND DEATH?

...Most of the poor people in the world are women.

In no country on earth are women economically equal to men...

Guardian 2015

In India, 60% of older women have no assets in their name.

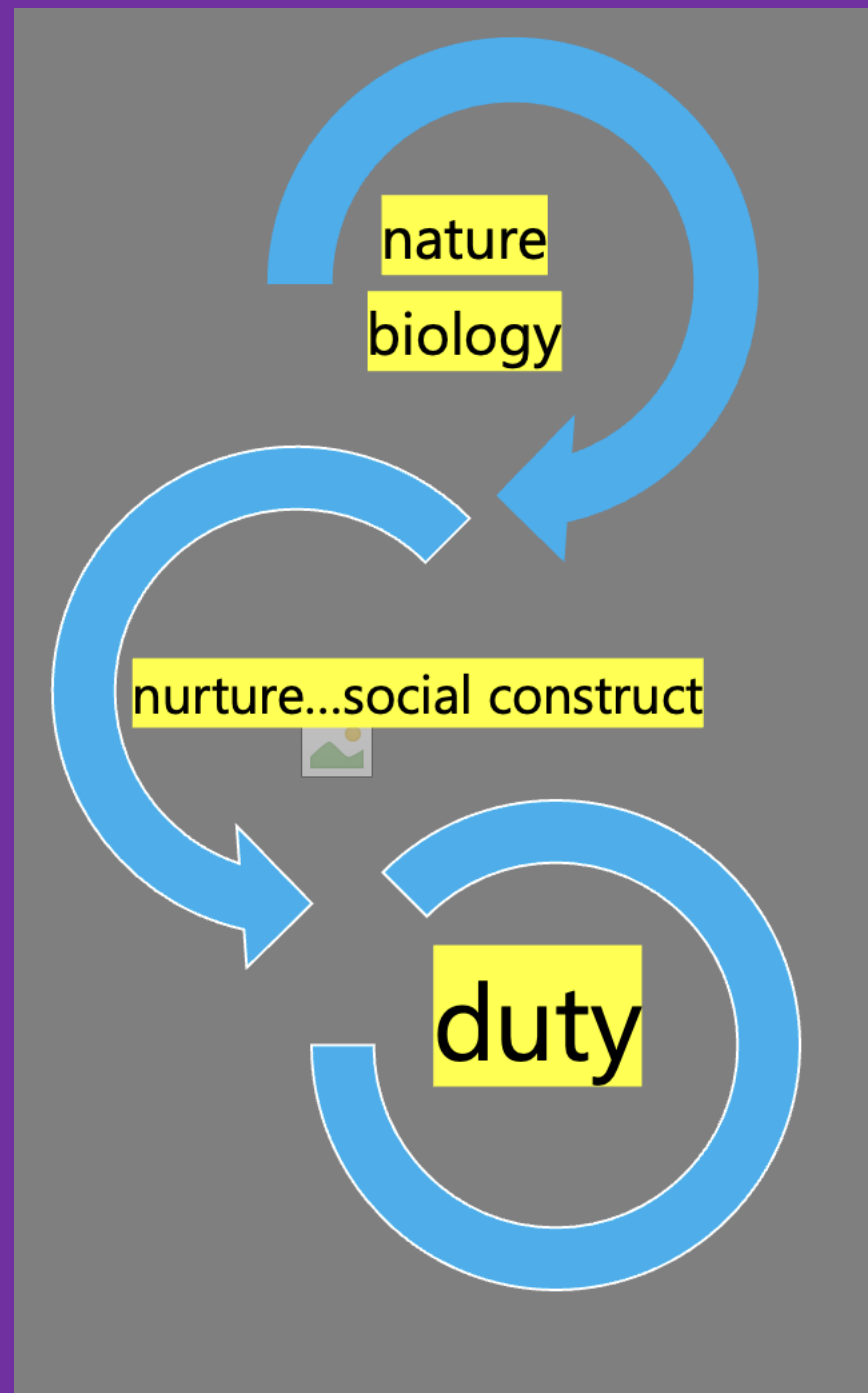
Gott 2020

# POVERTY, GENDER AND DEATH?

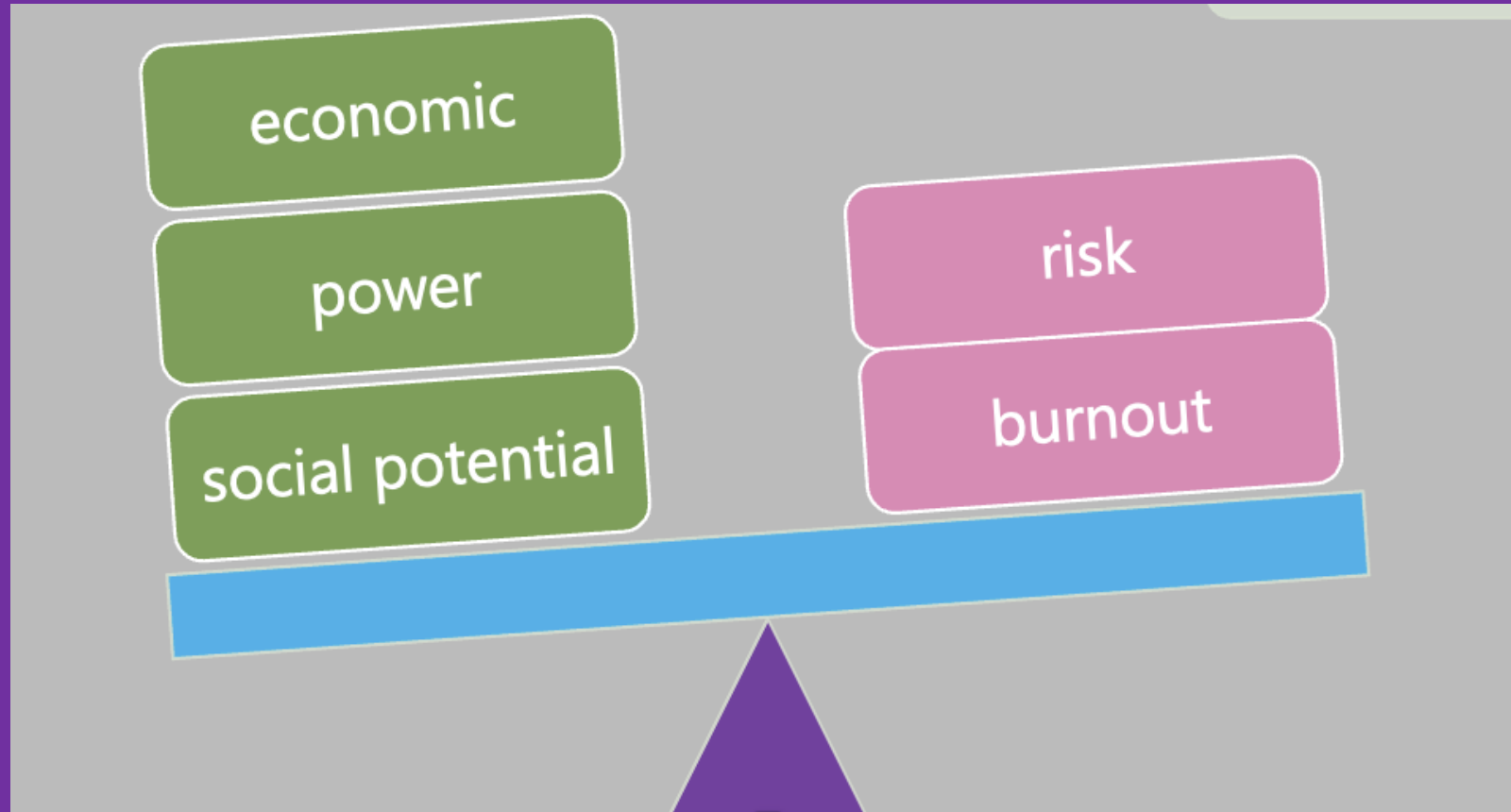
. "My home is not a nice place to live, she said, let alone a nice place to die."



WHY?



# IMPACT ON WOMEN



Applying feminist, multicultural, and social justice theory to diverse women who function as caregivers in end-of-life and palliative home care.

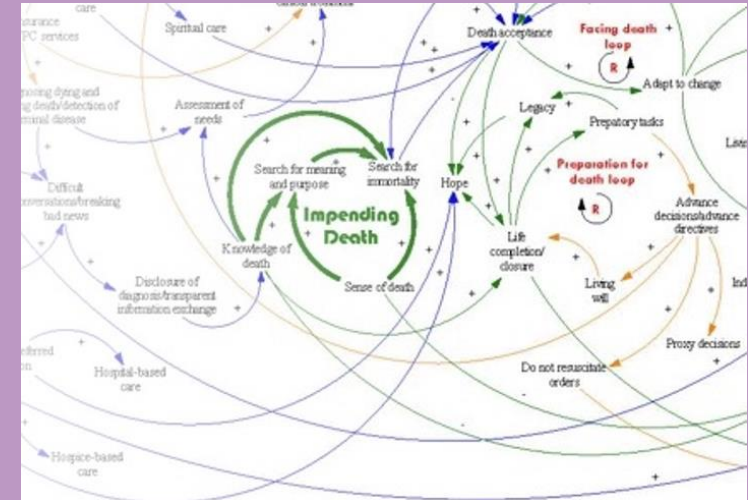
*Palliat Support Care*. 2009; **7**: 501-512.

CJ Mackinnon

# IMPACT ON DEATH SYSTEM

Delegated care or ...Relegated care

As social mobility increases we delegate the care of parents and children... to poorly paid women



THERE IS AN URGENT  
NEED TO ATTEND TO  
GENDER  
AS A SOCIAL  
DETERMINANT OF  
DYING

Realistic Utopia  
Lancet Commission Value of Death  
Section 12

# RECOMMENDATIONS TO REBALANCE POWER

Recognition of gender as a determinant of powerlessness

Coaching for care homes and informal carers

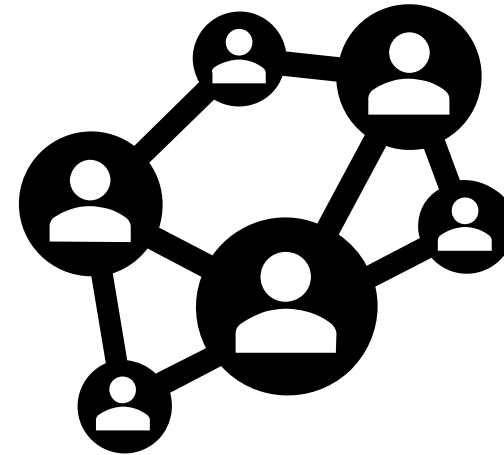
From lab to society, look through a gender lens

Benefits and leave for family carers eg frailty leave

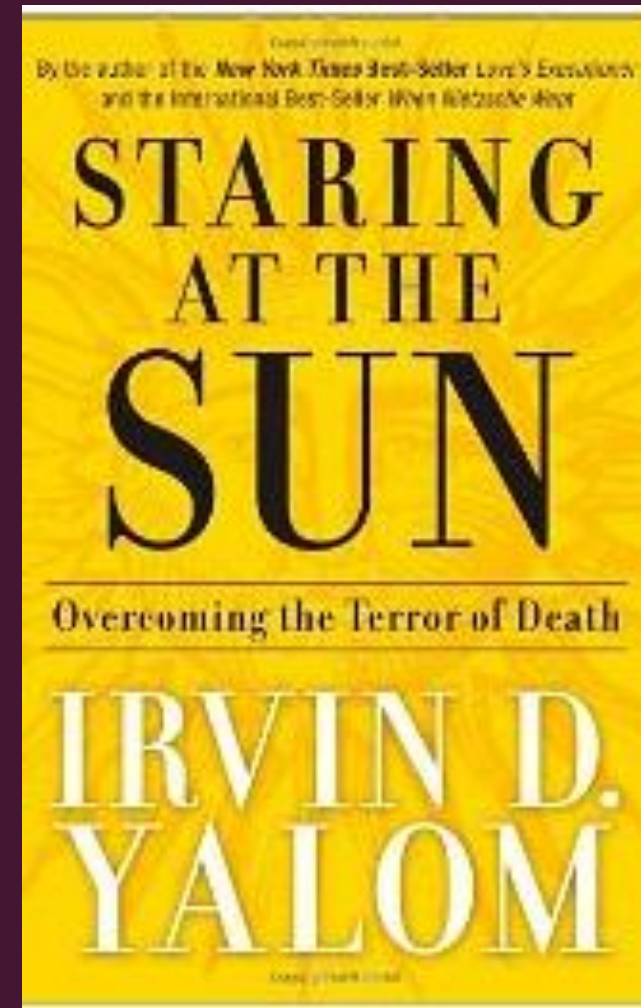
Status and pay parity for paid carers

## The realistic utopia of the Commission

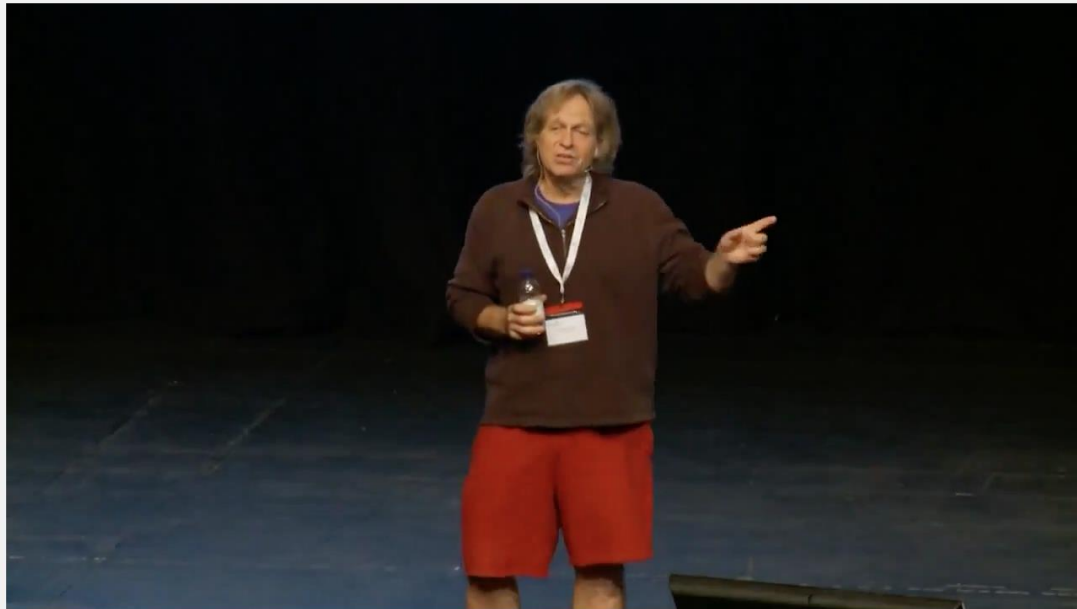
3. Networks of care lead support for people dying, caring, and grieving



people are  
anxious  
about dying



# Prof Sheldon Solomon



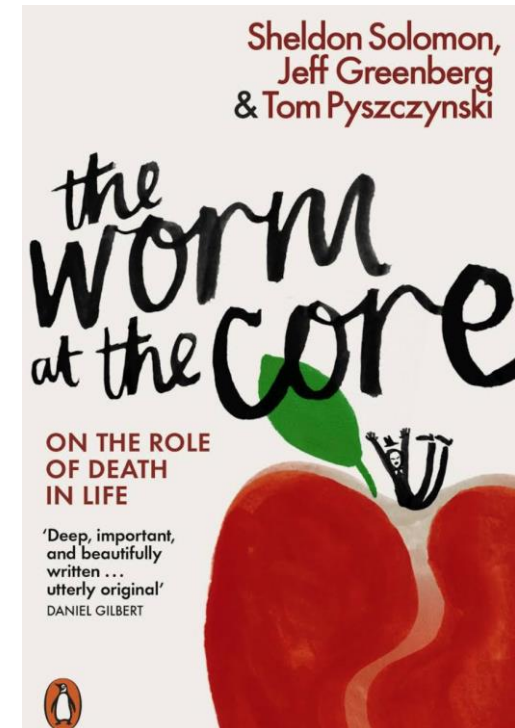
Video: Death anxiety – what does it mean for hospice care?



Hospice UK

 **Subscribe** 44

493 views





# *managing death anxiety*

*Promote  
connection*

+

*Self-  
esteem*

=

*Death  
Anxiety*



## Social Relationships and Mortality Risk: A Meta-analytic Review

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

Published: July 27, 2010 • DOI: 10.1371/journal.pmed.1000316

The quality and quantity of individuals' social relationships has been linked to morbidity and mortality

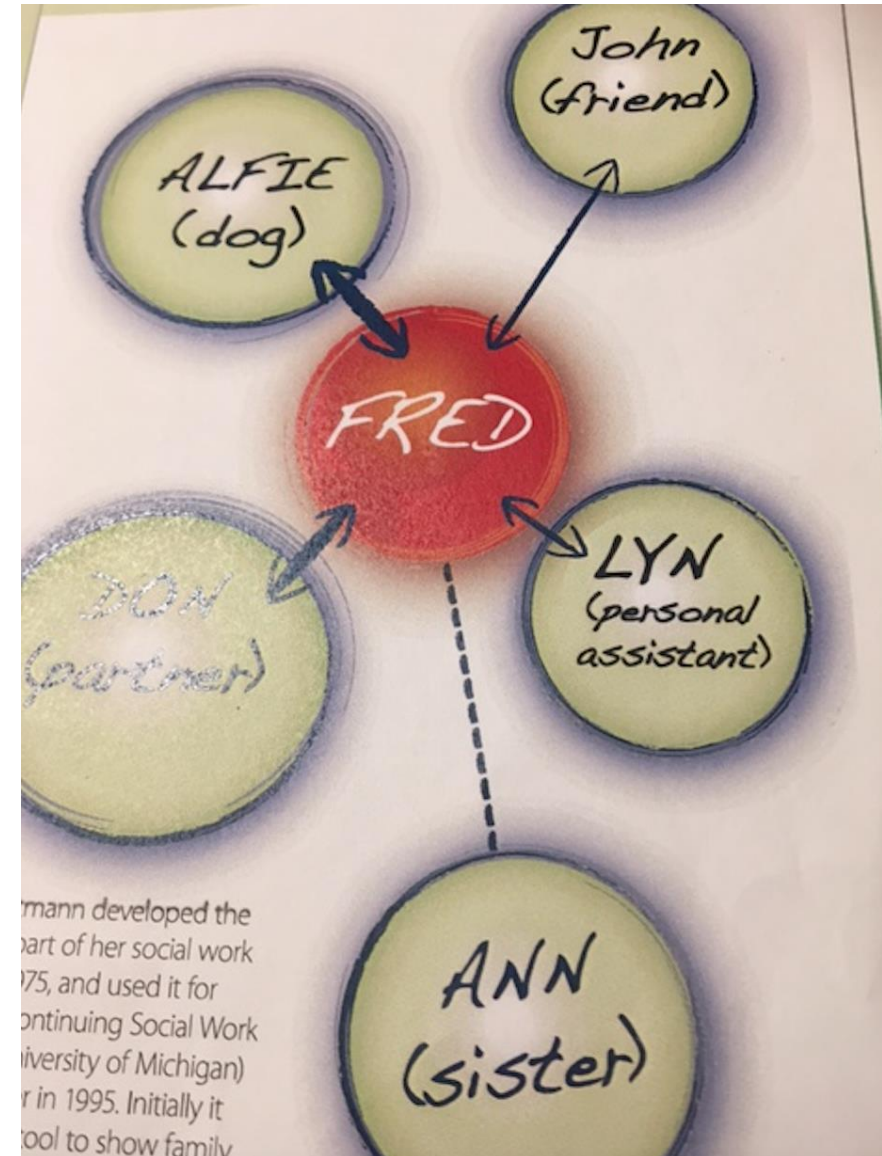


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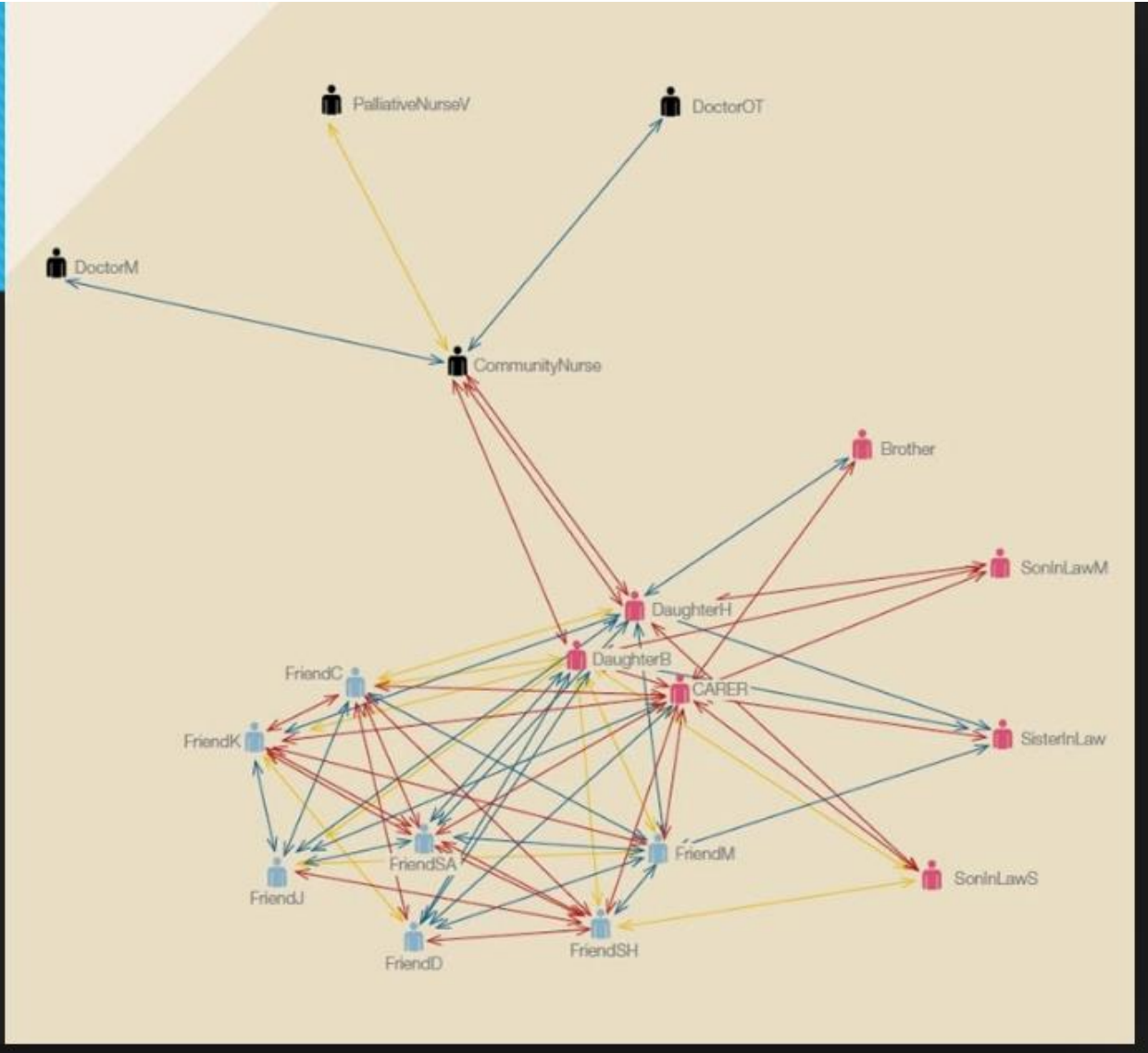
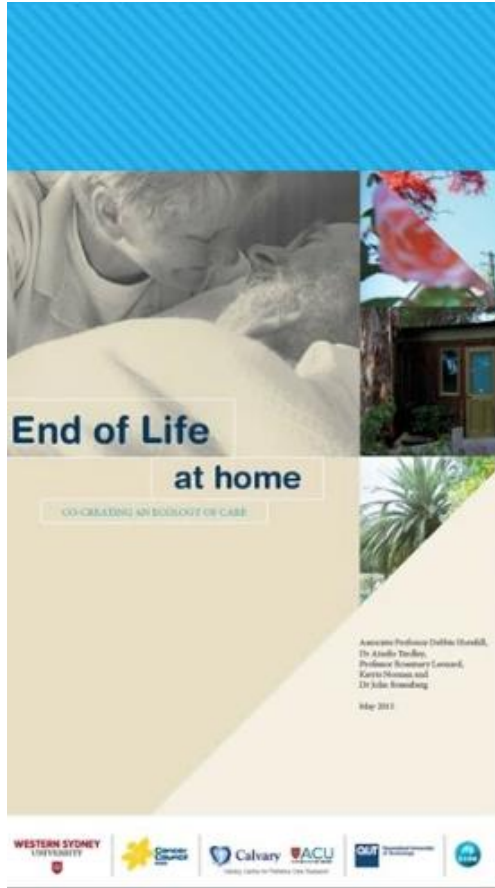
# Who matters to you?

*EcoMap*



**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?**



**8760 hours**

*what if.....*

**we trusted families to  
care and coached them?**

....





# *support carers in new ways*

- death brings family dynamics into focus
- **BUT** also brings
- resilience, coping, love and capability

# New public health in palliative care

**recognise the social nature of illness and dying**

**recognise local wisdom in communities**

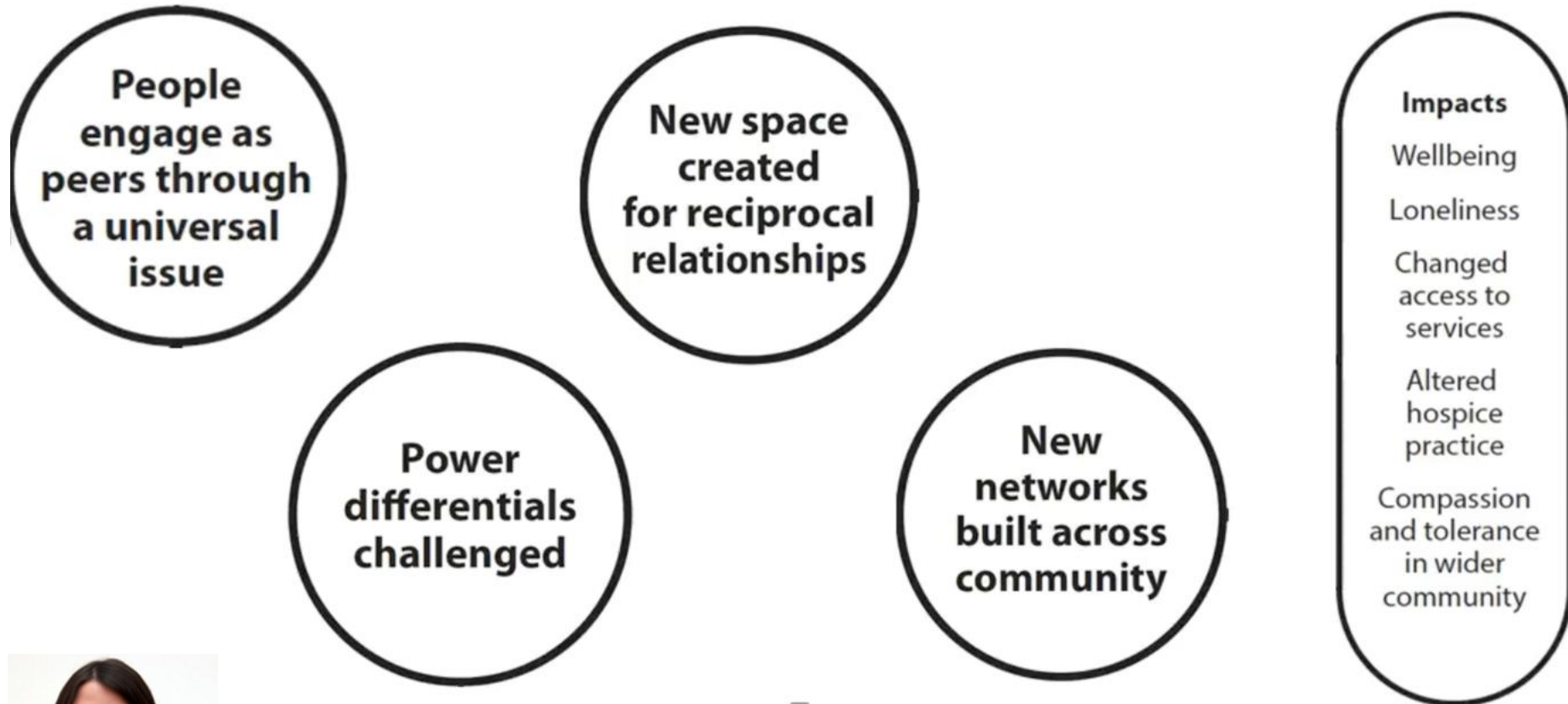
**done with and not to people**

The screenshot shows a website header for "Compassionate Neighbours" with a navigation menu including "ABOUT", "NEWS & EVENTS", "STORIES", "GET INVOLVED", "GET SUPPORT", "DONATE", and "CONTACTS". Below the header is a video player titled "Compassionate Neighbours - Reciprocity" from "Compassionate Neighbours". The video shows a man in a blue checkered shirt and a dark cap. To the right of the video is a green text box with the title "Reciprocity" and a quote: "It has changed him a lot and changed me too" by Kito. The video player has a play button, a progress bar at 01:17, and a Vimeo logo.

Relationships as mutual and reciprocal



# How compassionate communities are created



**power**



WhatsApp

## *Care of Harry - Group*

**Yes.... it was a real support mechanism for us and we thank you for the opportunity. It should definitely be part of the discharge criteria! You have our support! Thank you**

18:07



*Dr Kieran Sweeney*

A hesitation  
to be brave....



*Healing Connections: On moving from  
Suffering to a sense of Well-Being*

*Journal of Pain & Symptom Management 2007*

*Vol 33(4): 372*

## Examples of our recommendations

### For all

Relationships are central  
Death literacy built for all  
Partnership approach is important

### Civil society

Community action  
Stories of 'ordinary dying' shared  
Rituals and traditions preserved

### Health and social care systems

Healthcare profs competence  
Guidelines on withholding/withdrawing  
Relief of suffering as a goal

### Researchers and funders

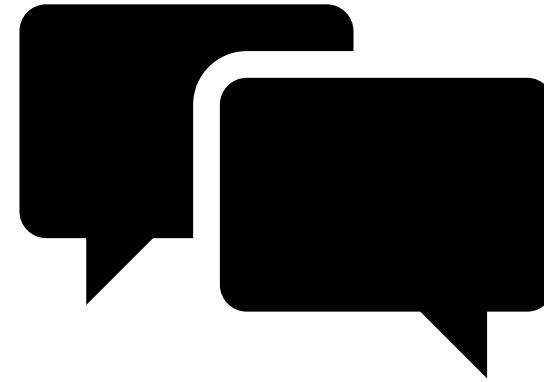
Focus on systems change outside healthcare  
Define over treatment at EOL  
Digital technology

### Governments and policy makers

End the silence on death in policies  
Out-of-pocket expenditure  
Compassionate leave policies

# The realistic utopia of the Commission

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





**Dr Ros Taylor** ❤️ @hospicedoctor · 1 Jan

Phoebe died by [#suicide](#) in 2021

Life in 2022 without her seems such a daunting prospect

So planning a Phoebe Day off work each month

To remember deeply, to meet with her friends, to walk in her steps, to plan her legacy, to eat ice-cream, olives and drink cocktails



Hi Ros, you don't know me but I just wanted to say you've had a huge impact on my life (and I'm sure the same of others). Your story and openness about Phoebe made me not carry on with my suicide attempt. I hope this message doesn't cause any upset - I just felt you needed to know the huge impact your tweets have.

# The realistic utopia of the Commission

5. Death is  
recognized as  
having value

