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THE CENTRE  
FOR AWARENESS  
& RESPONSE TO  
END OF LIFE

# Improving End of Life through community participation

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# Overview of presentation

**1. Why bother with community participation at end of life?**

**2. Who needs to participate and to what benefit?**

**3. What's the interface between community involvement and professional services?**

**4. How is such an approach enabled and to what end?**

**Why bother with community participation at end of life?**

# Why bother?

## Some starting propositions

- The relationship we have with death, dying and loss is unsatisfactory
- When people are dying or face loss their experiences are often poor and outcomes could be improved
- The increasingly professionalised and specialist approach within healthcare that we have adopted in recent years has not successfully redressed this problem
- The challenges are only likely to increase with growing and changing needs at end of life

“The idea of death, the fear of it, haunts the human animal like nothing else,”  
Earnest Becker in *The Denial of Death*

## How Long Do You Want to Live? This Technology Could Potentially Help People Live Forever

The idea of dying may become a thing of the past in the next 40-100 years.



By Donovan Alexander

Mar 22, 2020



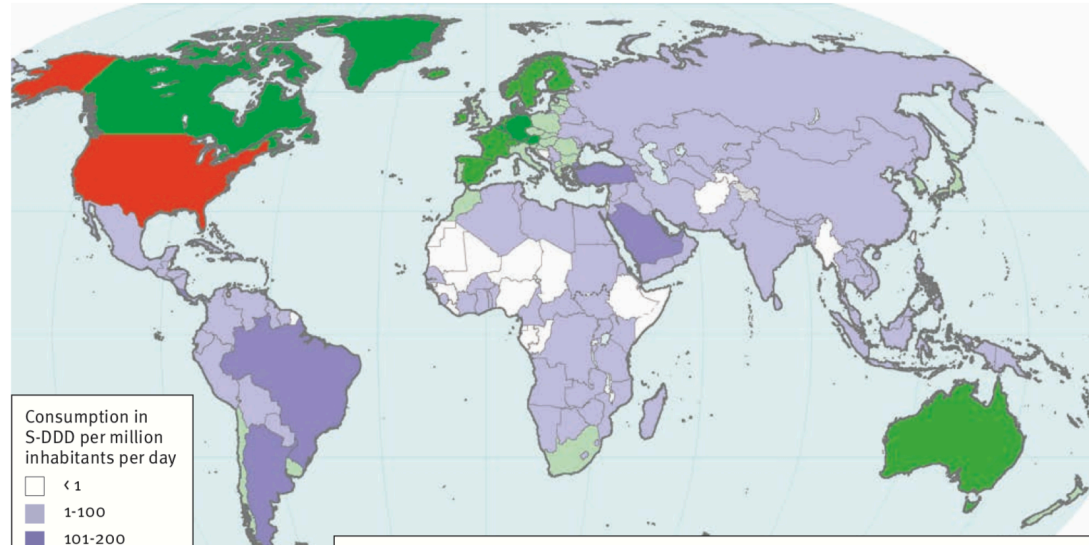
Here's what people in their 90s  
really think about death

May 19, 2016 8:38pm BST

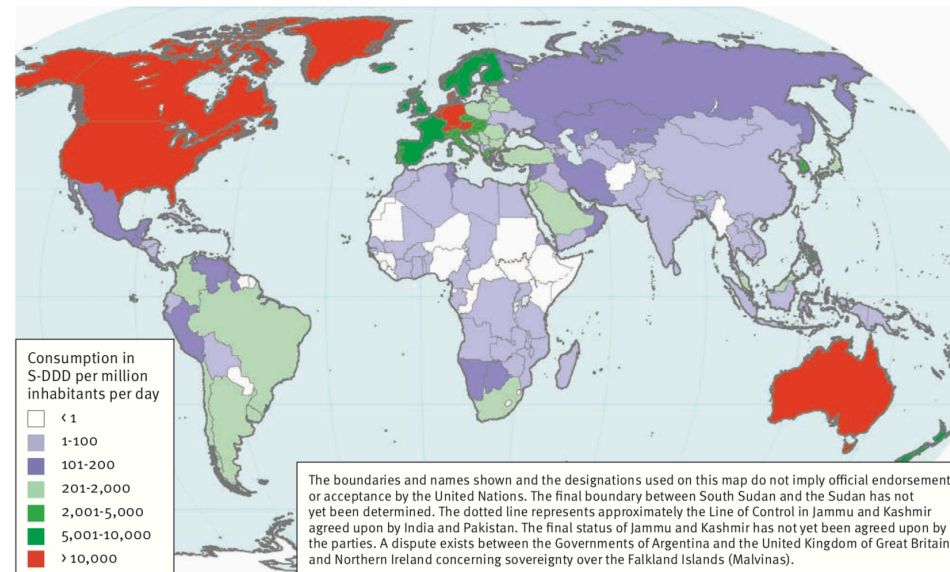


# At a global level this picture is even more disturbing

Map 1. Availability of opioids for pain management (2001-2003 average)



Map 2. Availability of opioids for pain management (2011-2013 average)



## Unacceptable inequalities exist

- x Availability of palliative care services
- x Availability of pain relief
- x Investment in general health
- x Lack of choice and autonomy

The burden of serious health-related suffering is huge and could in large part be alleviated with palliative care and pain relief....

Too little change to this situation over the last 20 years or so

The *Lancet* Commission on Palliative Care and Pain Relief—findings, recommendations, and future directions

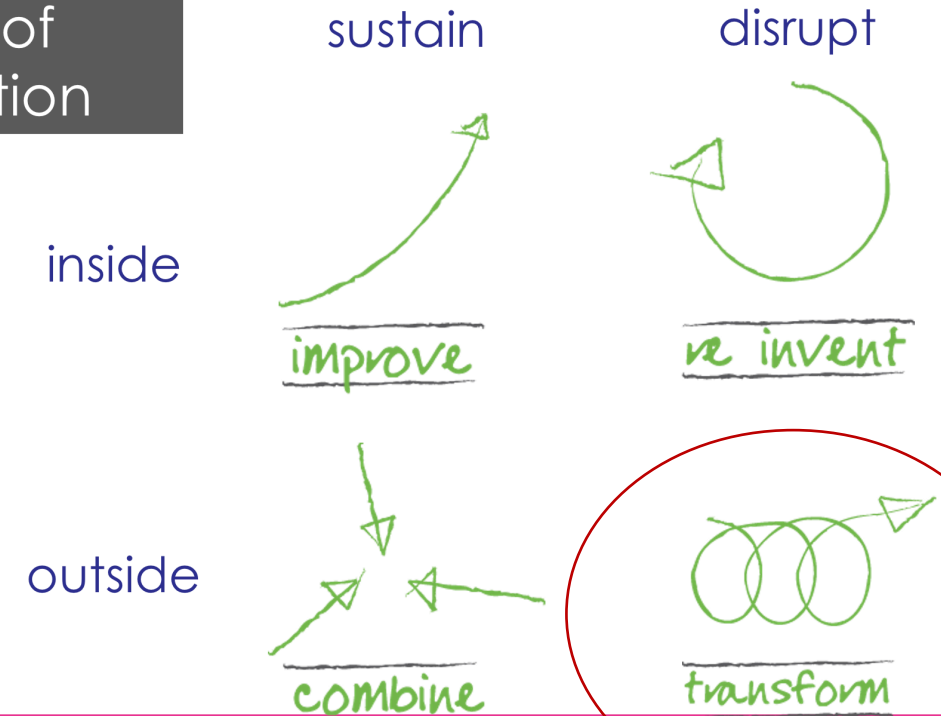
Felicia M Knaul • Afsan Bhadelia • Natalia M Rodriguez • Hector Arreola-Ornelas • Camilla Zimmermann

# So what's the answer?

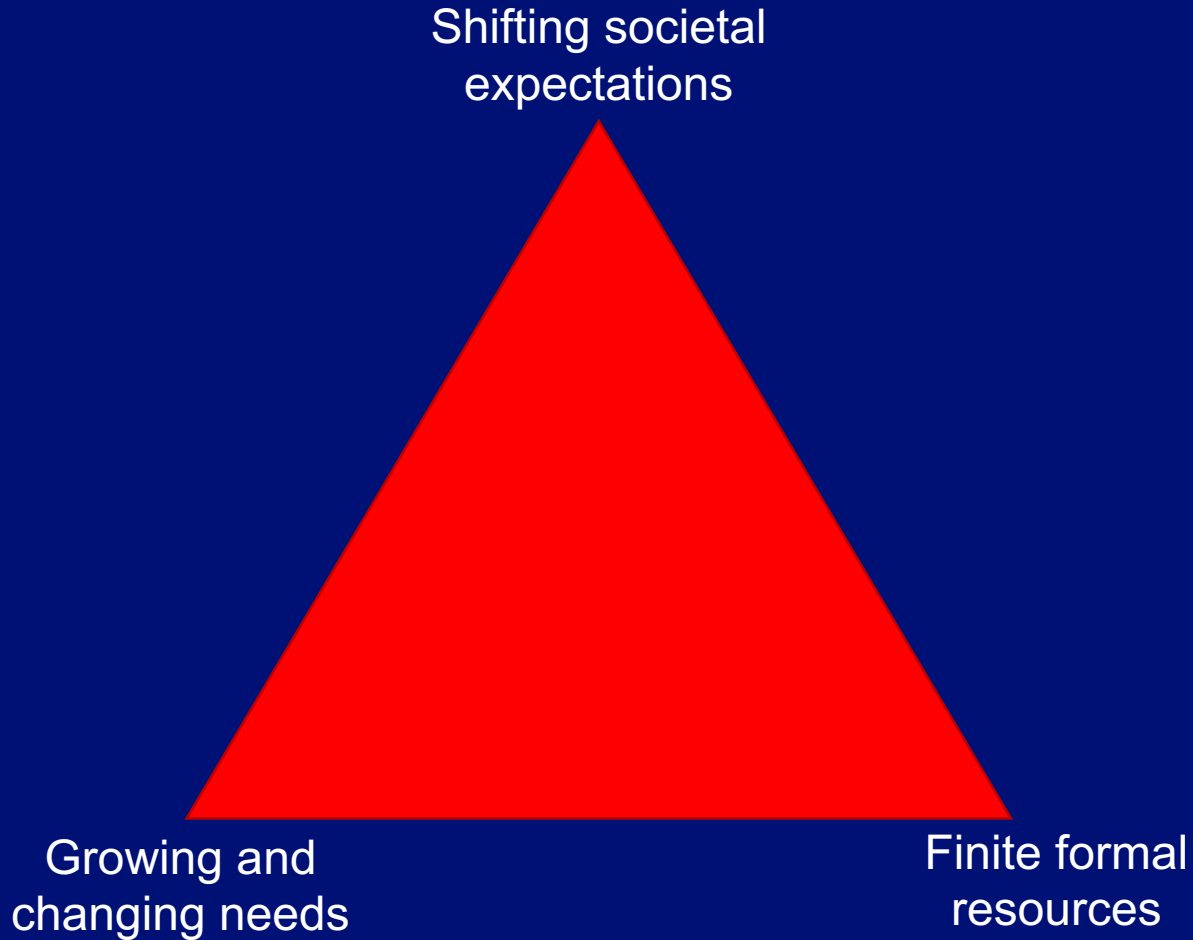
## Our response must be radical

- Reframing death, dying and loss beyond healthcare
- Recognising needs and opportunities beyond those that professional services can address
- Thinking about new and different participants
- Resetting parameters related to living and dying well and how that is achieved
- Building on the "opportunities" of COVID

4 kinds of innovation

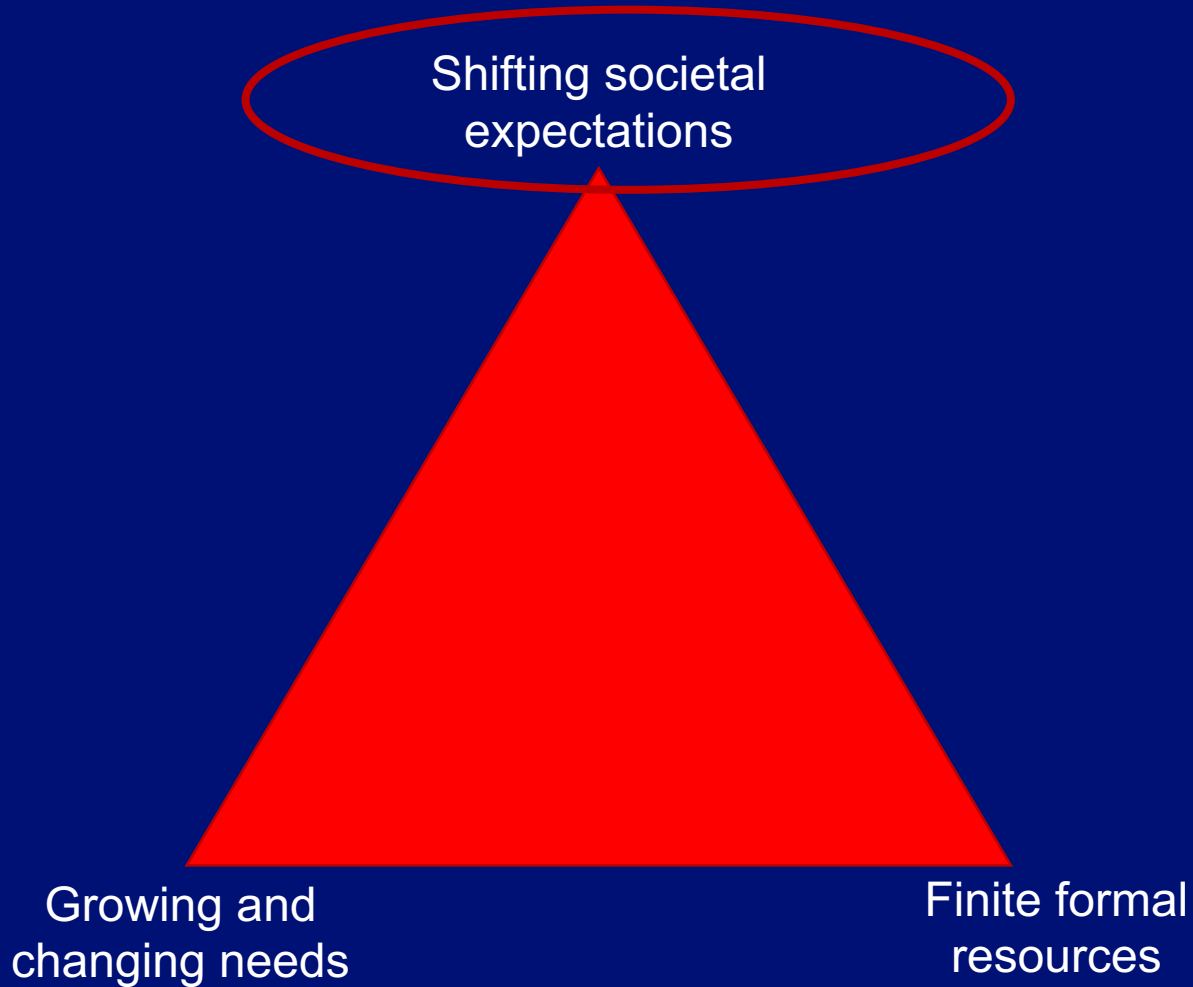


# What is at the heart of the current challenges in end of life?



- Growing numbers of people, particularly those living into late old age with multiple morbidities
- Lack of investment into end-of-life care or in period of life preceding this
- Limited professional workforce availability – numbers, skills, flexibility, full time presence
- Changing preferences and requirements on the part of individuals and society related to health and illness and their management

# But is this also where our solution lies?



- People are willing to challenge civil authority when it appears unfair
- Many people are taking greater responsibility for their own wellbeing and that of others in their households and communities
- They recognize that investment now may improve their health and wellbeing long term
- People have recently enjoyed more freedom and opportunity to enact intentions to support each other within a frame of civic responsibility



We saw this clearly in the COVID-19 pandemic in the UK..



<https://blogs.lse.ac.uk/covid19/2021/05/06/where-next-for-britains-4300-mutual-aid-groups/>



*I wanted to help because I suffer with poor mental health; and for me being involved in this and helping others actually helps me too by giving me a sense of purpose. Volunteer, Dons Local Action Group*



**Who needs to participate?**

# Who needs to be involved?

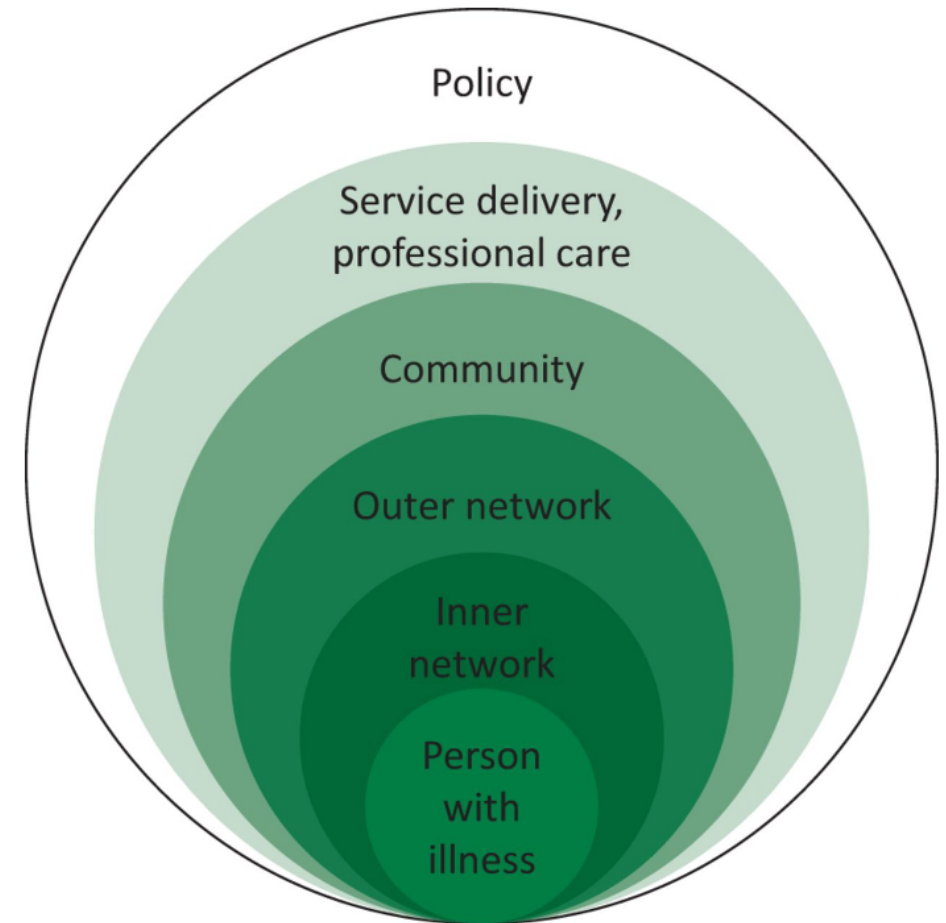
Thinking about “who?” and “how?” is best considered through a social ecology lens:

1. So that you give attention to the naturally existing supportive network around people who are dying in planning professional involvement
2. So that you where you engage with those who are most important in the lives of the person who is unwell
3. So that you don't deny people who are dying what they value most – relationships, connectivity, familiarity
4. So that you don't inadvertently deny carers the opportunity to participate, shape care and fulfil promises to self and others in relation to this role

“Failure to engage with and trust the caring network not only misses an important opportunity for enriching life for patient and carers, it may actually cause significant harm which can exacerbate bereavement reactions”

*Rosenberg et al Death Stud 2017:1–9*

Circles of care.



Julian Abel Clin Med 2018;18:6-8

# What happens when this approach is enacted and respected?

## Growing body of research about the opportunities and their value

From Australia: considering caring at end of life as an opportunity to increase social networks and community capacity

Key findings:



1. Appetite existed to resist the Western expert-based approach to EOL care
2. Carers successfully mobilised and negotiated complex webs of relationships;
3. Embodied learning about caring contributed to the development of social capital and compassionate communities.

Bringing our Dying Home: How caring for someone at end of life builds social capital and develops compassionate communities

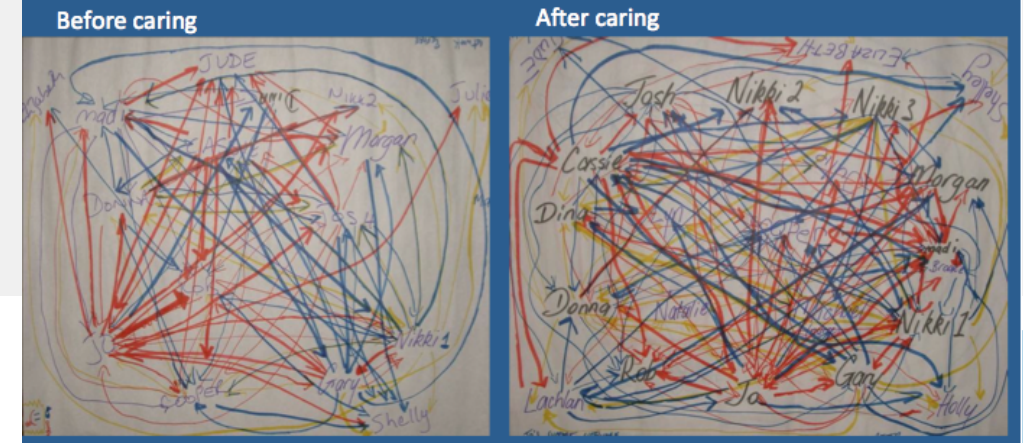
January 2013 · Health Sociology Review 21(4):373-382

DOI: [10.5172/hesr.2012.21.4.373](https://doi.org/10.5172/hesr.2012.21.4.373)

Project: Caring at End of Life

 Debbie Horsfall ·  Kerrie Noonan ·  Rosemary Leonard

## How the networks changed



# It makes a difference to the quality of caring and dying....

## “It takes a community”

“There’s a strength in numbers and knowing that you’ve got good people around you who don’t care what you say, don’t care what you look like, don’t care how things are but will always be there for you and not just say they’ll be there for you.

They do things sometimes without you even noticing and don’t expect to be appreciated. Sometimes you don’t get the chance to say, ‘I really appreciate it’ but you intrinsically know that they know. It’s almost organic isn’t it?”



Courtesy of Kerrie Noonan



# It has benefits for others too....

## Reflecting on the programme Compassionate Neighbours (UK):

- ✓ Upstream as well as downstream impact
- ✓ Changes in the experience of wellbeing on the part of individuals involved
- ✓ New skills and confidence
- ✓ New relationships
- ✓ Compassion and tolerance beyond the programme

Ref: Sallnow PhD 2017

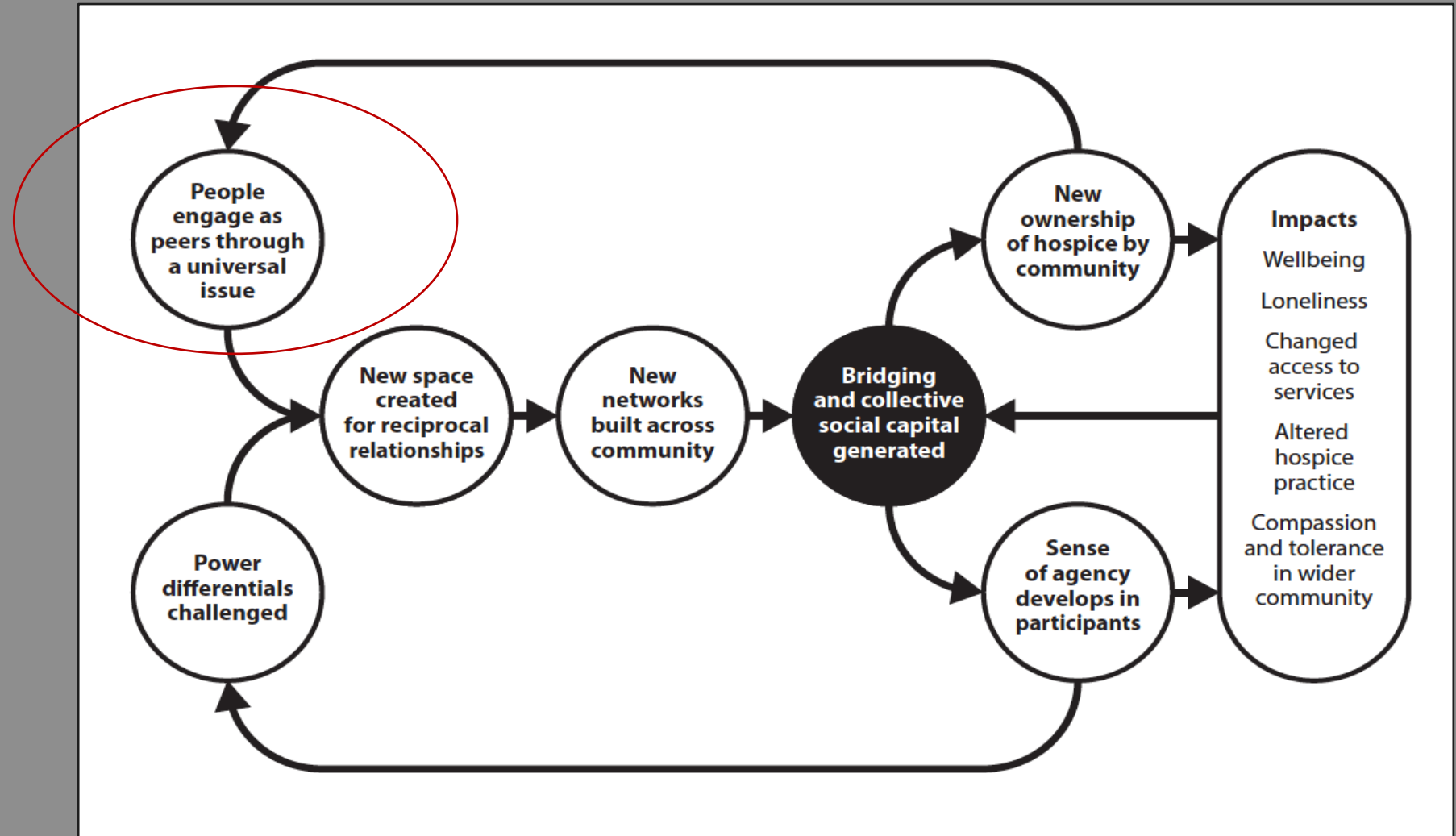
All about  
living well!





# Death and related loss has some qualities that make civic involvement easier to get underway...

It is arguably the greatest leveller in society – because it happens to everyone regardless of who you are, where and how you live .....



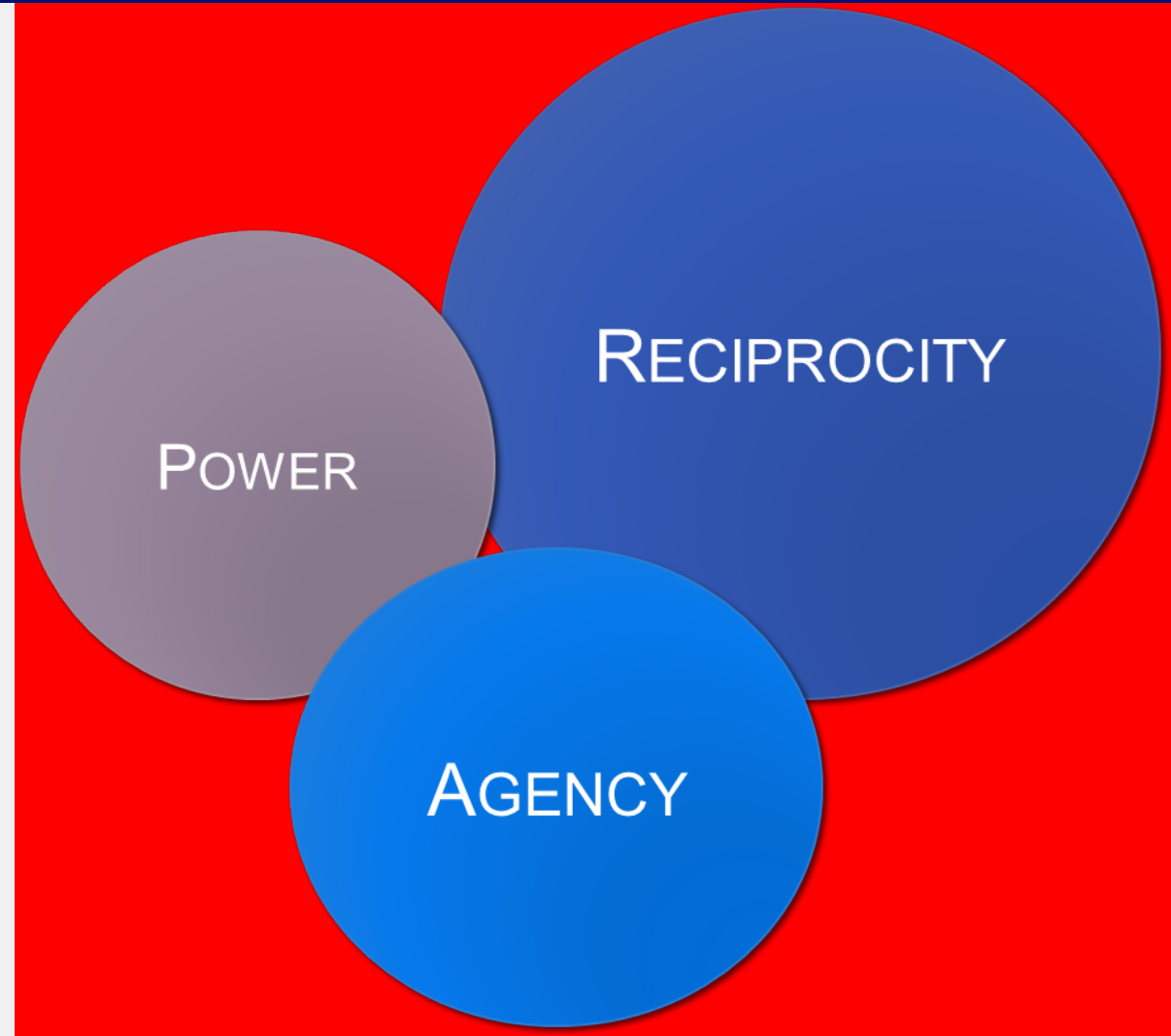
Sallnow, L (2017) Collective Social Capital: a new model of social capital in end-of-life care

# Some interesting things can happen in this space

- Power is more equitably shared
- People feel more empowered to shape their own position, contribution and experience of end of life
- There is much more give and take within the many different relationships that exist and are generated

## But:

- Professionals cease to have centre stage
- The relationships they must negotiate extend beyond the patient, health and social care
- They are no longer in control



### **3. What's the interface between community involvement and professional services in theory and in practice?**

# This is an important interface to navigate..

“Our challenge is to help people to achieve what is most important to them at the end of life. That will require the creation of a network of health and social supports so that people can die at and closer to home, with the support of their family and friends, as well as professionals”

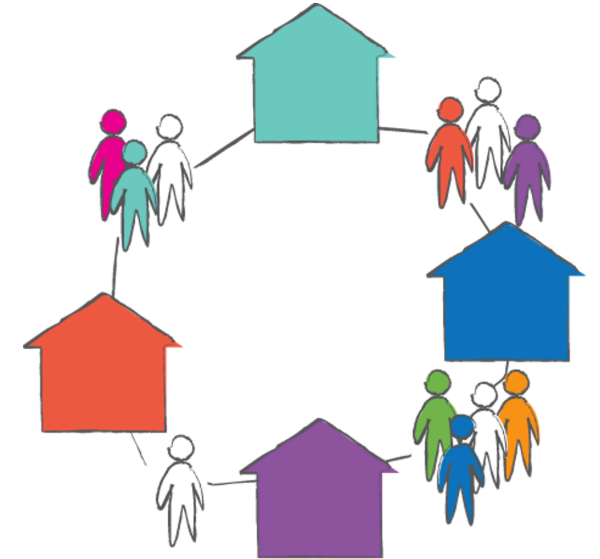
Ref: Dying for Change. Leadbeater and Garber 2010.  
Demos

## Social system for dying

From institutions to  
communities

From process to  
relationships

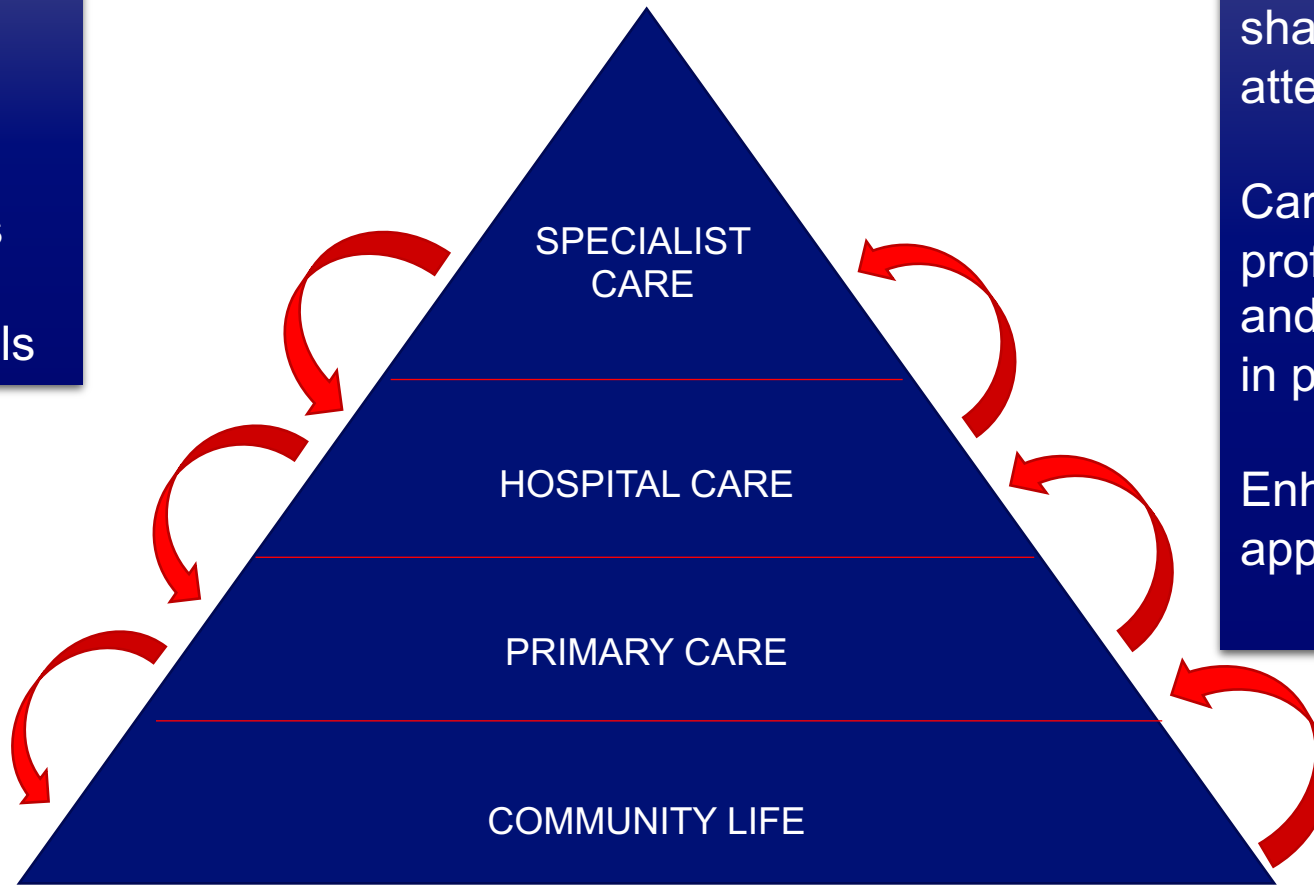
From services to and  
for people, to  
creating solutions  
with and by them



### Key characteristics:

Across private, public and NGO sectors

Draws in communities and their members alongside professionals



### Inter-relationships:

Quality of care and coverage shaped by national policy that attends to inequalities

Care made available by professionals, lay health workers and community members trained in palliative care

Enhanced by availability of appropriate medications



# Our related ambitions at St Christopher's

**StChristopher's**  
More than just a hospice

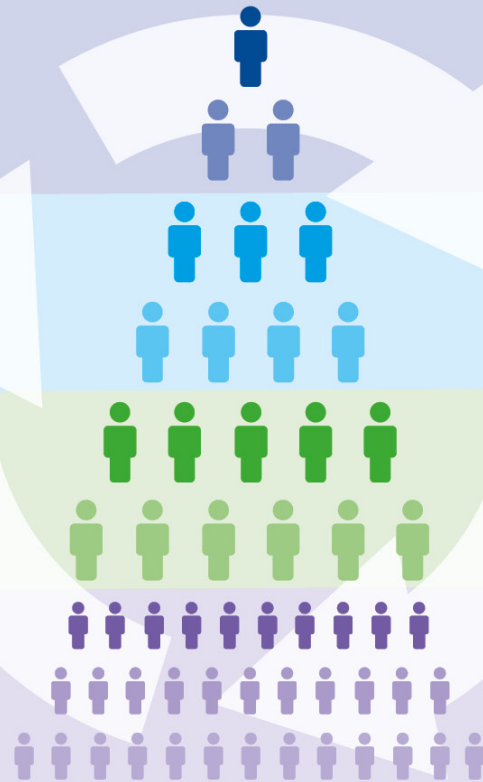
what we offer

DIRECT CARE  
AND SUPPORT

A RESOURCE TO  
OTHER SERVICES AND  
PROFESSIONALS

PUBLIC SUPPORT AND  
EDUCATION

SOCIETAL  
CHANGE



- Building on expert specialist care that we have been extending and refining over the last 50 years
- Integrating our education and training offer
- Extending new training and information offers to local people to enable them to assume greater control
- Promoting new conversations, expectations and roles in the public arena

Underpinned by a new approach to risk, investment in community action, new spaces for the public to engage with professionals and learn together and new structures to support social innovation

## 4. How is such an approach enabled and to what end?

# At St Christopher's

1. Development of death literacy as a means of widening participation

*Building foundational knowledge, skills and capability to enable individuals to deal well with death dying and loss and to act with broader social benefit*

2. Drawing on lived experience by working with people with a direct experience of death dying and loss

*Supporting those going through a particular experience to act to improve their own experiences with broader social benefit*

3. Facilitating organisational change through advocacy and teaching

*Enabling colleagues and other organisation understand power sharing and shared leadership, social innovation principles and participation as a basis for supporting social change*



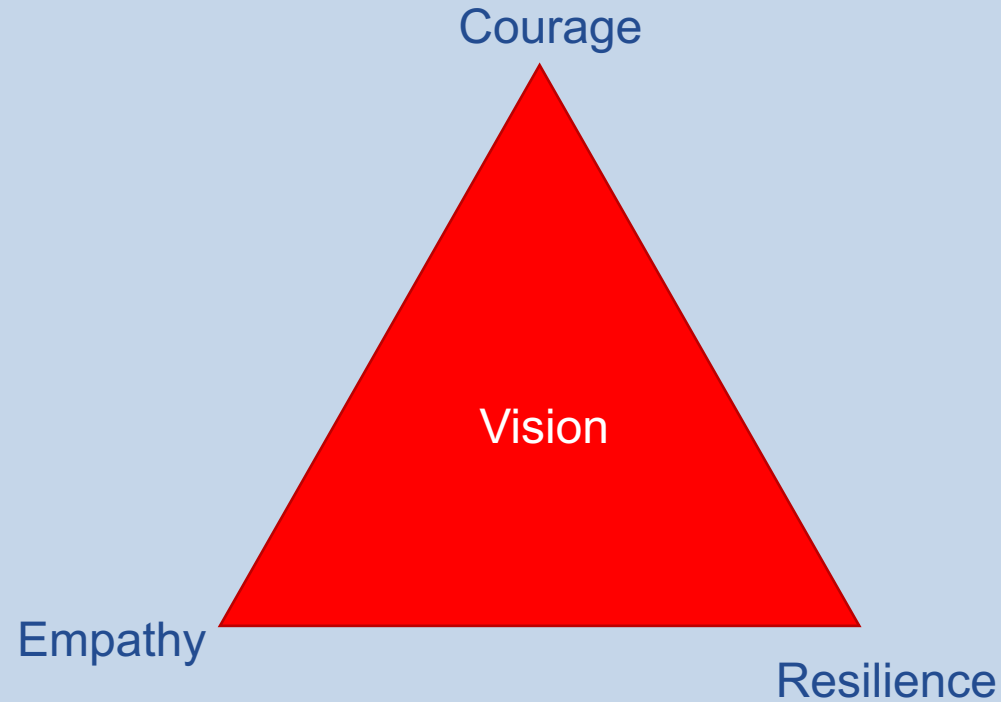
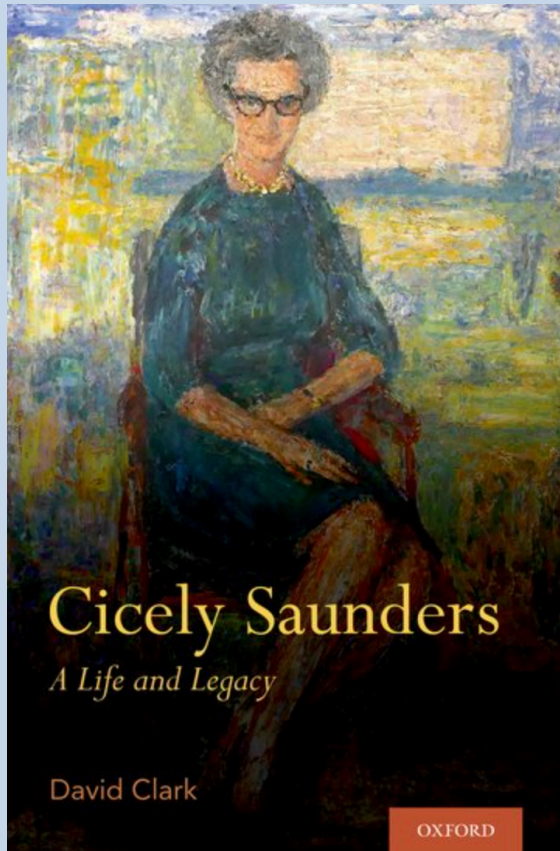
# A Cross cutting approach



**AND  
ACROSS**

Connected by aspirations for a different world  
Sharing: Expertise, skills, time and energy, insights, relationships

# It is about starting a new social movement



[https://www.ted.com/talks/derek\\_sivers\\_how\\_to\\_start\\_a\\_movement?language=en](https://www.ted.com/talks/derek_sivers_how_to_start_a_movement?language=en)



## SOME GREAT REPORTS OF CHANGE

I was present in house when my community member died and so able to support her daughter, then help her sort stuff out

**I've got a good insight into my community member's lives and background e.g. how they came to UK. Its been good fun**

Great scheme. I've realised that the reaction of my community member to her grief was similar to my own reaction and that my grief wasn't strange

Great sense of purpose, doing some good, contributing to community

**My community member is "happy as Larry" and we always have something to chat about. I know what really interests her now"**

**"I feel so inspired by my community member! She tries to keep herself active in the house. I have been self-isolating and I live on my own so it was so nice to get to talk to her."**

**"I'm so glad I have this to do. I'm feeling really positive for having helped someone. Its helping me to help out."**



# Final thoughts

**Community participation in end of life might feel like a challenging proposal**

**It is certainly counter -cultural in most resource rich countries in which health care is well developed**

**But it has huge benefits for individuals facing end of life or bereavement, their households and communities, institutions involved in their care and the wider system**

**It requires a different mindset and willingness to share power, risk and opportunity**

**It could make all the difference.....**

## **A realistic utopia in which:**

- The social determinants of avoidable deaths and avoidable suffering are addressed;
- Dying is recognised as a relational and spiritual process;
- Communities and their health and social care systems work in partnership;
- The conditions that allow people to die well are available to all;
- The value of death is recognised.

*Ref: Upcoming Lancet Commission into the value of dying*

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