Ethical challenges for hospice trustees

Dr Julian Abel

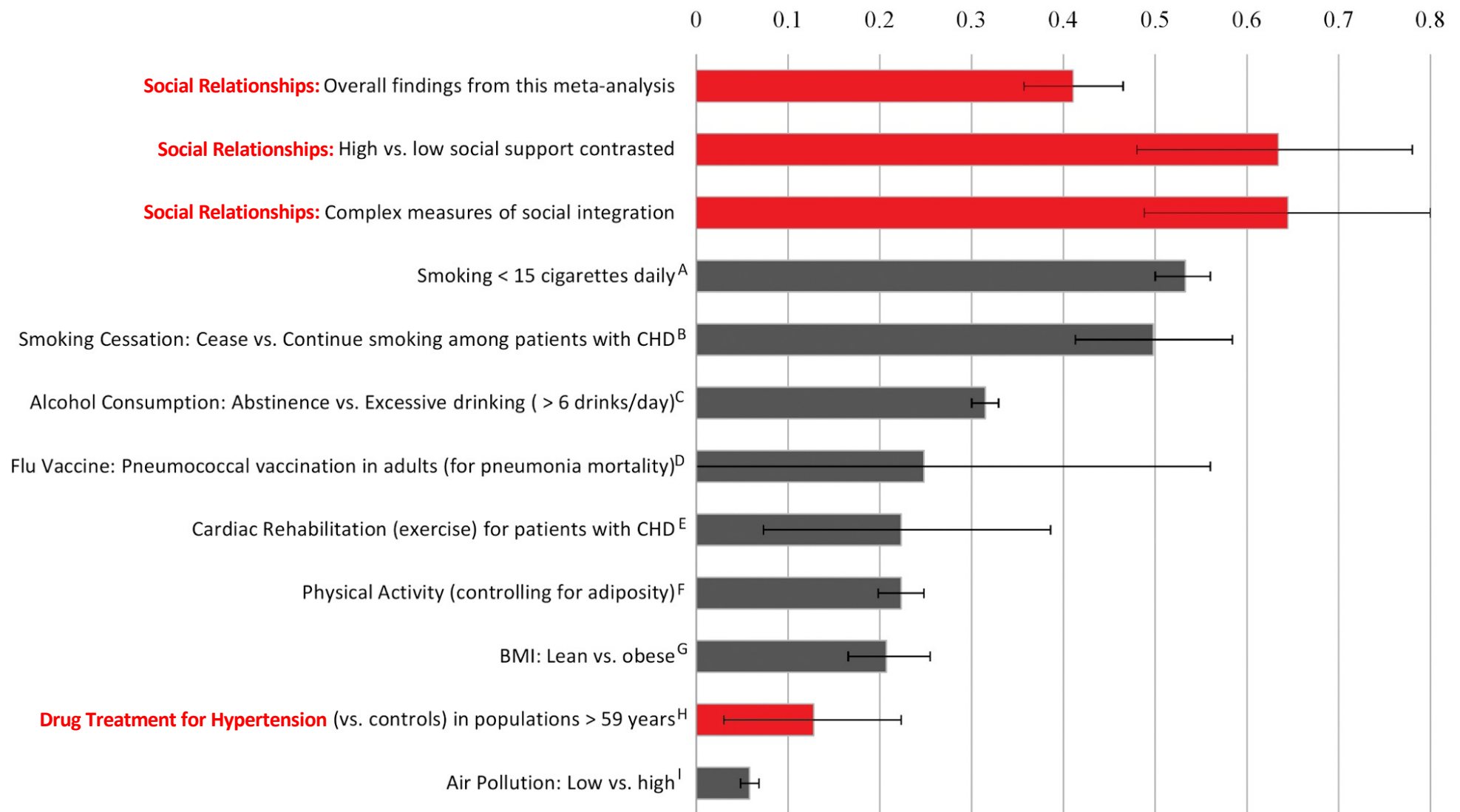Director, Compassionate Communities UK

Scene setting

- Introductions and current challenges and approaches
- Setting the scene – a bit of background about public health palliative care
- Discussion of implications and plotting a way forward

Three major weaknesses of current palliative care model

1. Deficit focus rather than living well
2. Equity
3. Bereavement

1. Comparison of odds (lnOR) of decreased mortality across several conditions associated with mortality.

Holt-Lunstad J, Smith TB, Layton JB (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. PLOS Medicine 7(7): e1000316. https://doi.org/10.1371/journal.pmed.1000316
https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000316

1. Deficit focus rather than living well

- Control of symptoms and needs assessment does not mean to living well

- Literature on what living well means at end of life

- Humans are social animals

Compassion is a potential in all of us

Part of our evolutionary heritage – survival of the kindest.

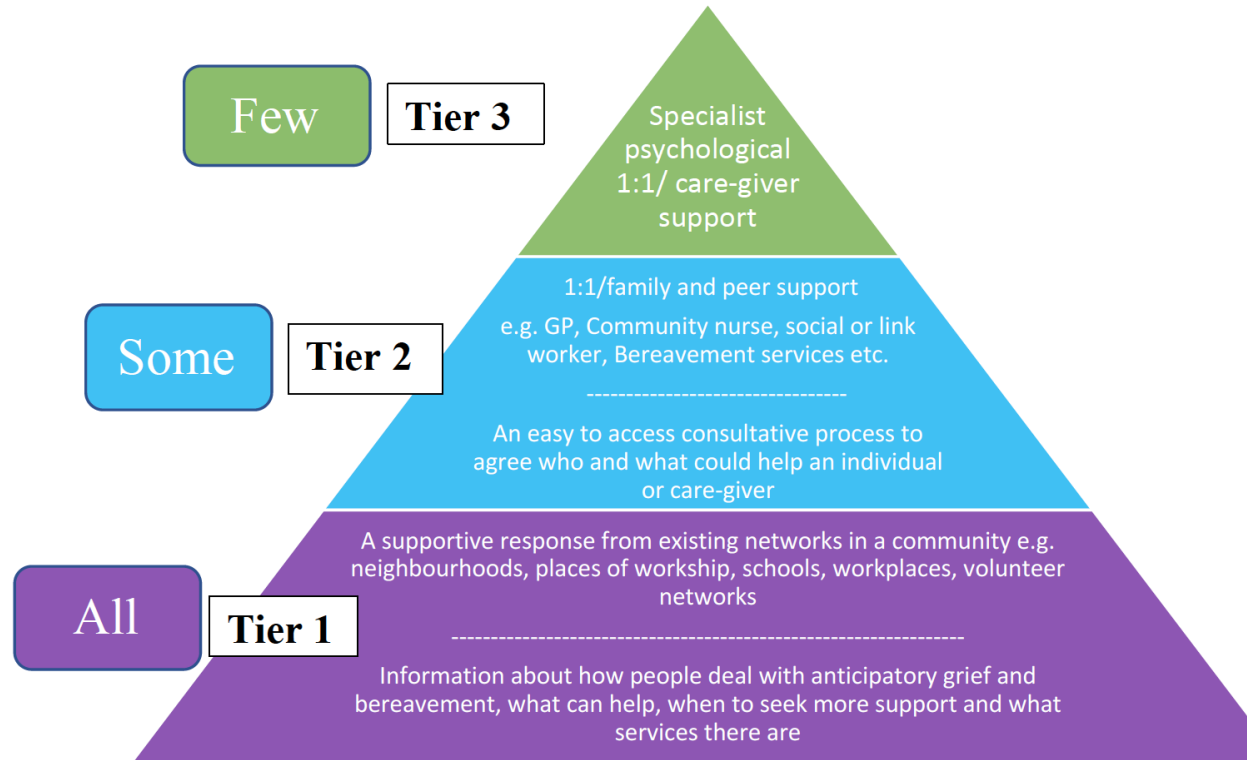Found in every part of us, genomics, biochemistry, physiology, behaviour, social etc

We have to recognise it within us before we do anything else
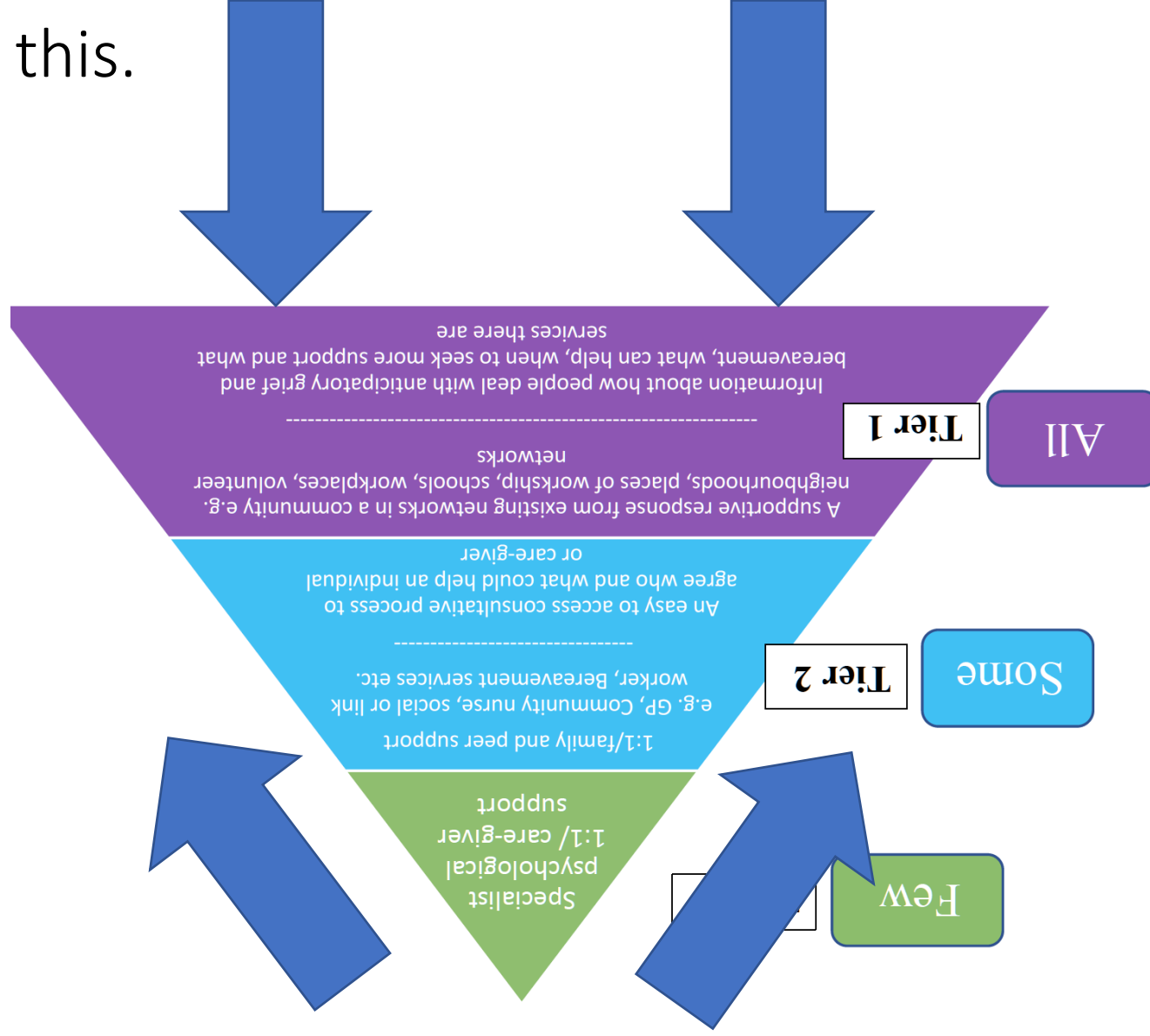
Recognise that others are the same.

2. Equity

- Palliative care mostly for cancer but this is only 25% of deaths. What happens to the other 75%?

- The terrible phrase hard to reach represents the majority of people who do not have direct or indirect access to palliative care.

- **Social morbidities, physical morbidities and mortalities** are all there and should not be ignored. This is the moral dilemma facing palliative care.

- Who is missed out by palliative care services? (By disease, by cause of death, by diversity, by structural inequity.)
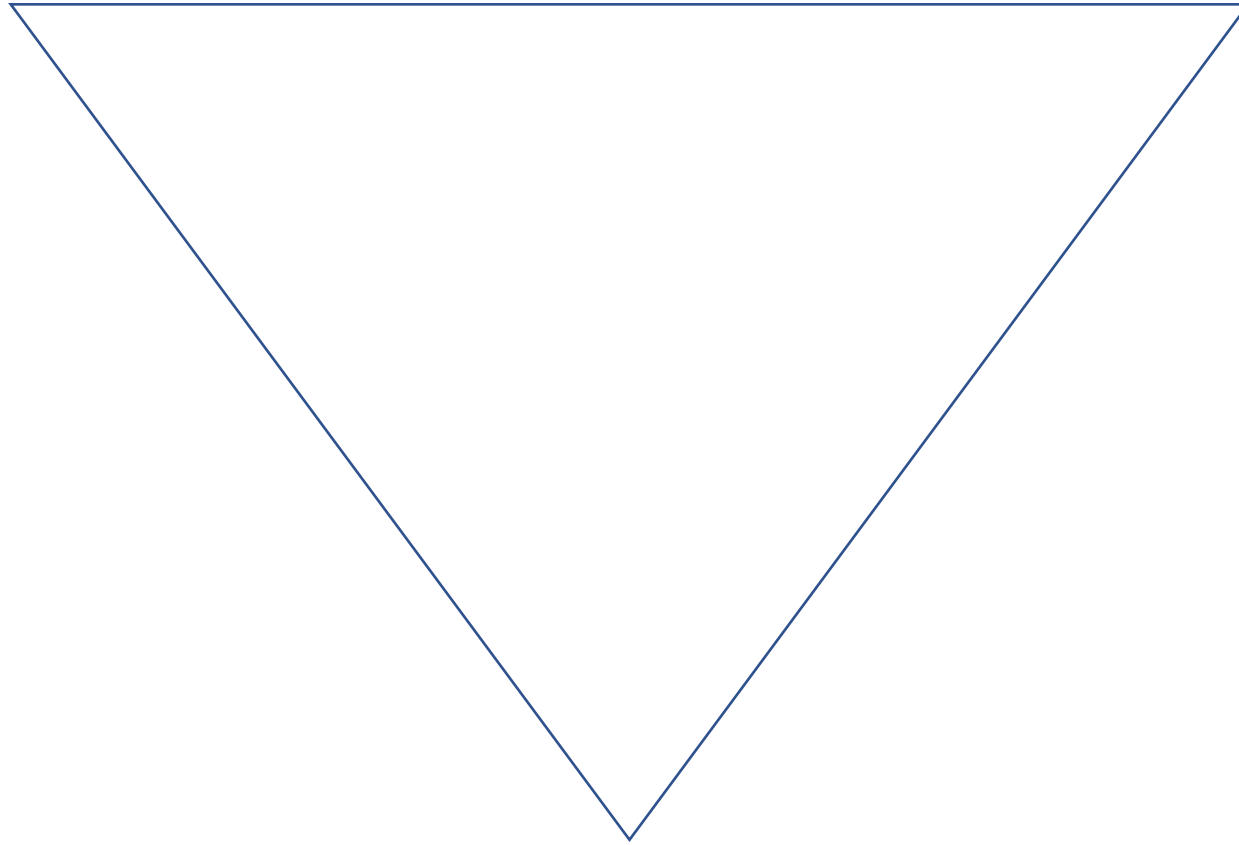
3. Bereavement

Few — **Tier 3**

Some — **Tier 2**

All — **Tier 1**

Specialist psychological 1:1/ care-giver support

1:1/family and peer support

e.g. GP, Community nurse, social or link worker, Bereavement services etc.

An easy to access consultative process to agree who and what could help an individual or care-giver

A supportive response from existing networks in a community e.g. neighbourhoods, places of workship, schools, workplaces, volunteer networks

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Information about how people deal with anticipatory grief and bereavement, what can help, when to seek more support and what services there are
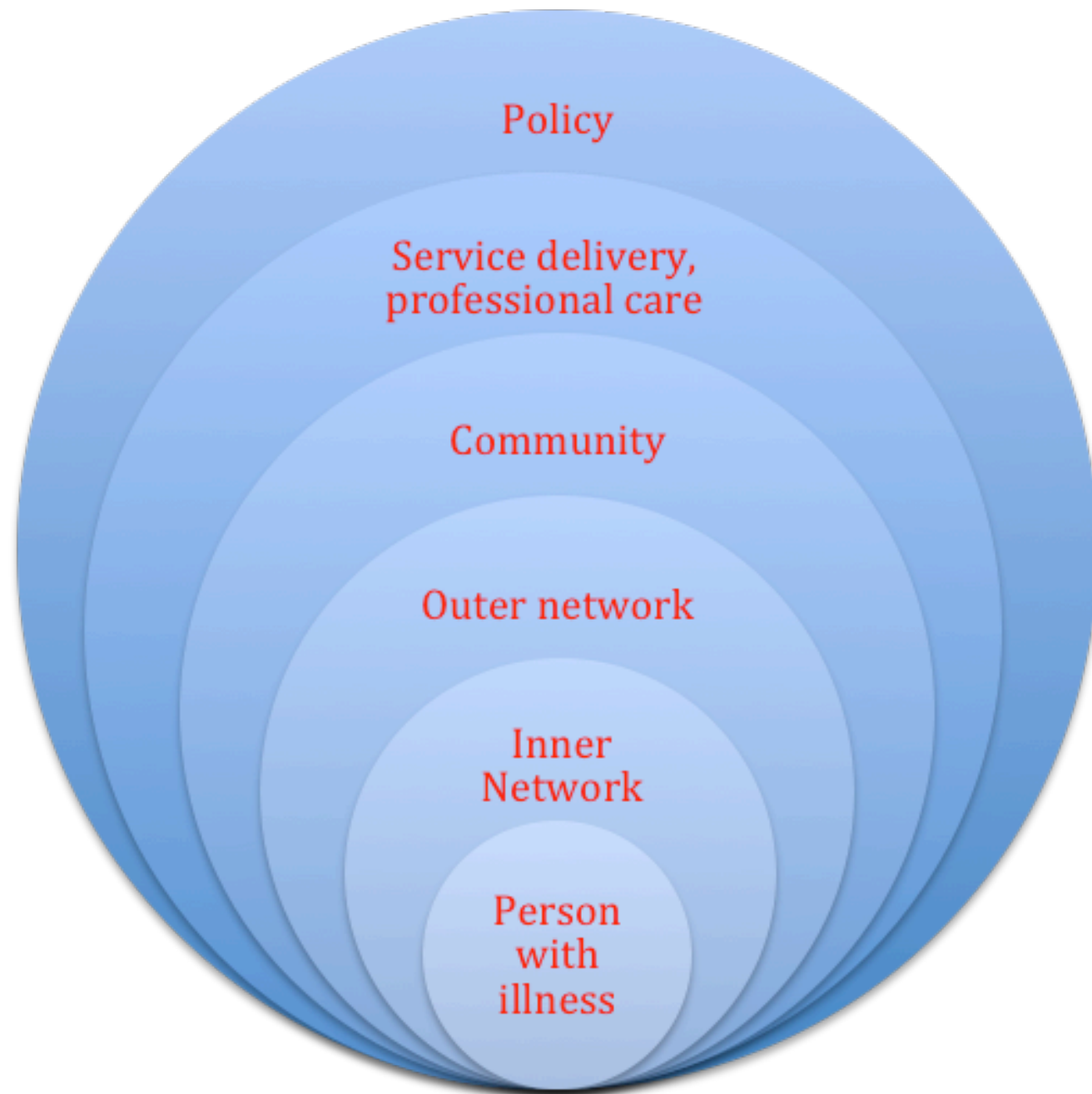
Graphic of 95% rule

Three issues

1. Importance of relationships at biological and personal levels

2. Power relationships, community development and unintended harms of professionalisation

3. Redesigning professional care in the light of the above

Prof Bessel van der Kolk – The Body Keeps the Score

Social support is not the same as merely being in the presence of others. The critical issue is reciprocity, being truly heard and seen by the people around us, feeling that we are held in someone's mind and heart. For our physiology to calm down, heal, and grow we need a visceral feeling of safety.

No doctor can write a prescription for friendship and love. These are complex and hard earned capacities.

2. Power relationships, professionalisation and community development

THE DENVER PRINCIPLES - (Statement from the advisory committee of the People with AIDS)

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

RECOMMENDATIONS FOR ALL PEOPLE

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.

2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

Yarning about Sad News and Sorry Business Know the community you are going into

- For many non-Indigenous Australians there has been limited opportunity to interact with and learn about Aboriginal and Torres Strait Islander peoples and their diverse cultures, including communication styles, family structures, lived experiences and beliefs.

- A failure to appreciate diversity and acknowledge complexities within communities *'condemns policies and programs to failure'.*

- Knowing the community is the best way to ensure the most effective method of consultation, which extends to more than geography, language or health statistics, to include consideration of politics, key stakeholders, other current and past engagement processes and topics, and other important issues taking place in the community.

Yarning about Sad News and Sorry Business

- *It is different in each community and you just don't know if you are getting it right.*

- *I would be ok in my community but if I went to another place and had to talk I'd make sure I talked to some other people quietly first so I could work out what the people in the room expected or thought was ok*

- *Don't think that individuals or organisation represent everyone, talk to all people and the right people about the topic, the ones who are part of the topic and living it*

COVID-19 RESPONSE:
Compassionate streets and neighbourhoods

The challenge for health and social care services during the time of the COVID-19 pandemic, in which physical distancing is a mainstay of the response, is how to maintain vital human social contact without increasing the risk of virus transmission.

Resilience of caring networks at end of life in particular can make the difference between a peaceful death at home and an emergency admission to hospital which ends in death. Carer exhaustion in end-of-life care is common in usual circumstances. Reducing hospital usage in these current circumstances is particularly important.

Providing both physical and emotional support is a demand of the heart, our own compassionate response in these times of hardship with the fears and concerns brought by the COVID-19 pandemic. **Particularly urgent is the need for support and social connection to those undergoing the experiences of death, dying, loss and caregiving.**

PHPCI
Public Health Palliative Care International

CC
Compassionate Communities UK

Information provided by PHPCI and Dr Julian Abel
www.phpci.info

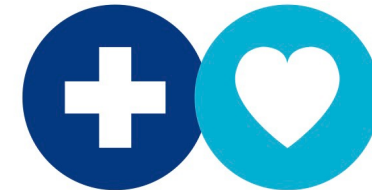A compassionate community response can be thought of as fitting into three categories.

What **communities** are best placed to do

- Identify street or neighbourhood champions
- Organise street or neighbourhood teams of helpers
- Providing practical help – shopping, cooking, cleaning, gardening, and more
- Giving emotional support – compassion, love, laughter, listening, friendship and more
- Forging new connections now and in the difficult months ahead

What **communities and professionals** best do **together**

- Monitor and provide symptom control
- Understand nursing care at home
- Share the resources of communities and service
- Support advance care planning
- Build support around people who are grieving and isolated

What **professionals** best do

- Manage difficult symptoms
- Provide video consultations and assessments
- Give training in symptom control at home
- Link with street teams when professional resources are absent
- Provide specialist bereavement care to those with complex grief
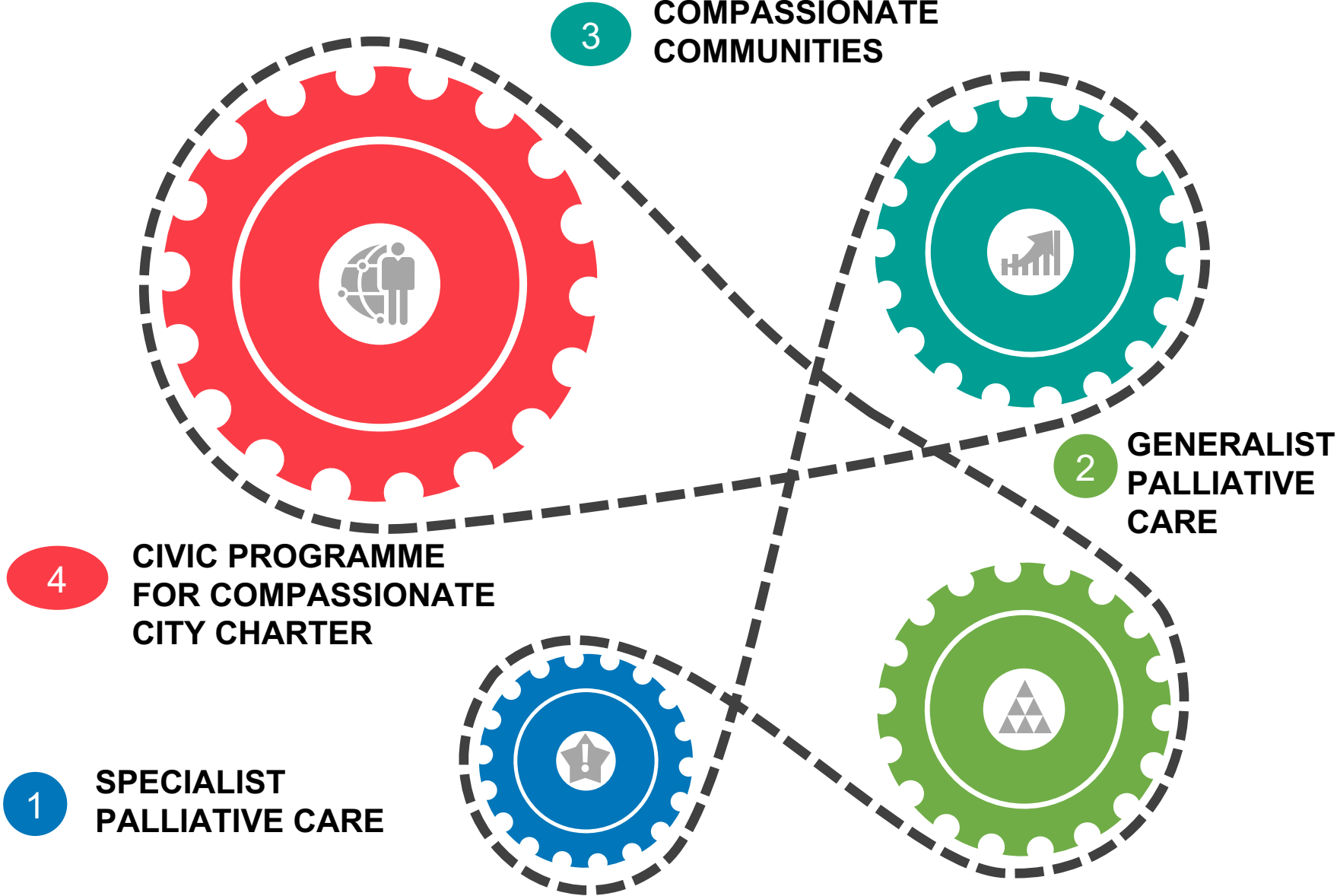
3. Redesigning palliative care

- Ground up participatory community development
- Compassionate communities and compassionate cities.

Compassionate Communities
The neighbourhood is the unit of change (Cormac Russell)

- Building of resilient networks of support around families of care, main emphasis is love, laughter and friendship with practical tasks

- Skilling up of caring networks

- Increasing neighbourhood capacity to care for those who experience death, dying and loss

- Integration and building of trusting relationships with health and social care teams

- Develop of service directory

- **Community development worker as professional role**

Palliative Care – The New Essentials

3 COMPASSIONATE COMMUNITIES

2 GENERALIST PALLIATIVE CARE

4 CIVIC PROGRAMME FOR COMPASSIONATE CITY CHARTER

1 SPECIALIST PALLIATIVE CARE

Specialist Palliative Care

- Ease of contact with palliative care services – Zoom, Teams, Facetime, video link.

- Immediacy of advice and visits

- Specialist beds open to all

- Training of carers in the community – network development, manual handling, injections

- Participation in implementation of compassionate city charter
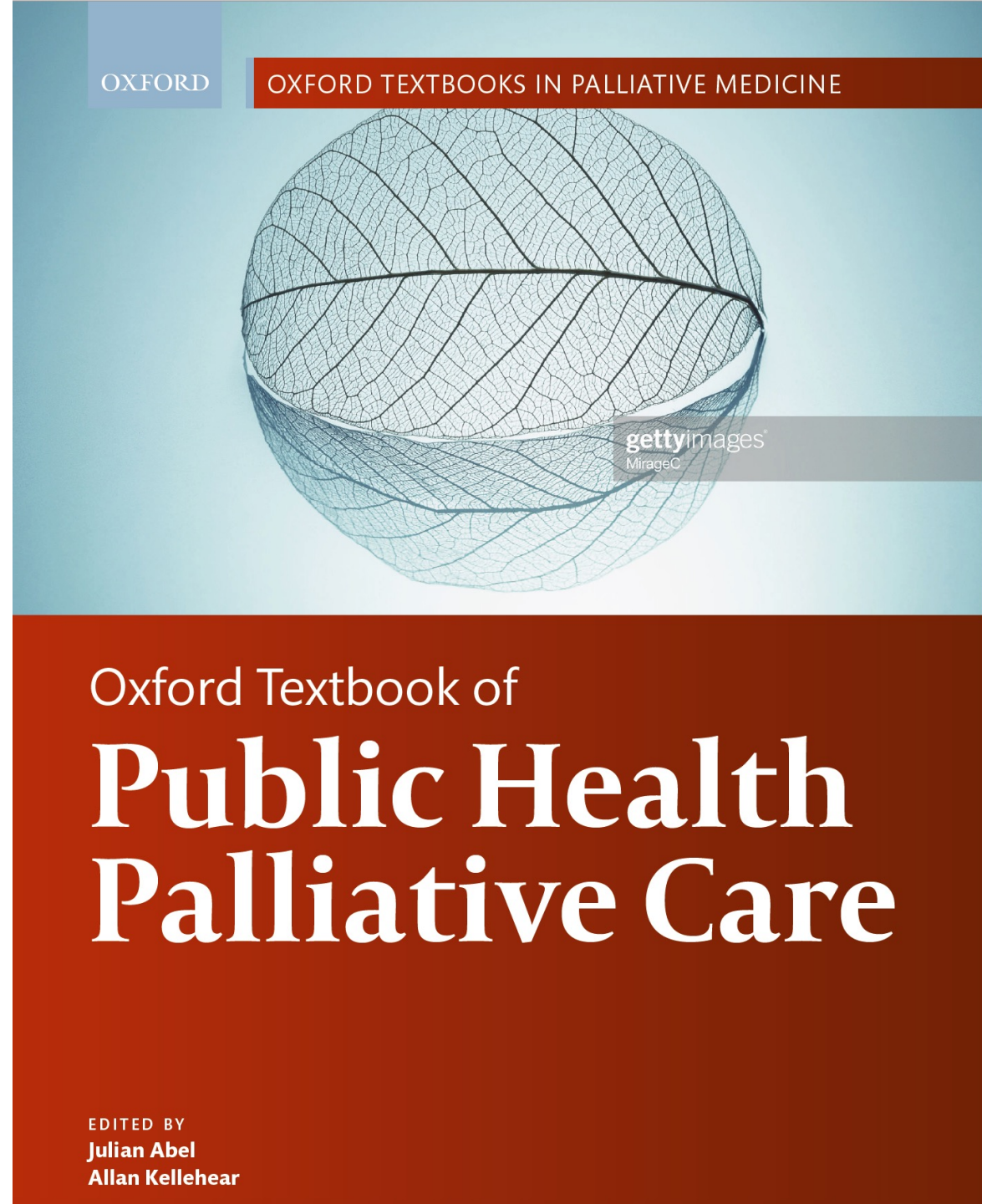
Generalist palliative care/primary care

- Proactive identification of people in need of support
- What matters conversations
- Linkage and coordination with community resource at point of contact
- Systematic after death audits for continuous improvement (QI methodology)
- Community development workers are part of the clinical team
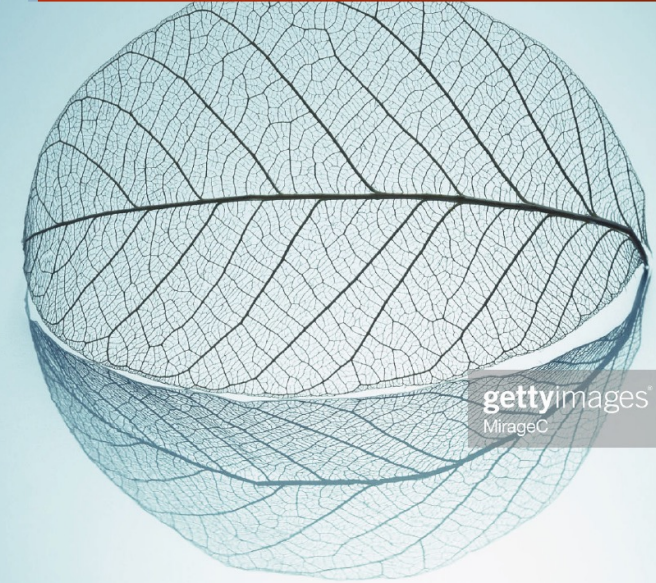
Other videos if we have time.

- **Brereton and Ravenhill**
- **https://www.youtube.com/watch?v=sIM6XOXueyw&list=PLVA2ZDXTI_2SYYpmi5_aA1Yy940--0nZ4**

What does palliative care look like reimagined?

Resources

- **Prof Julianne Holt-Lunstad on Survival of the Kindest Podcast** https://www.compassionate-communitiesuk.co.uk/podcast/dr-julianne-holt-lunstad

- Holt-Lunstad J, Smith TB, Layton JB (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. PLOS Medicine 7(7): e1000316. https://doi.org/10.1371/journal.pmed.1000316 https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000316

- **Prof Steve Cole on Survival of the Kindest Podcast** https://www.compassionate-communitiesuk.co.uk/podcast/professor-steve-cole

- **Prof Dacher Keltner on Survival of the Kindest Podcast** https://www.compassionate-communitiesuk.co.uk/podcast/dacher-keltner

- **Born to Be Good: The Science of a Meaningful Life** Dacher Keltner

- **The Power Paradox** Dacher Keltner

Resources

- Ernesto Sirolli https://www.ted.com/talks/ernesto_sirolli_want_to_help_someone_shut_up_and_listen/transcript

- https://blogs.bmj.com/spcare/2021/10/01/community-sources-of-bereavement-support/

- The Denver Principles https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf

- Dr Libby Sallnow Survival of the Kindest https://www.compassionate-communitiesuk.co.uk/podcast/libby-sallnow

Resources 2

- Holly Prince Survival of the Kindest https://www.compassionate-communitiesuk.co.uk/podcast/holly-prince

- United Nations Human Rights Based Approach https://unsdg.un.org/2030-agenda/universal-values/human-rights-based-approach

- Cormac Russell – Nurture Development https://www.nurturedevelopment.org and Survival of the Kindest https://www.compassionate-communitiesuk.co.uk/podcast/cormac-russell

- Angela Fell Survival of the Kindest https://www.compassionate-communitiesuk.co.uk/podcast/Angela-fell

- https://gatherfor.medium.com/maslow-got-it-wrong-ae45d6217a8c

Resources

- Compassionate Communities UK website https://compassionate-communitiesuk.co.uk

- Compassionate Communities UK YouTube channel https://www.youtube.com/channel/UCUPnQsd1iuHFOSybGaYJFIw/videos