



Comisiwn  
Bevan  
Commission

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# *Going for Gold*

*Prof. Ilora Baroness Finlay of Llandaff*

**ldw**  
living and dying well

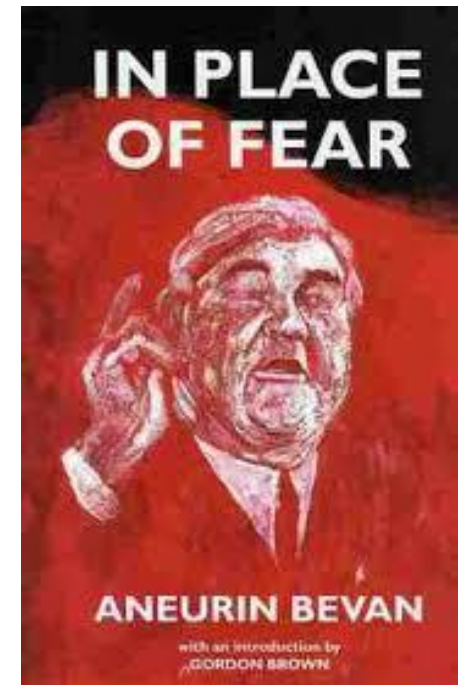
  
hospice **UK**

YMDDIRIEDOLAETH GIG  
FELINDRE  VELINDRE  
NHS TRUST

CARDIFF  
UNIVERSITY  
PRIFYSGOL  
CAERDYB

# As the light fades

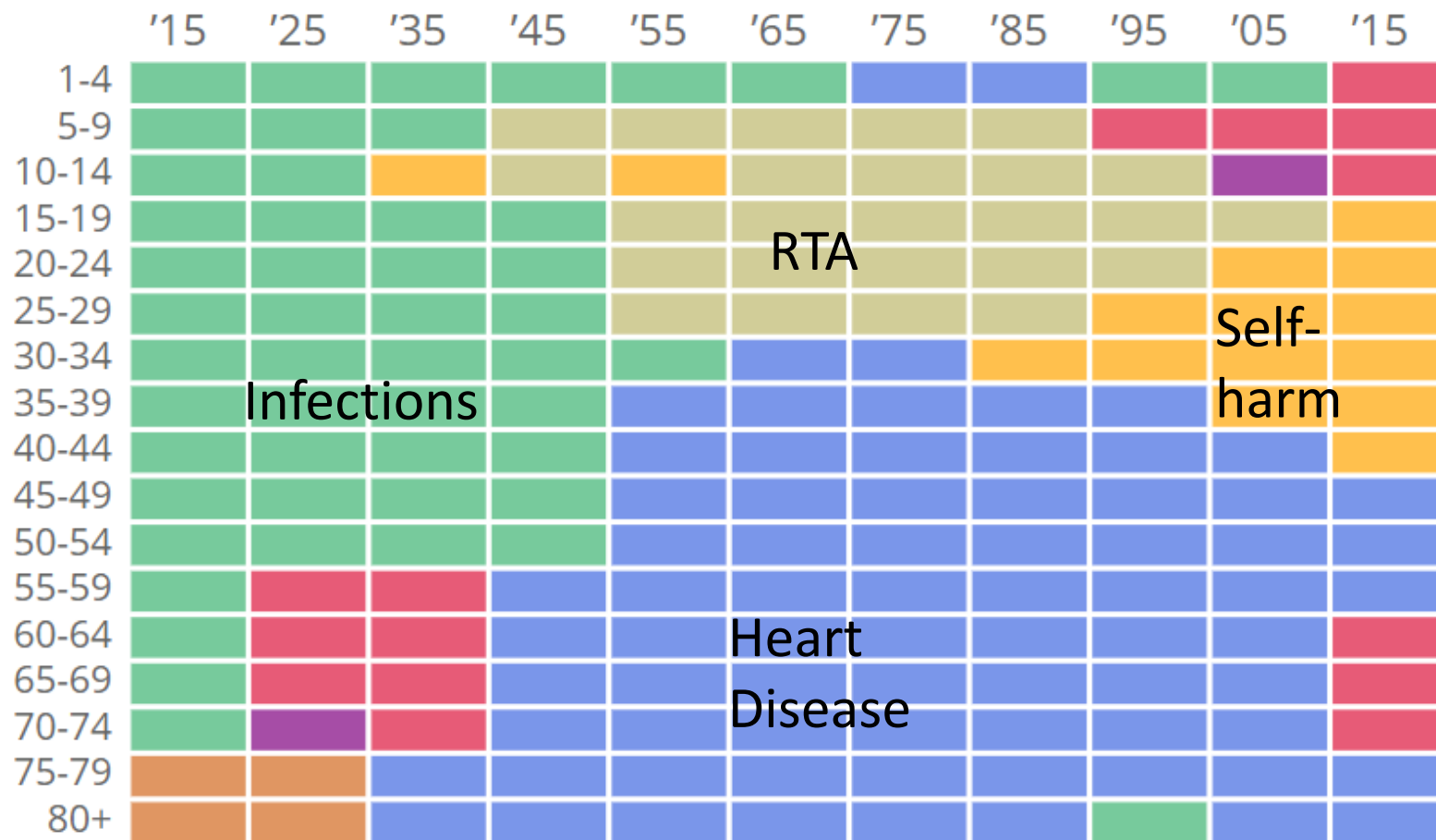
- Where we have come from
- What lies ahead
  
- The NHS
- Congratulations to all GSF



# Most common cause of male death:



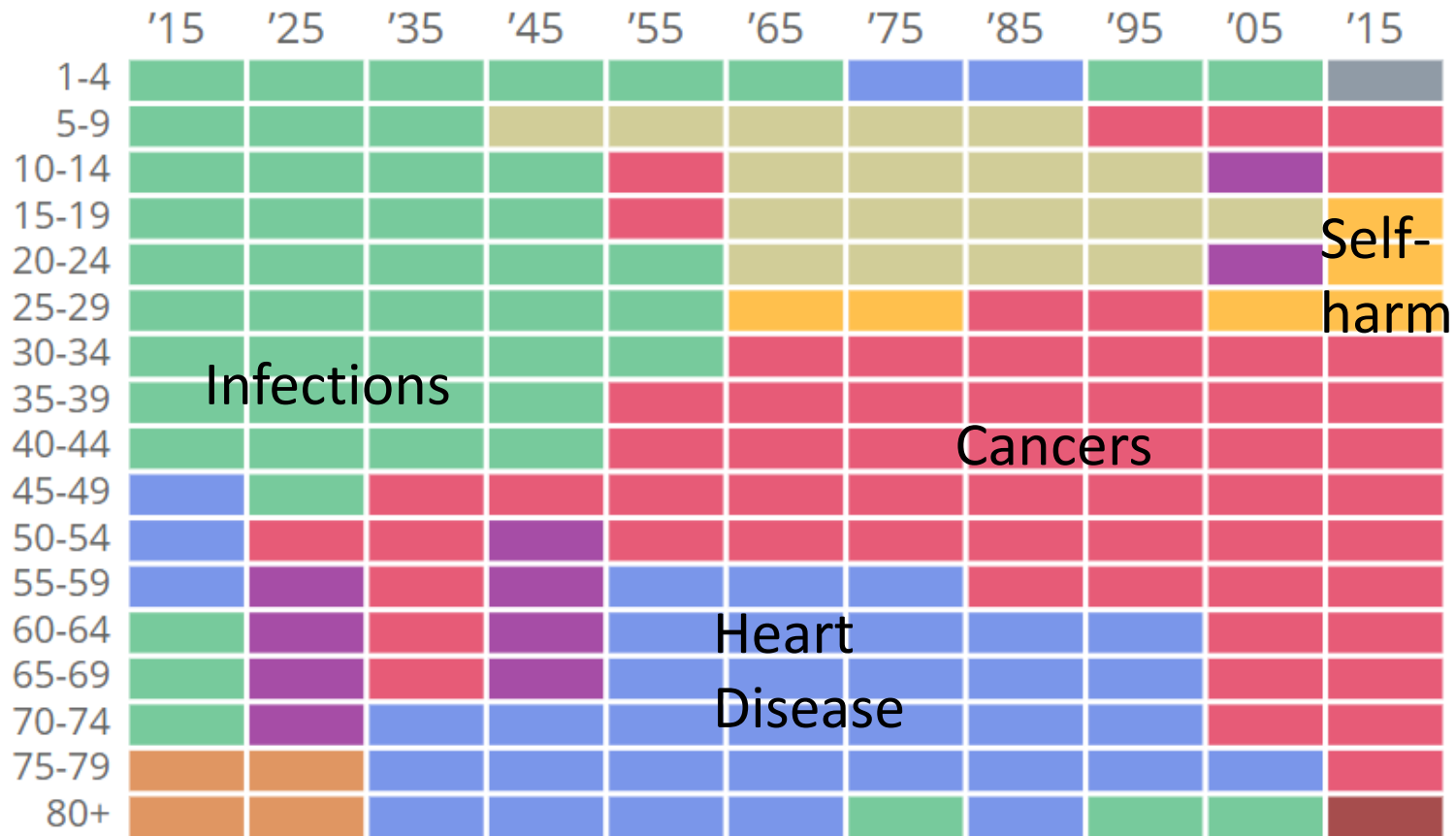
Total



# Most common cause of female death:

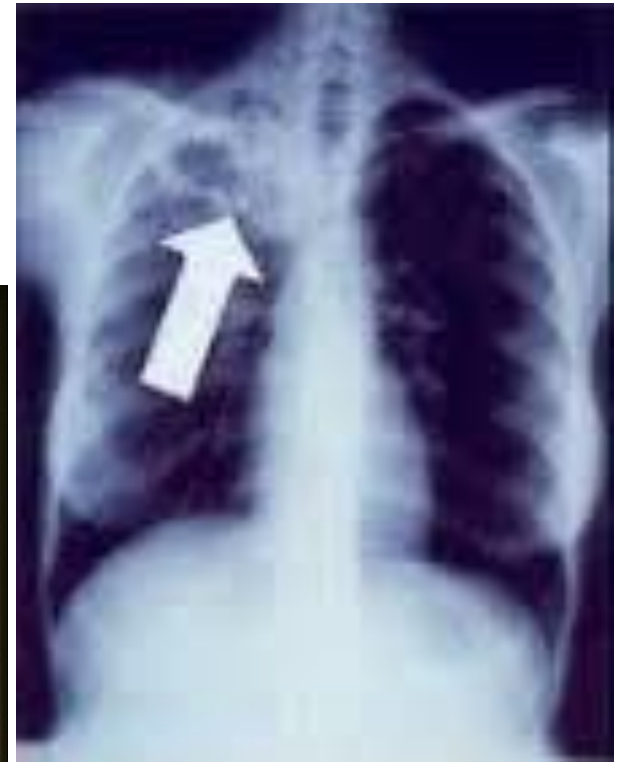
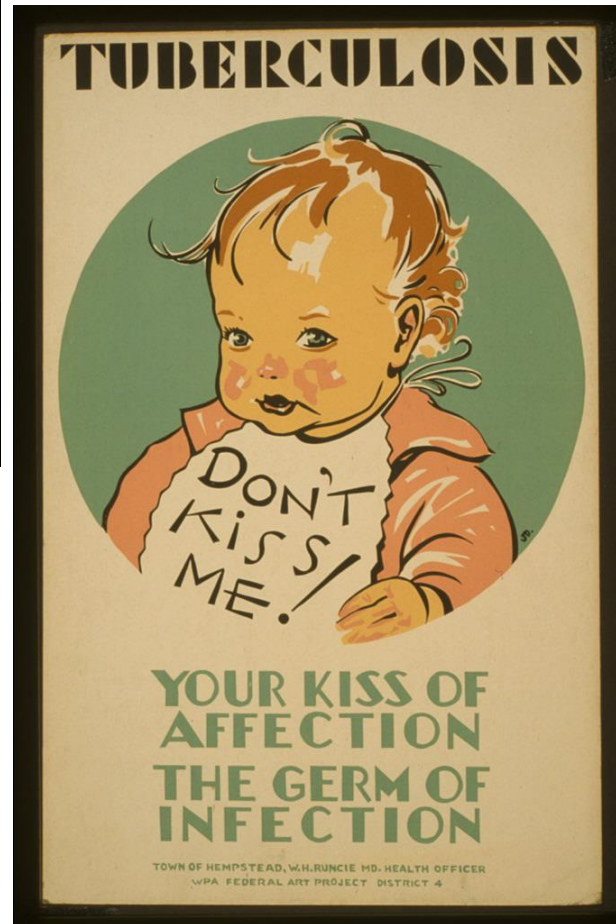


Total



Source: 21st century mortality files, ONS  
and 20th century mortality files, ONS

# Tuberculosis

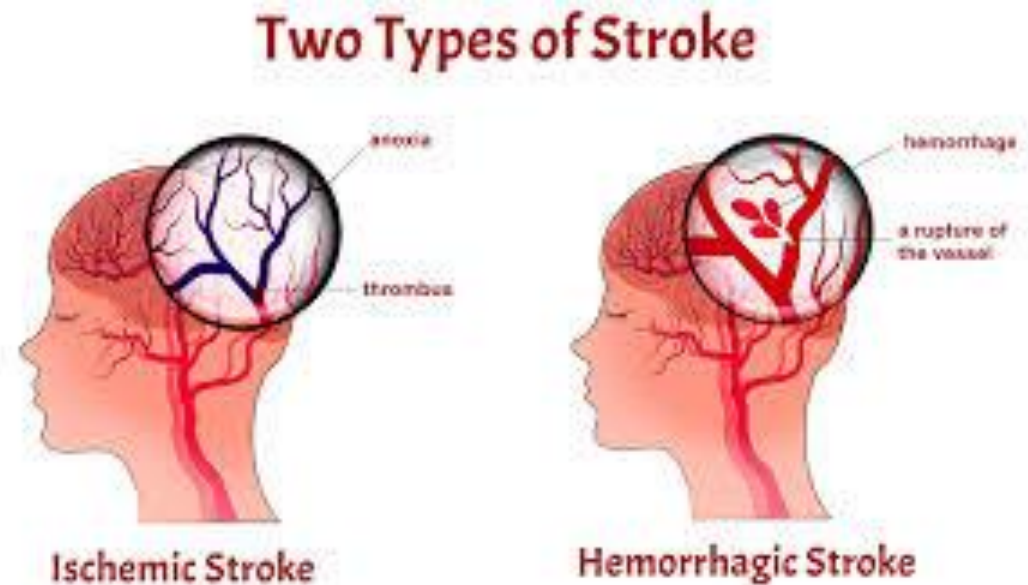


# 1916, 1950s Polio epidemics ... pre-Salk major cause of paralysis



# Dying after stroke

- Acute – massive stroke
- Late complications / resultant disorders
- Prognosis is unpredictable





1967



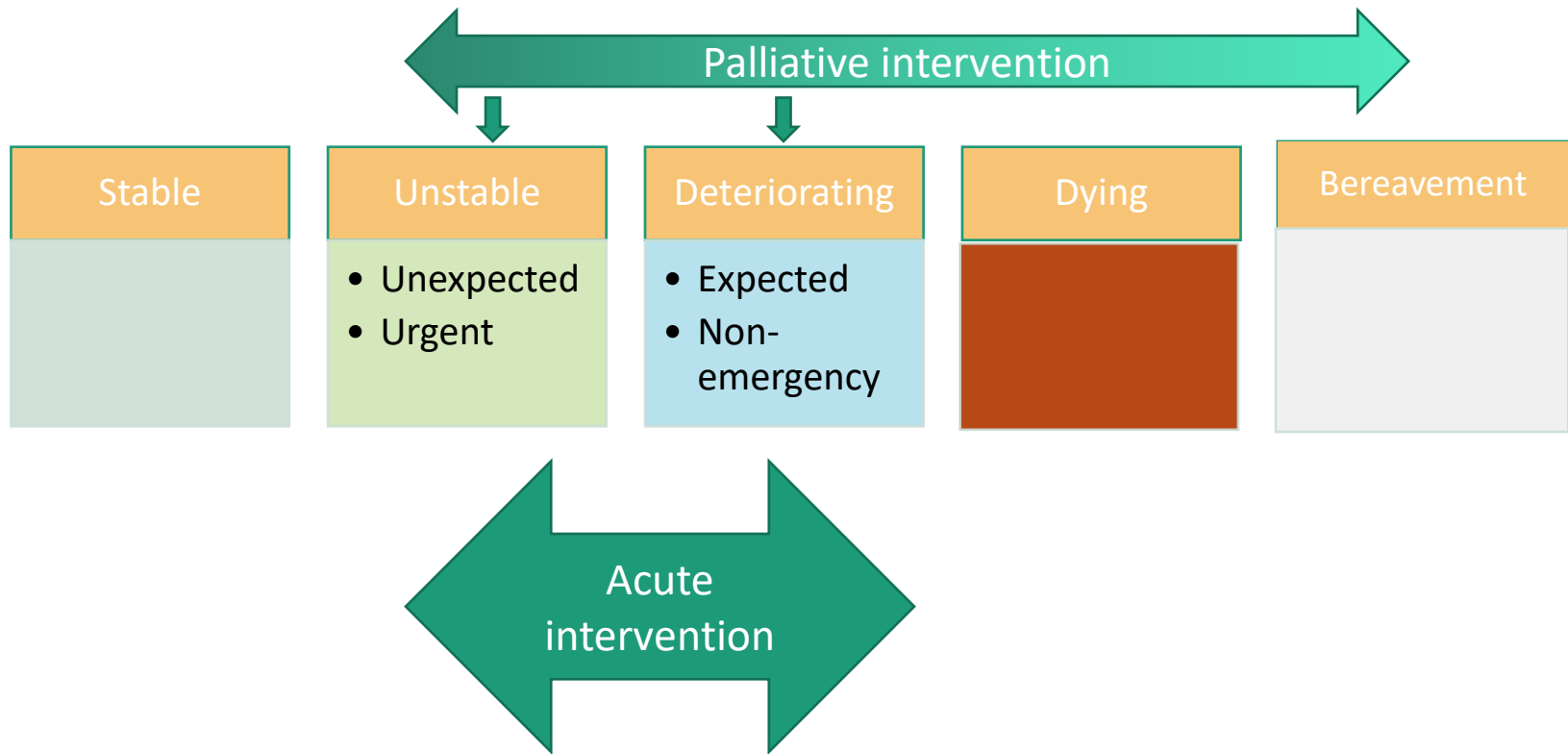
“You matter because you are you, and you matter to the last moment of your life.

We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders (1918-2005)



“It is obviously preferable to prevent suffering than to alleviate it.”



The diagram features a central orange starburst shape with the word "Pain" written in white. Surrounding this central element are four 3D rectangular blocks, each representing a domain of pain. The "Emotional" block is blue and positioned at the top. The "Spiritual" block is green and positioned on the left. The "Social" block is green and positioned on the right. The "Physical" block is red and positioned at the bottom. The blocks are arranged in a circle around the central starburst, with the "Emotional" block at the top, "Physical" at the bottom, "Spiritual" on the left, and "Social" on the right.

Emotional

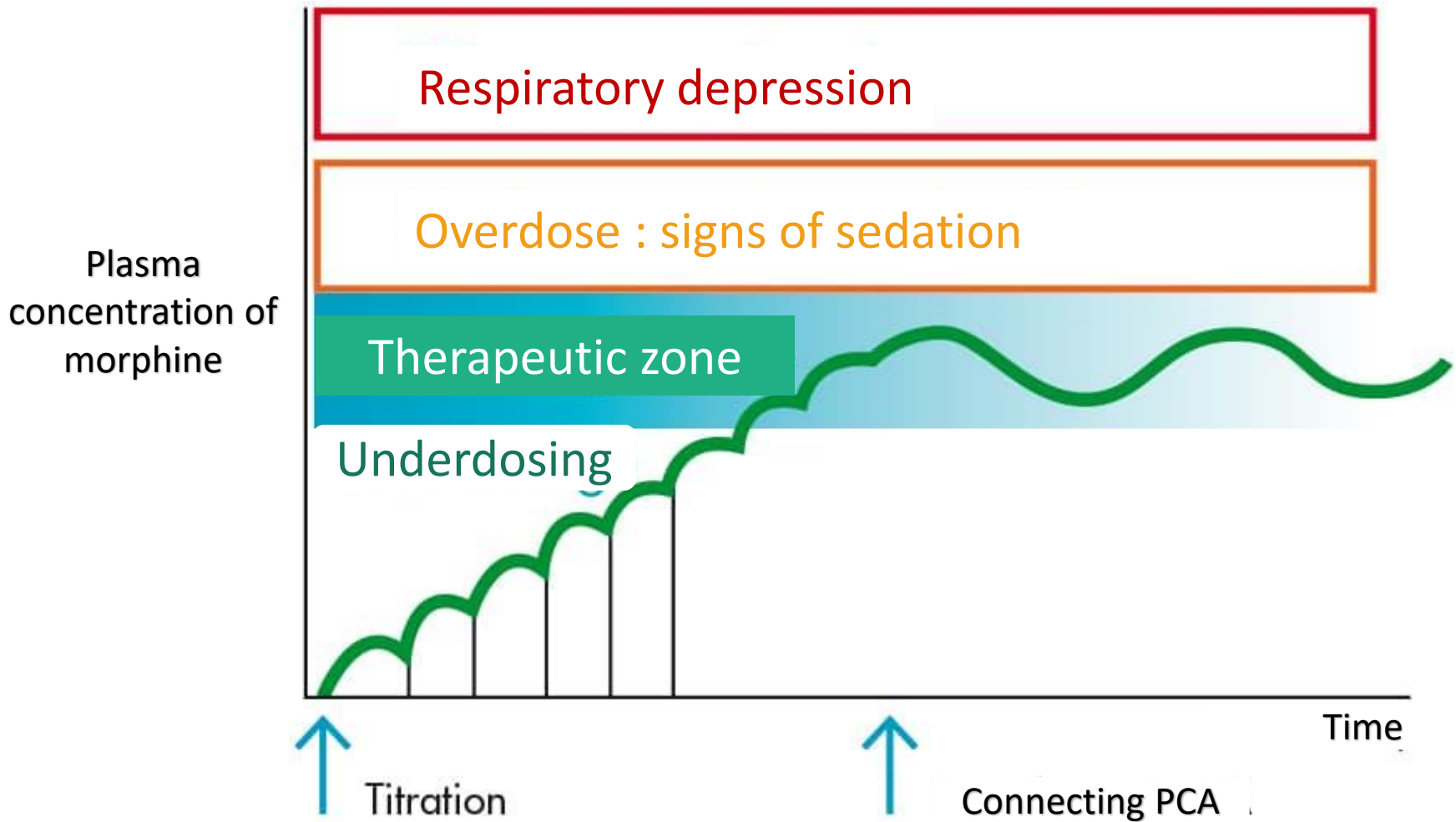
Pain

Spiritual

Social

Physical

# Morphine titration



# Palliative care – developed world

Science of helping dying patients live as fully as possible **with our humanity and kindness**

*For most people, dying is  
not a sudden presence of death,  
but a gentle absence of life.*

# What happens as you die of progressive disease

- Increasingly weary
- Often a final burst of energy / activity in last days
- Drowsy and weak
- Slip into a coma
- Breathing slows – may sound bubbly
- Breathing more shallow, pulse weaker
- Colour changes and pulse weakens
- Heart and breathing stop

# Care at home – Covid

← → ↻ bevancommission.org/publications/covid-19-caring-for-a-dying-relative-at-home/ 🔍 📄 ☆ 🔌 🌐 🗄️ 📱 🟡 Paused



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## COVID-19: Caring for a dying relative at home

Published: Apr 06, 2021

Authors: Baroness Ilora Finlay, Bevan Commissioner, Lesley Bethell, Bevan Advocate

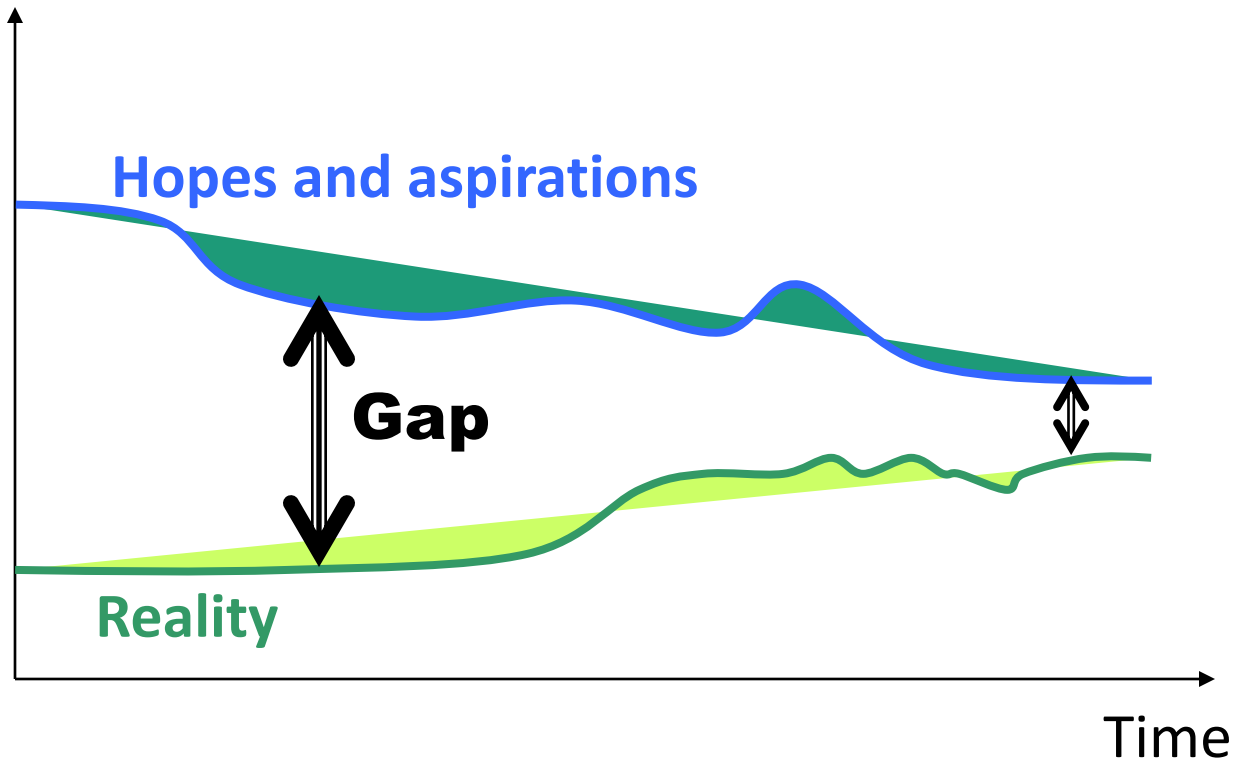
Download

# Recognition that death imminent

- 100% Cancer centre
- 64% General hospital trust
- Warning family?
- Provide appropriate care; stop some interventions
- Visit while it can be meaningful, even if that means missing the funeral



# 'The quality of life gap'



Dignity  
is having  
a sense of personal worth

Dame Cicely Saunders 1992

In place of fear - listening –  
what matters to the person?

The image features a large, bold Chinese character '聽' (listen). The character is composed of two parts: '耳' (ear) on the left and '聦' (listen) on the right. The '聦' part is further broken down into '目' (eyes) and '心' (heart). Annotations are placed around the character to explain its components: 'Ear' is on the left, 'Mind' is below it, 'You' is above the right part, 'Eyes' is to the right of the '目' radical, 'Undivided attention' is to the right of the '心' radical, and 'Heart' is below it.

Ear

Mind

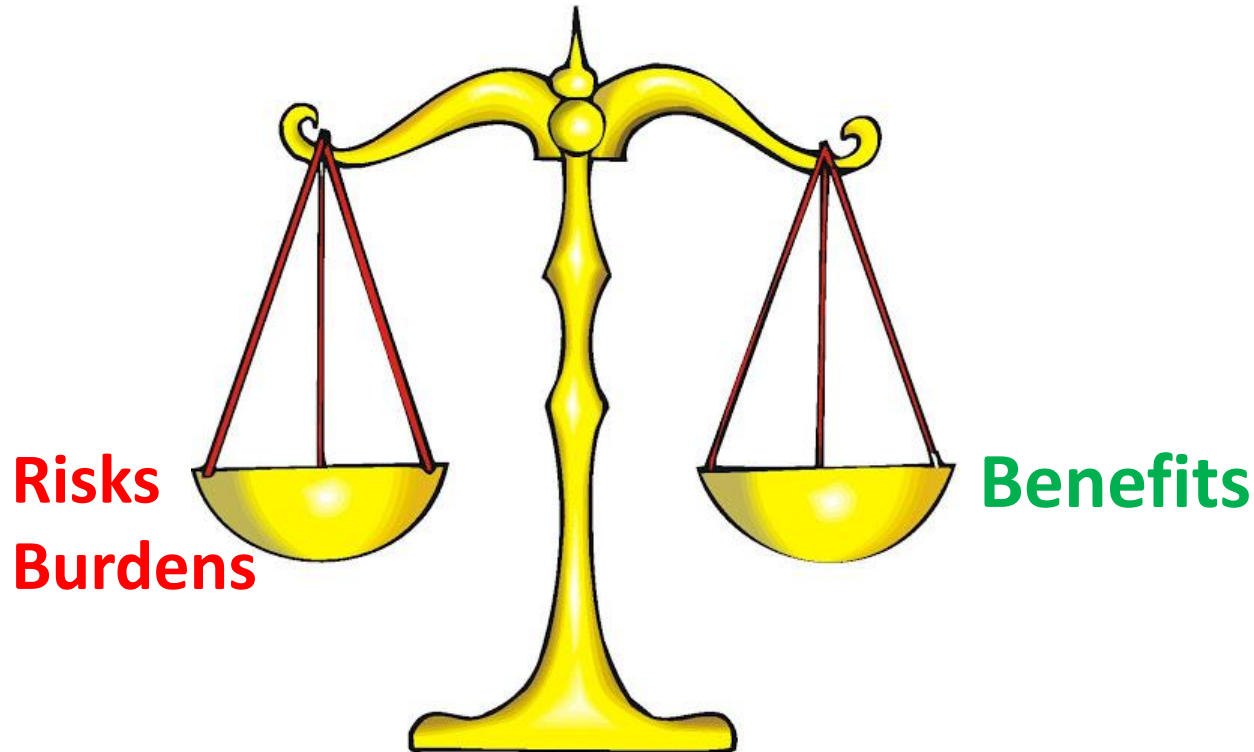
You

Eyes

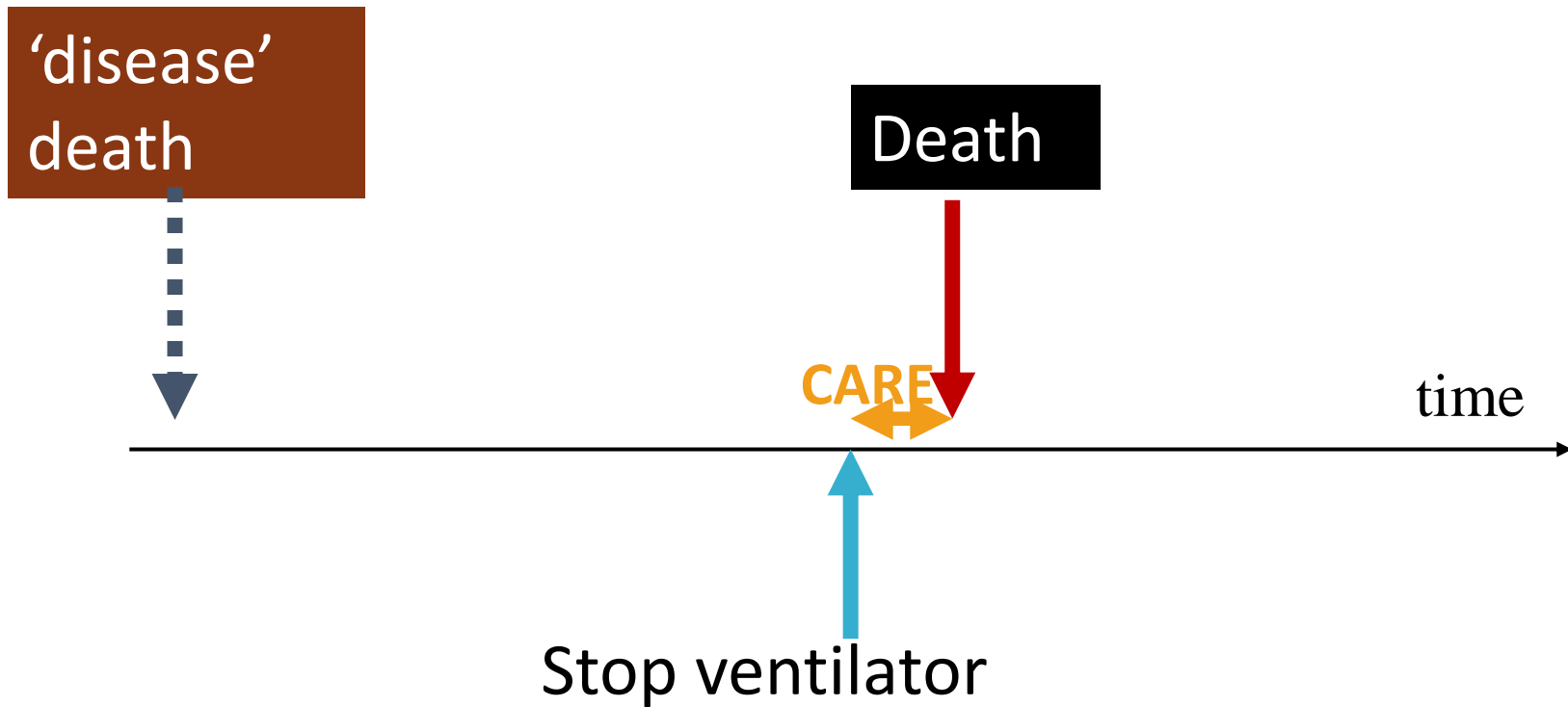
Undivided attention

Heart

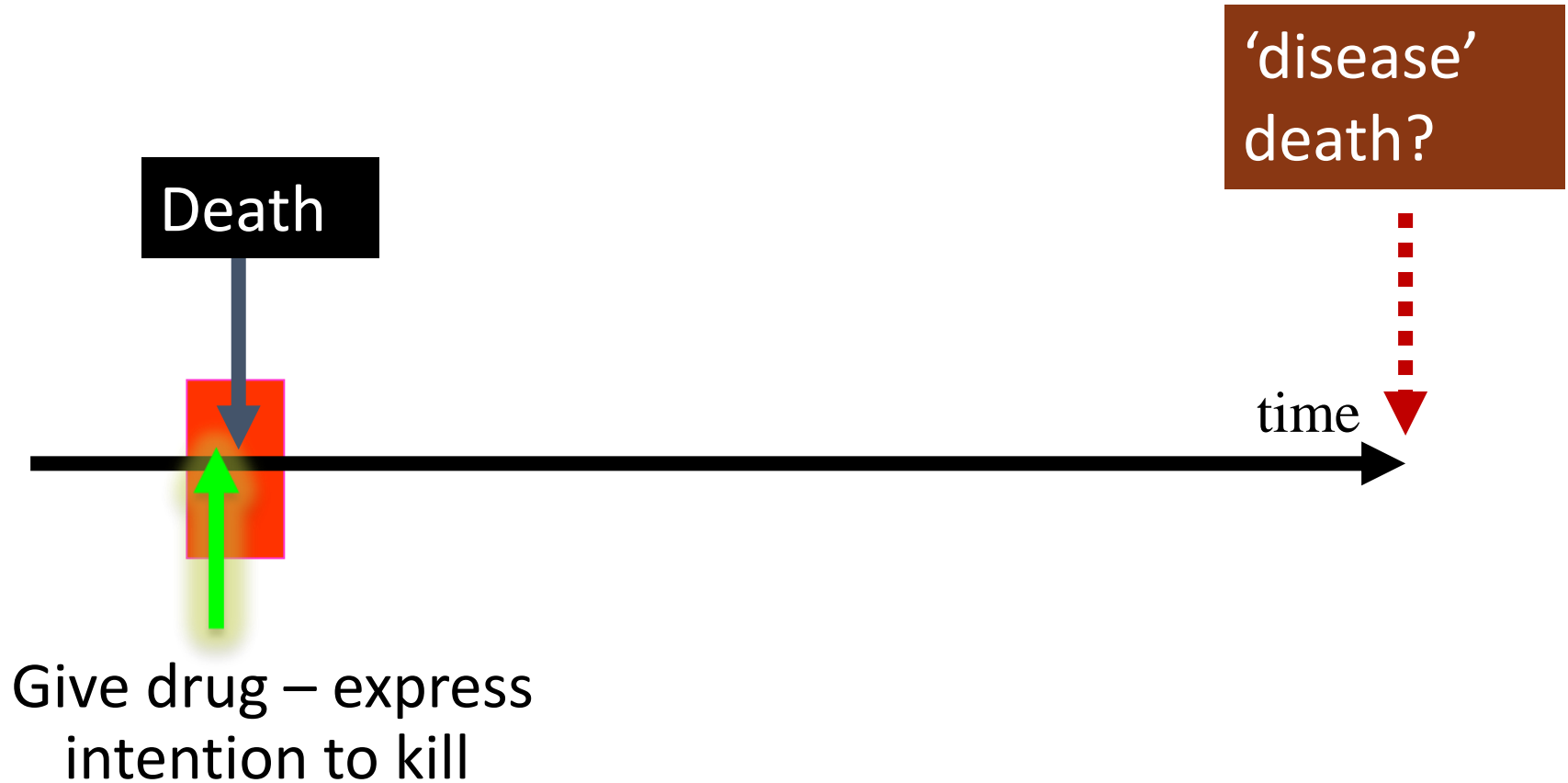
A treatment ... needs consent  
You cannot be treated against your will



# Motor neurone disease



# Euthanasia / physician assisted suicide/ Assisted suicide



# Consent to treatment



Doctor's role - provide information

Relevant, Understandable, Honest, Respectful, Recognise uncertainty,



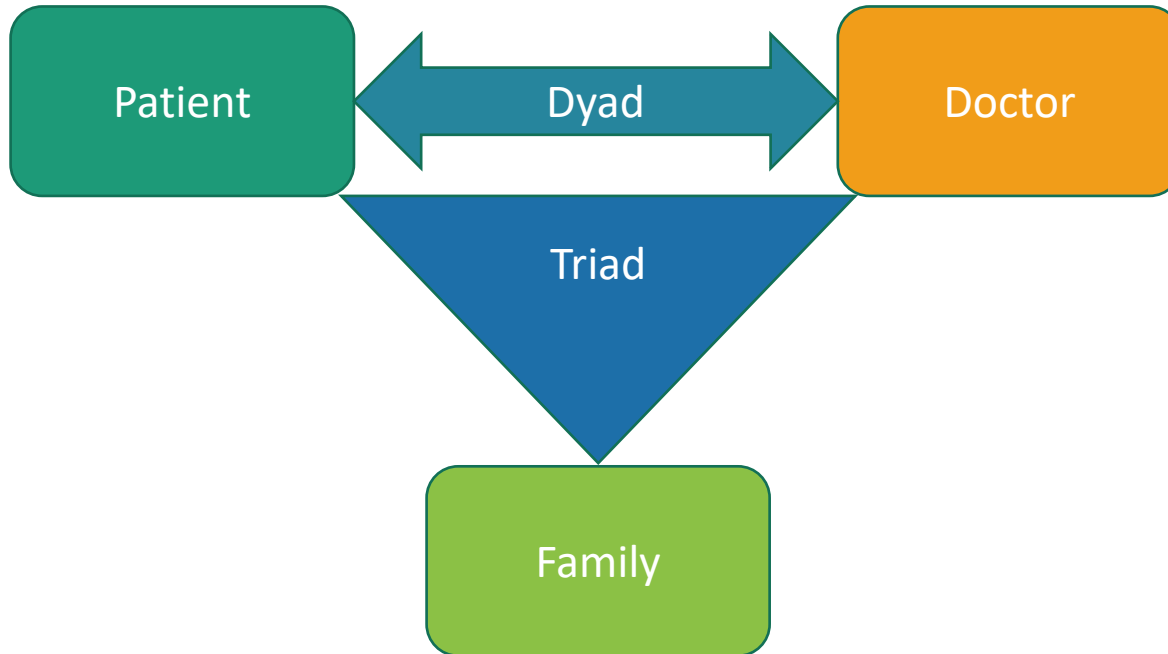
CONSENT is given by the person or parent on behalf of child



Treatment started with an aim – communicate at all stages – withdrawal of treatment requires joint planning



# Autonomy of one cannot override the autonomy of another



- Roest B, Trappenburg M, Leget C <https://doi.org/10.1186/s12910-019-0361-2>

# Children

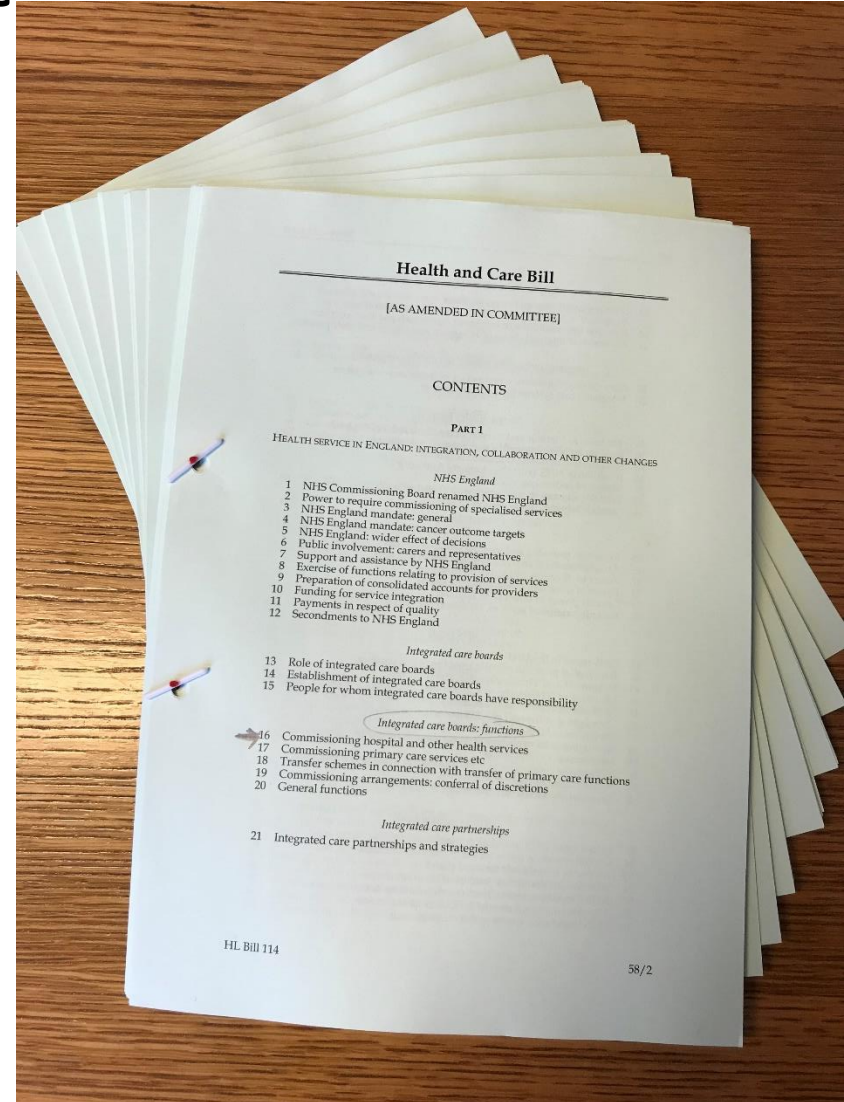
- The way a person dies lives on in the memory of those left behind



# Health and Care Act

- Clause 16

## Integrated care boards: functions



# Health and Care Bill – from my amendment

- insert— “(ga) such other services or facilities for palliative care as the board considers are appropriate as part of the health service,”

- ***Member’s explanatory statement***

*This amendment would specifically require integrated care boards to commission such services or facilities for palliative care (**including specialist palliative care**) as they consider appropriate for meeting the reasonable requirements of the people for whom they have responsibility.*

# “specialist multi-professional palliative care services” must include support

in every setting

beds when required, including urgent admission

advice at all times of day every day,

skilled workforce, equipment and medication

point of contact

share information about needs,

open conversations about what matters to them,

education and training

relevant research and disseminate evidence-based

24/7  
7 days  
Rapidly responsive  
Person centred



**Keep the patient at  
the centre of all you  
do**