

Ministry
of Justice



Department
of Health

National Mental Capacity Forum

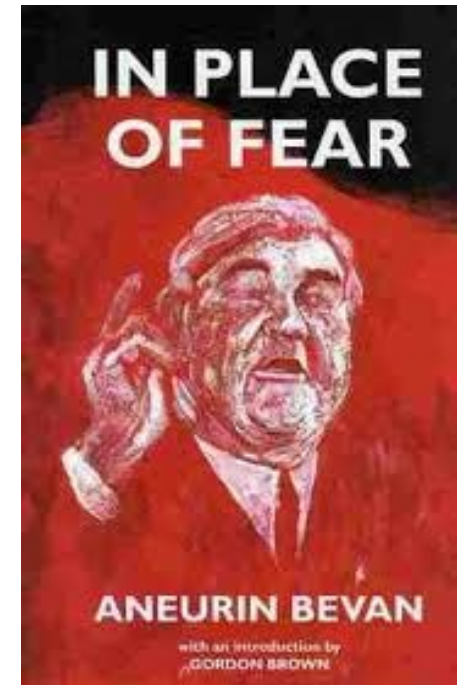
Dying in today's world

Prof. Ilora Baroness Finlay of Llandaff



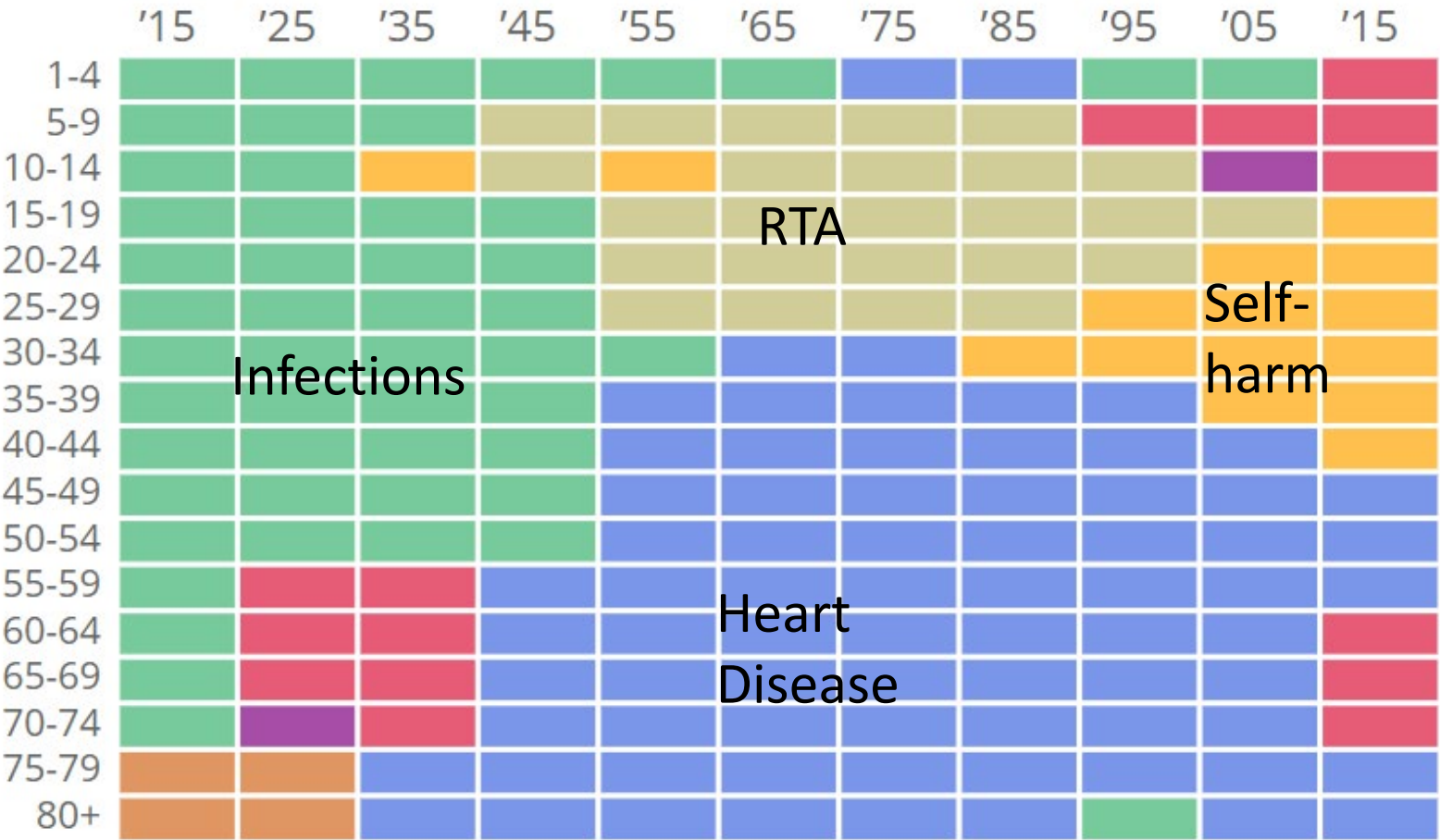
As the light fades

- Dying – yesterday, today and tomorrow
- The changes
- A personal journey in the time of the NHS



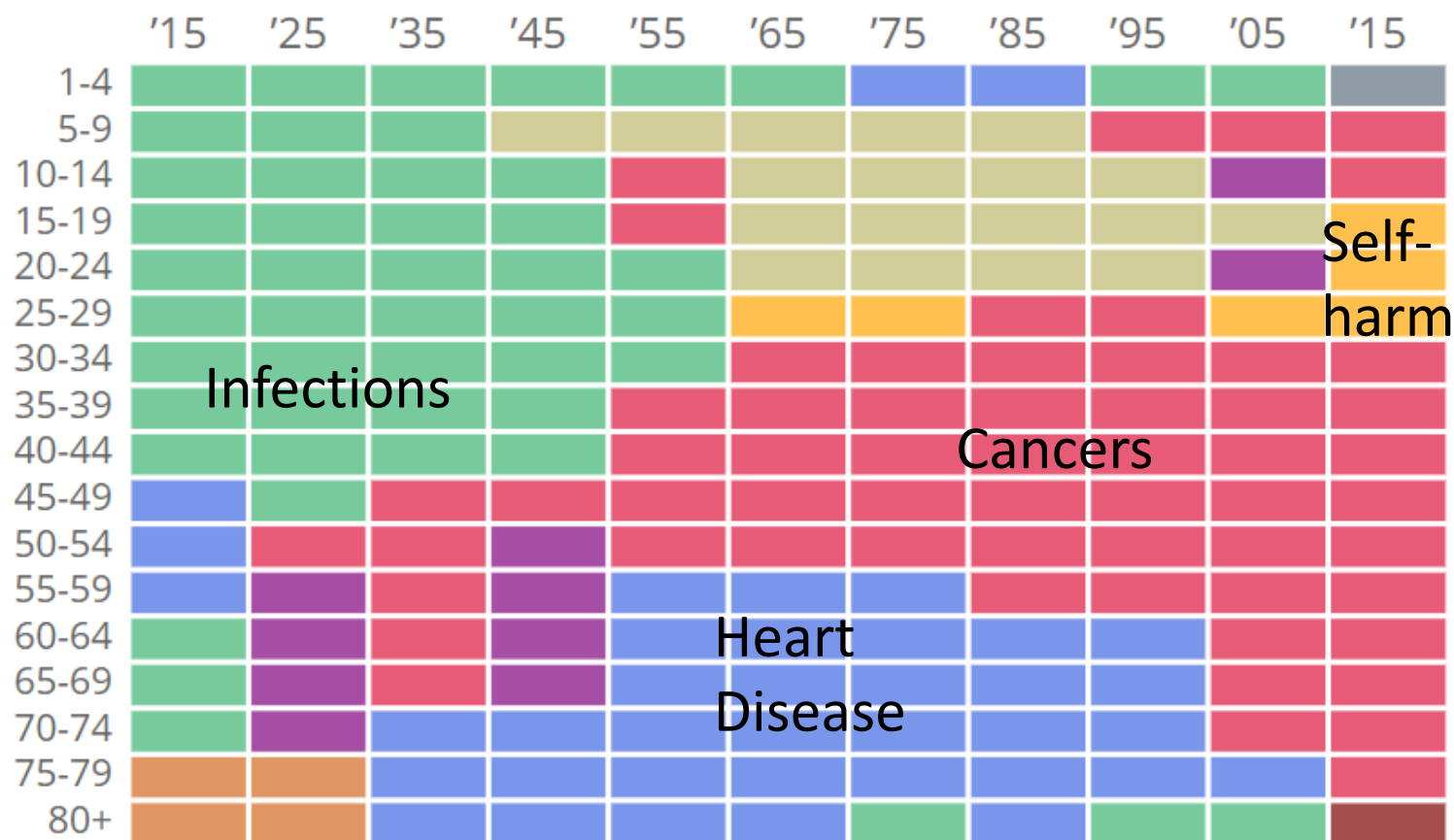
Most common cause of male death:

Total



Most common cause of female death:

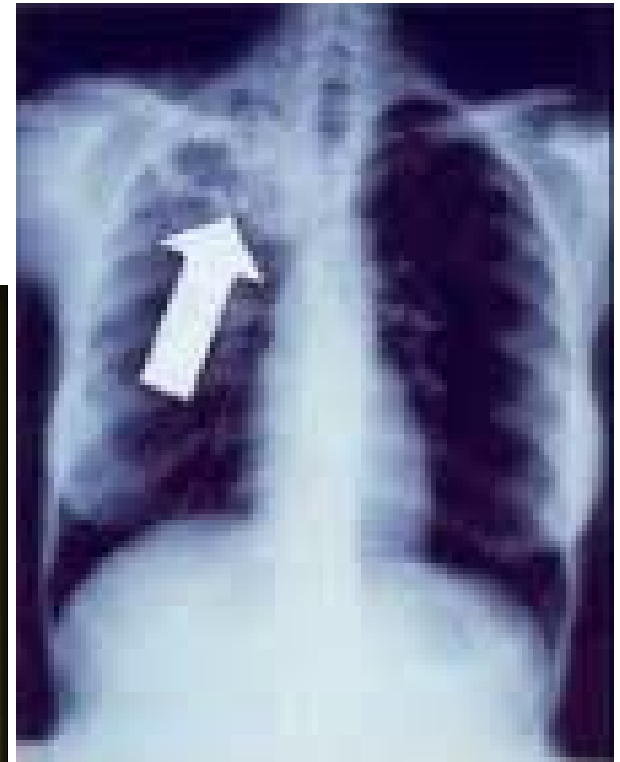
Total



Source: 21st century mortality files, ONS

and 20th century mortality files, ONS

Tuberculosis



1916, 1950s Polio epidemics ... pre-Salk





1967



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)



Emotional

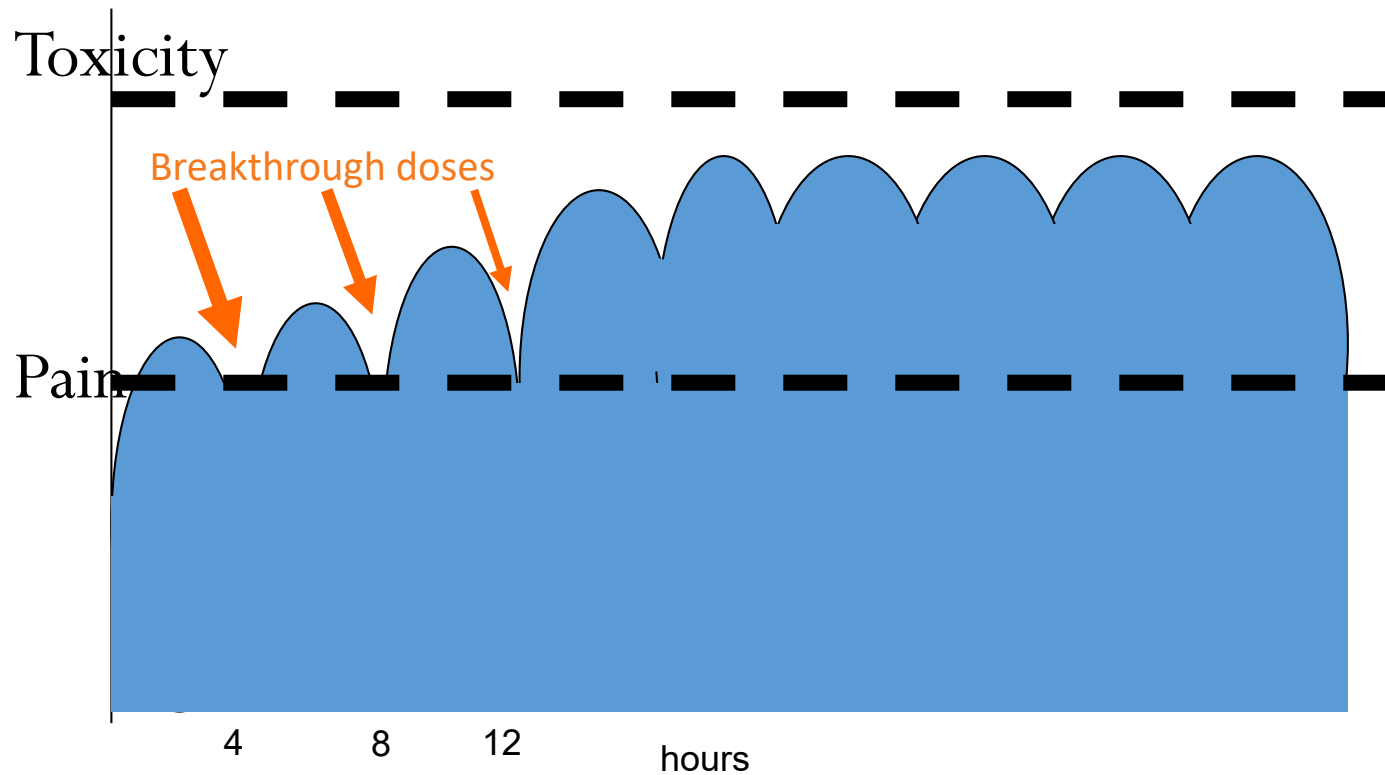
Pain

Spiritual

Social

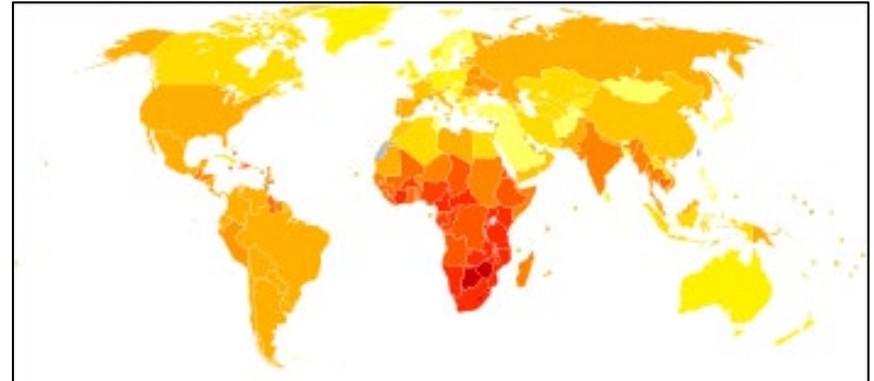
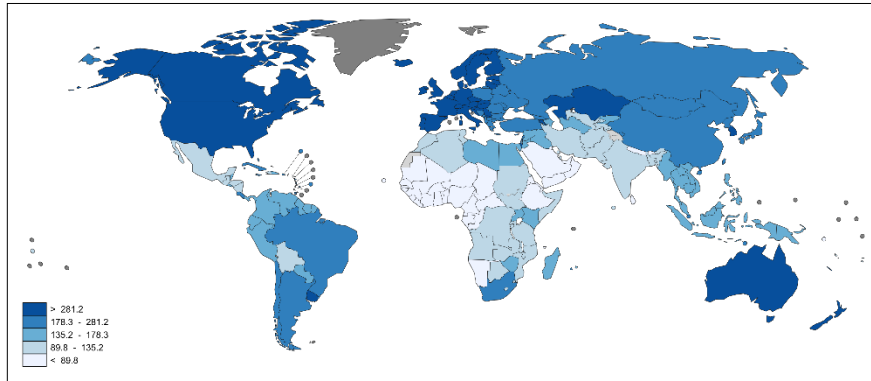
Physical

Morphine 'kills the pain, not the patient'

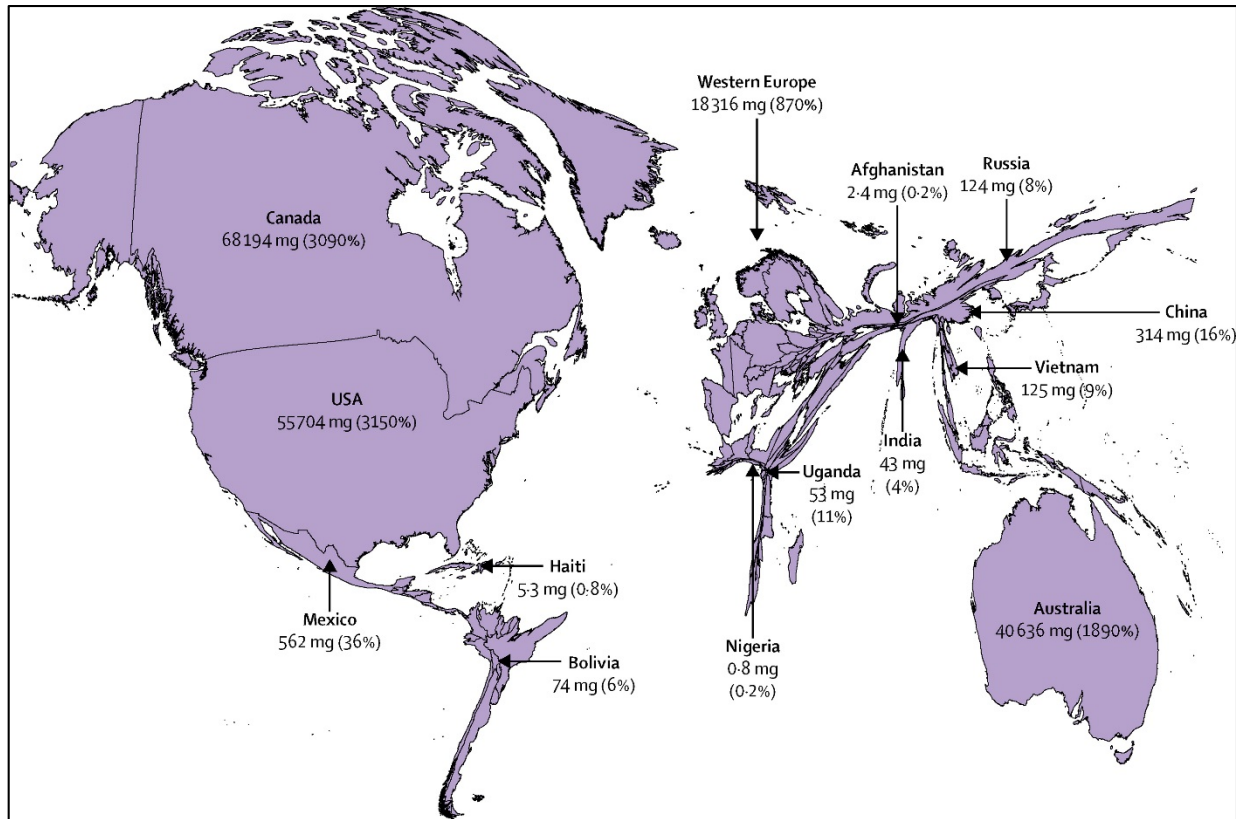


Deaths today from: Cancer

HIV



Morphine availability globally



**80% of the world's dying
do not have access to morphine;
6% are children**

Palliative care – developed world

Science of helping dying patients as they die

*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

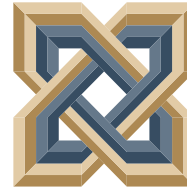
Recognition that death imminent

- 100% Cancer centre
- 64% General hospital trust
- Warning family?
- Provide appropriate care; stop some interventions

Holme Tower hospice 1987



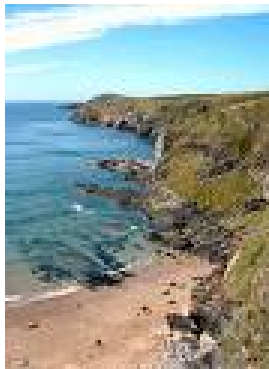
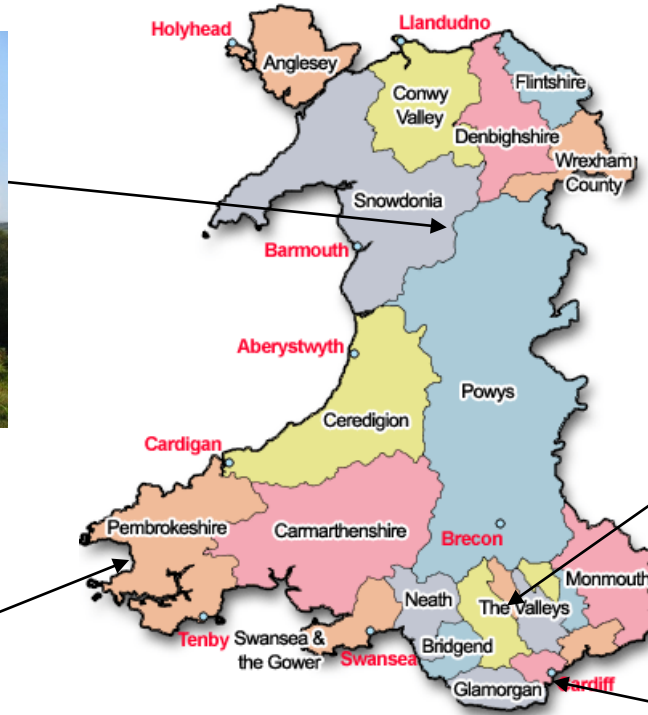
Core Principles



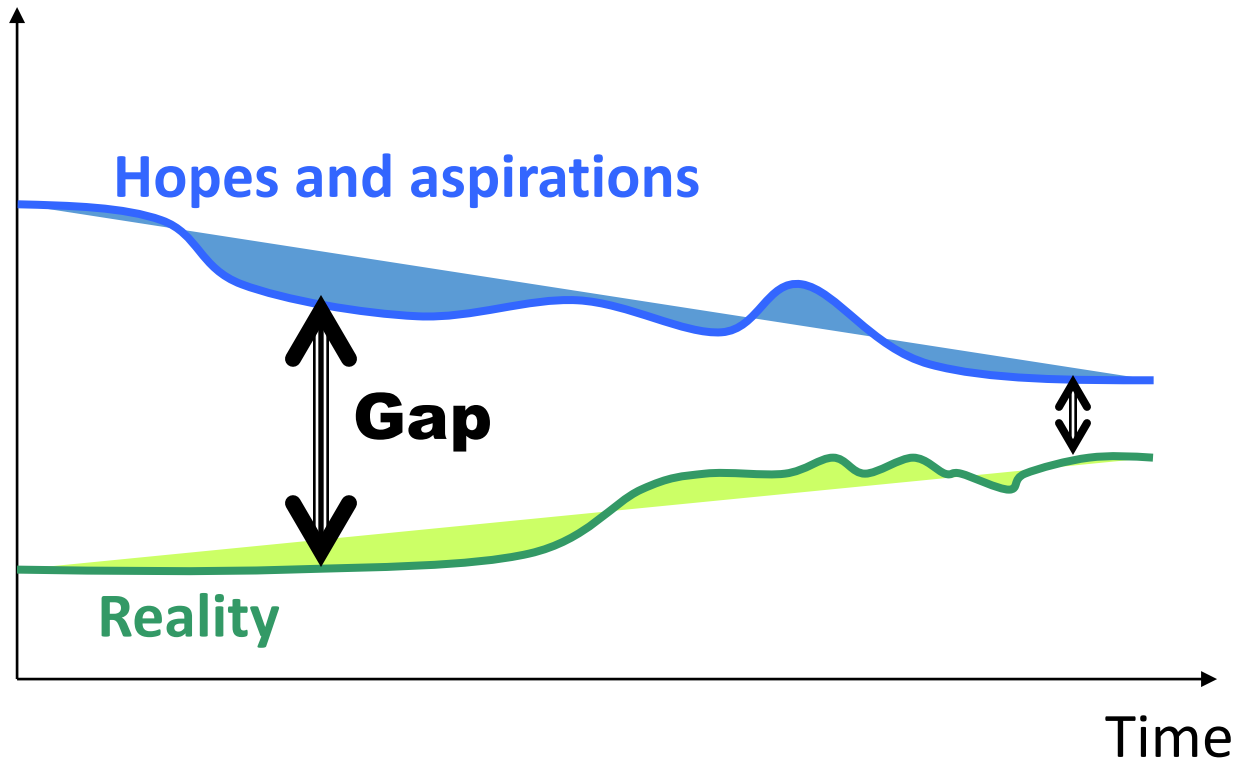
bwrdd gweithredol
goŵal lliniarol cymru
palliative care cymru
implementation board

- Universal access to good end of life and palliative care across Wales 24/7.
- Fairness of service provision, underpinned by high standards in End of Life Care.
- Close integration of services is essential, whether provided by the NHS or by voluntary sector providers.

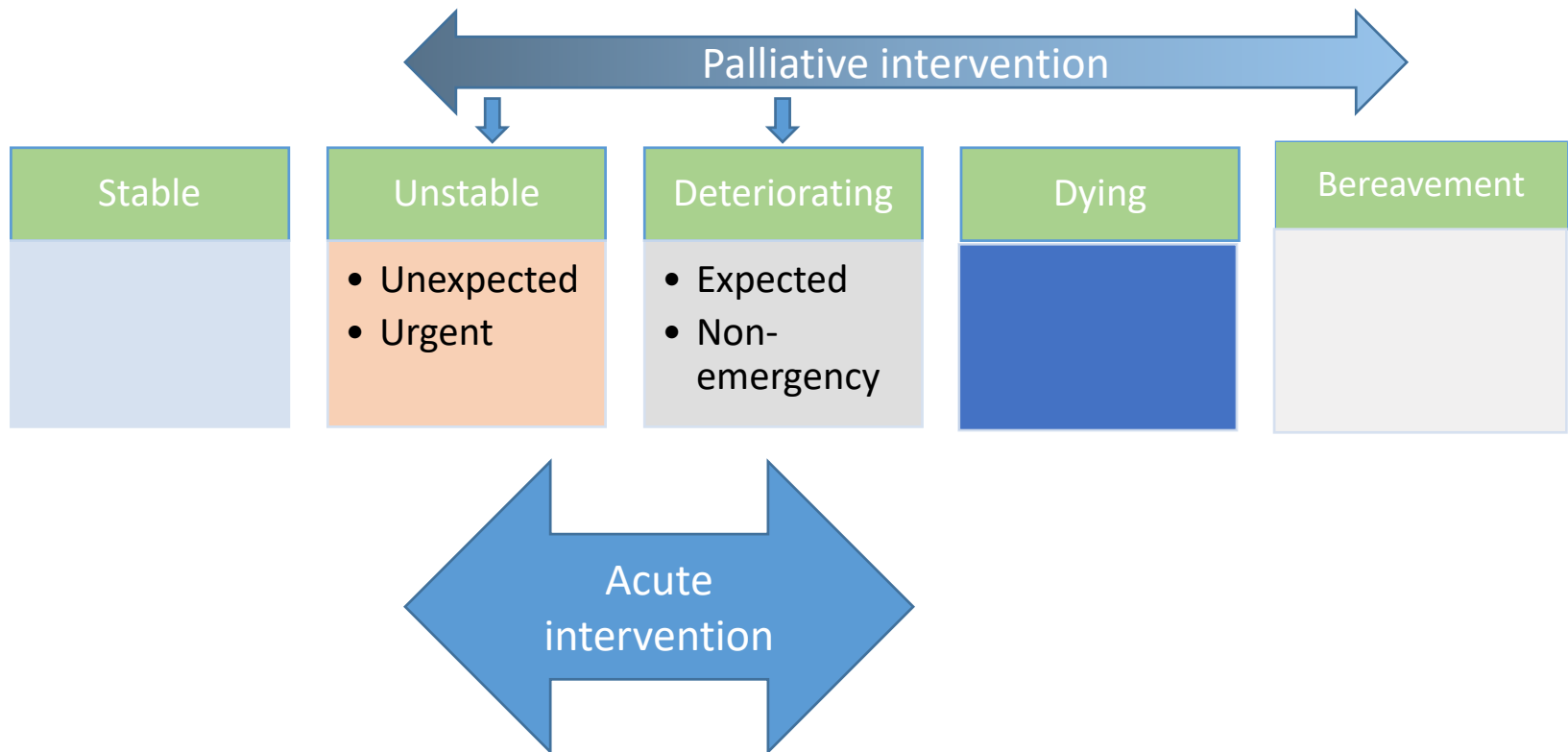
Palliative care - fairness in Wales:



'The quality of life gap'



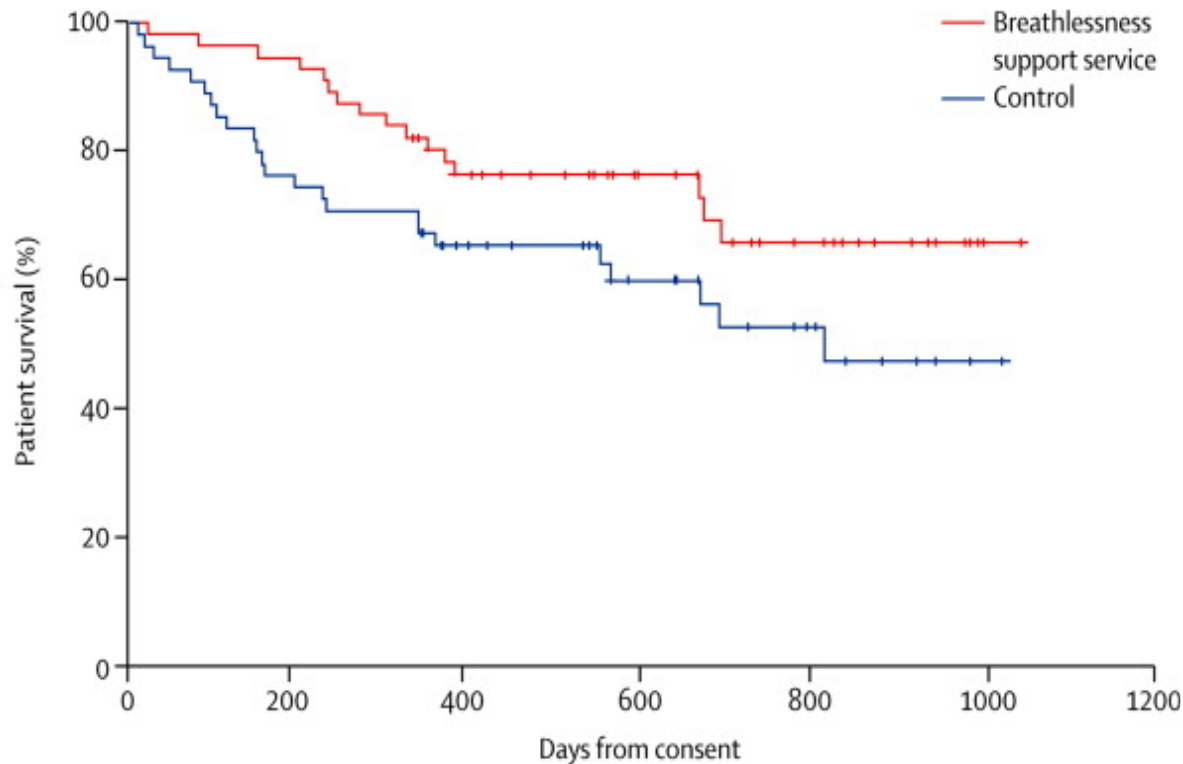
“It is obviously preferable to prevent suffering than to alleviate it.”



Impact of early palliative care

- Temel JS et al NEJM 2010;363:733-42
- **Early palliative care for patients with metastatic non-small-cell lung cancer**
- **Quality of life**
- **Mood**
- **Survival** (11.6 v 8.9 months, $p=0.02$)

Early integration of palliative care: randomised trial UK

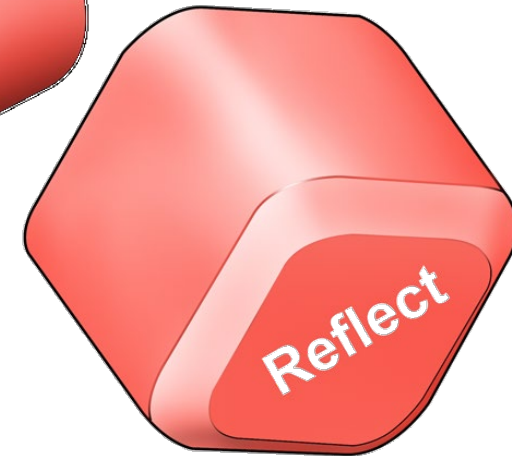
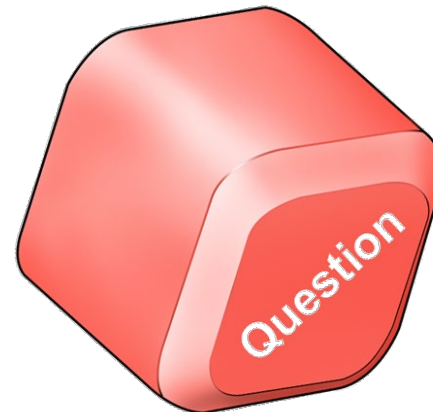
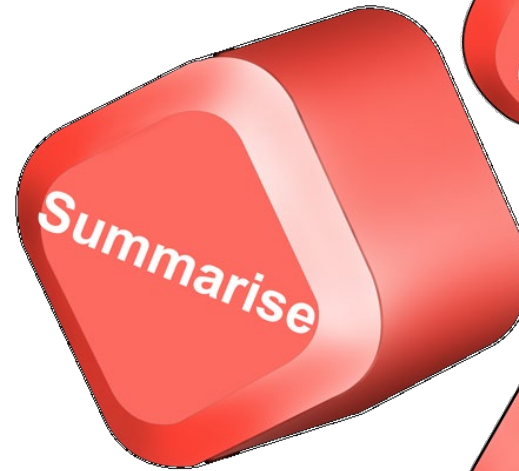
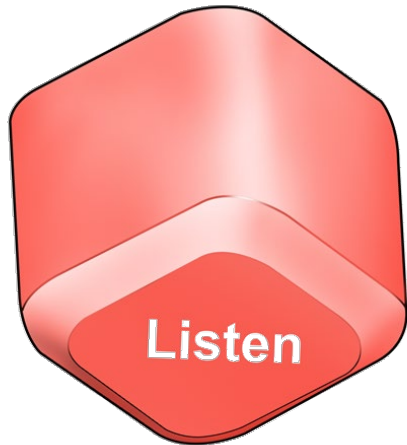


- **Significant benefit in primary outcome**, QoL component, **16%** better
- Significant **survival** benefit
- **No difference in costs**

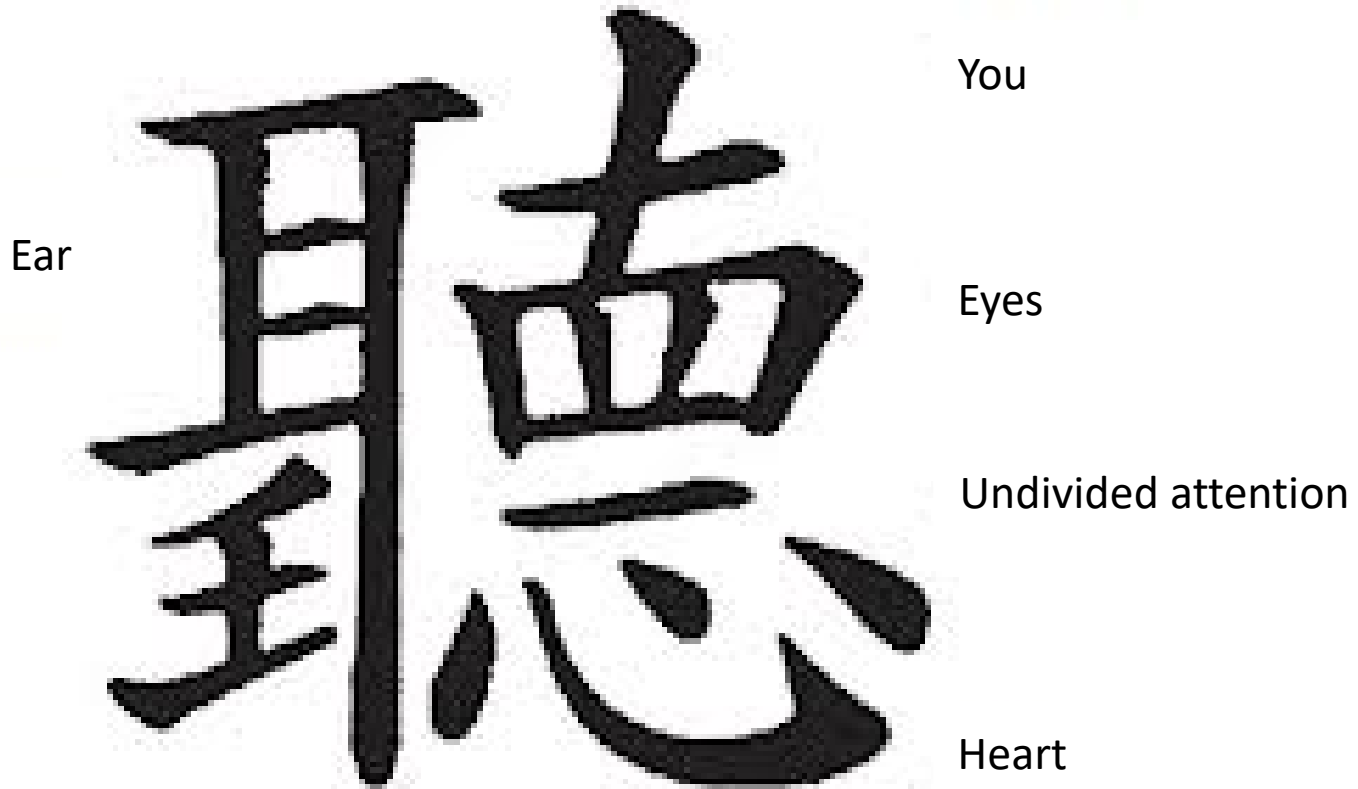
Communication Skills - Cardiff Six Point Toolkit



- Comfort
- Language
- Listening
- Question
- Reflection
- Summarising



In place of fear - Listening

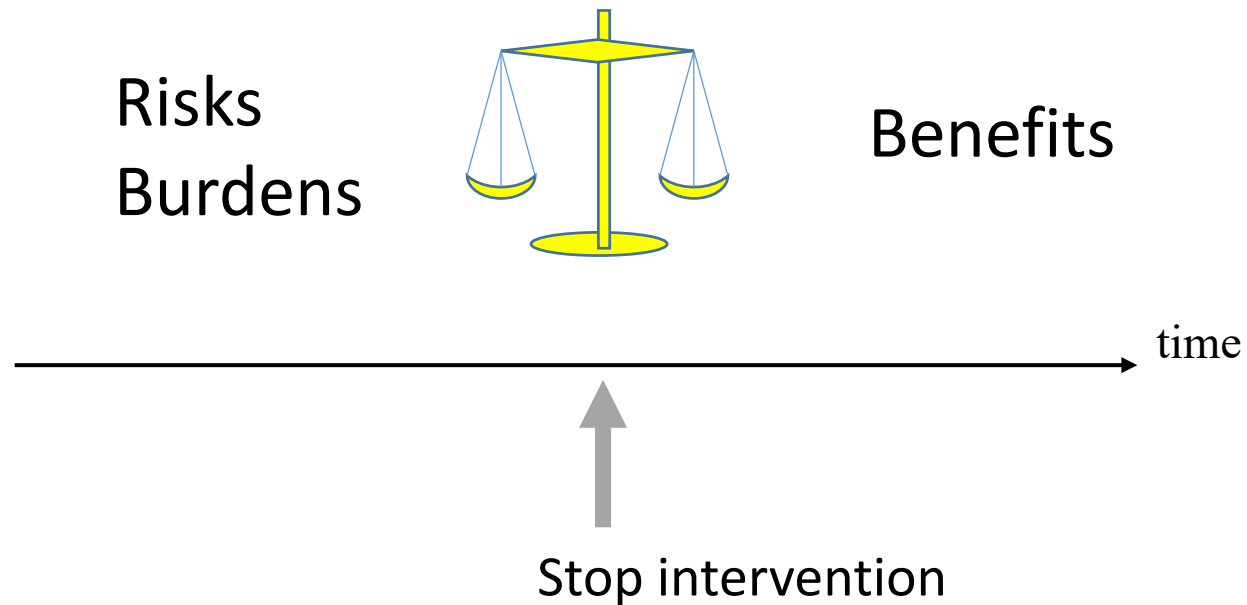


Dignity
is having
a sense of personal worth

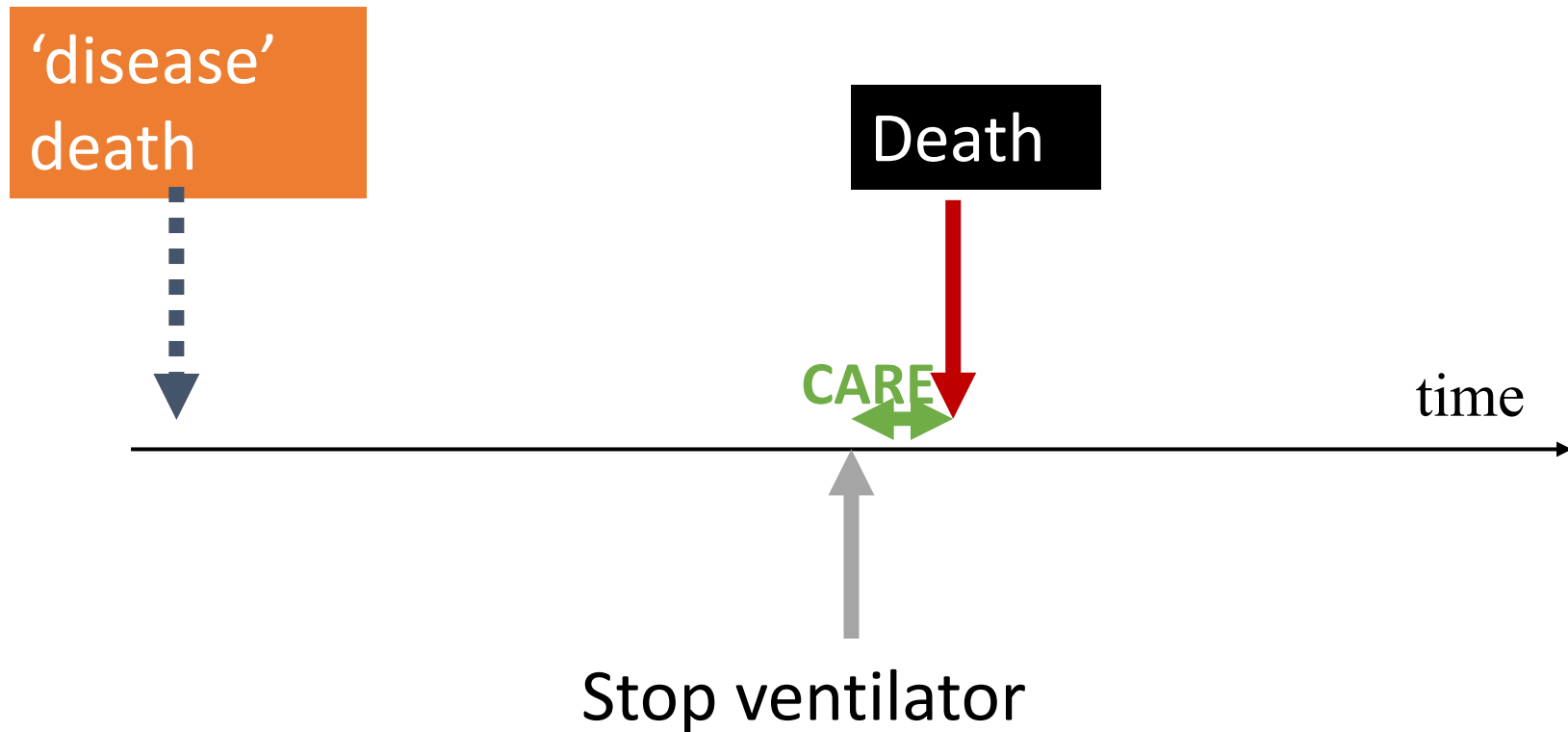
Dame Cicely Saunders 1992

No law against stopping treatment

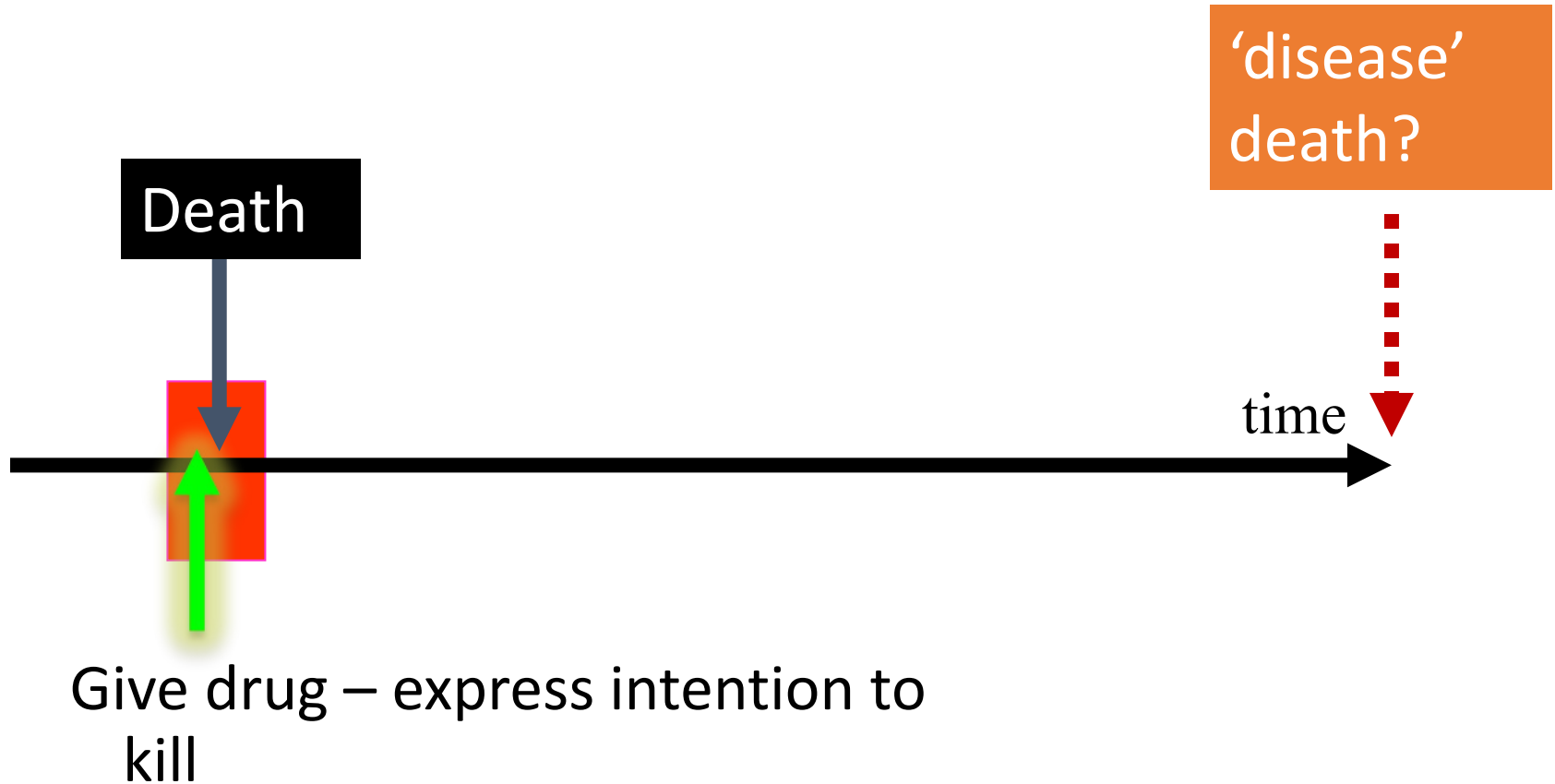
You cannot be treated against your will



Motor neurone disease (ALS)



Euthanasia / physician assisted suicide/ Assisted suicide



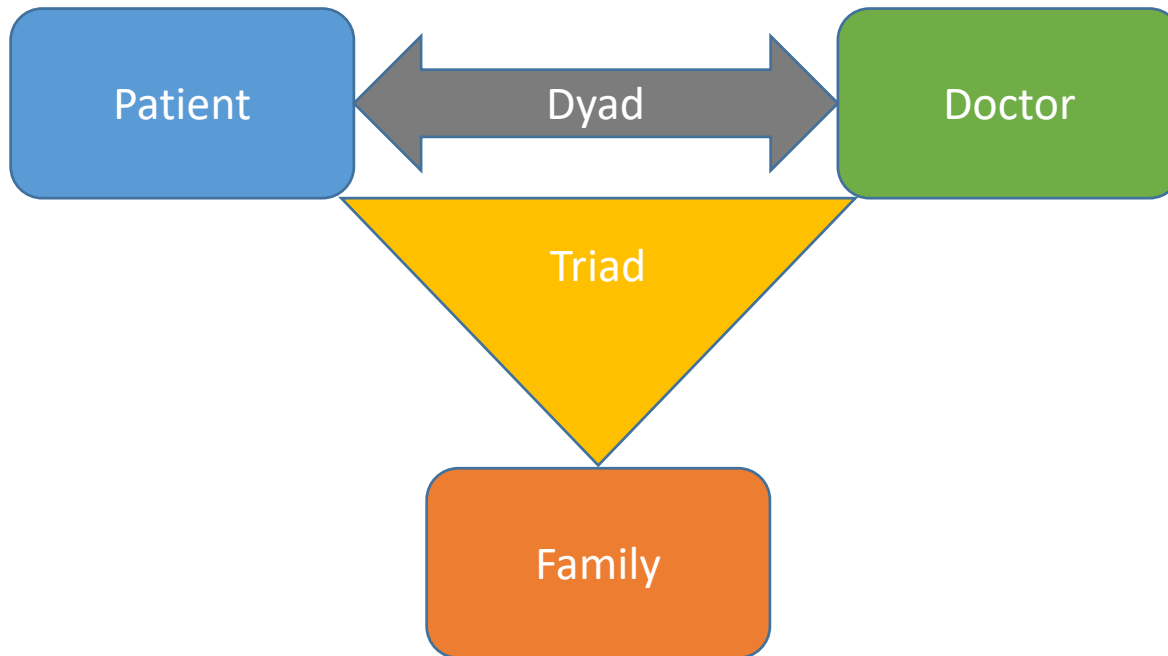


Autonomy is
relational

Our living and our
dying have an
effect on those
around us

Photo by Sara Burns

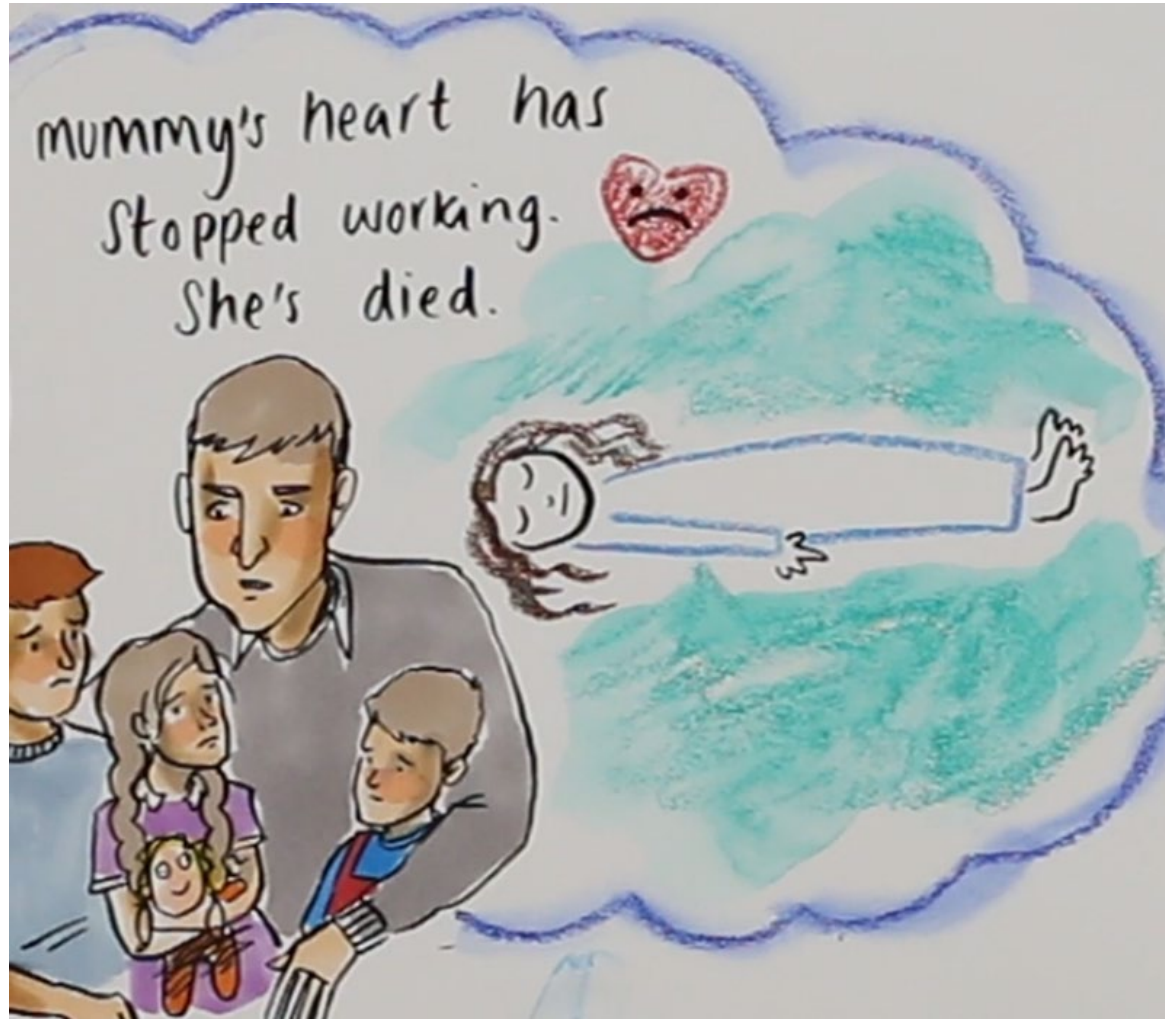
Autonomy in decision making



- The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review
- 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





➔ SUPPORTING A CHILD?



HOW YOU CAN HELP

➔ RUNNING A SERVICE?

Are you a service provider looking for information to help you support children in your area?

CBN supports professionals working with bereaved children and young people, with information updates, key resources and networking opportunities. Find out more about how we can help you.

FIND RESOURCES

➔ FIND SUPPORT NEAR YOU



SEARCH NOW

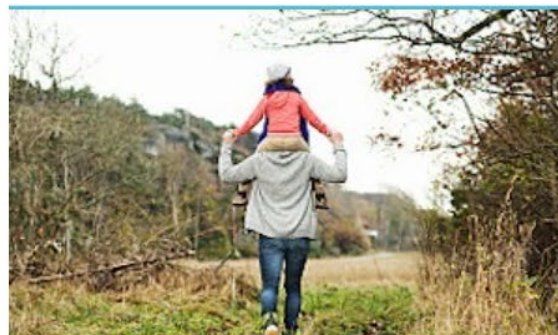
➔ MY STORY



Young people's own experiences

READ STORIES

➔ ABOUT BEREAVEMENT



Find out more about how children grieve

LEARN MORE

➔ OUR TWEETS

Tweets by @CBNtweets



ChildhoodBereavement Retweeted



Kelly Willison
@Kelly_willison

I am in desperate need of a venue that can accommodate 30 children on a Wednesday evening. If you can help or signpost? Thank you x #Trafford area or surrounding

Embed

View on Twitter

Fears

The future worse than today

Pain

Loss of dignity (mind / body)

Loss of control

Loss of autonomy

Being a burden

A right to die?

- **Licensing doctors to assist suicide or inject lethal drugs**

- **Physician assisted suicide**

Oregon's *'Death with Dignity Act'* 1997

- **Euthanasia**

The Netherlands *'Termination of Life on Request and Assisted Suicide Act'* 2001

Belgium

Canada *MAID*

What do you need to make any decision?

1. Accurate information
2. Capacity to take that decision
3. Voluntary

Information – terminal illness?

Diagnostic errors – 5% post-mortems

Prognosis

<6 months is notoriously inaccurate

“medicine is a probabilistic art”

“predict in hours or days, but when it gets to months, the scope for error can extend into years”

Cannot foresee death even when imminent

Cancer? Heart disease? MS or MND? Anorexia?

Tallis; RCGP evidence to House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill 2005

Diagnosing dying: an integrative literature review.
Kennedy C, Brooks-Young P, et al. *BMJ Support Palliat Care* 2014

Capacity to make decisions

“Mental capacity, written down in law, looks simple. It sounds like something objective”.

- MND - 30% cognitively impaired ([Assoc Br Neurol](#))
- Medication / metabolic changes impair capacity
- Desire for death
 - Feeling a burden
 - Depression and hopelessness are mutually reinforcing, independent predictors
 - Major depression ($p < .001$)
 - 1:6 cleared for PAS (Oregon) had undiagnosed clinical depression *“the current practice of the Death with Dignity Act may not adequately protect all mentally ill patients”*

Voluntary – societal not clinical

- Pressures - internal or external
 - Fear of being a burden
 - Financial costs of care
 - Fluctuating desire for death
 - “Compassion”
-
- Influence of doctor’s attitude
 - Normalisation in society becomes expectation

AUGUST 17 2017, 12:01AM, THE TIMES

Even loving families can turn on each other

JENNI RUSSELL

Elderly people's finances need better protection than the
power of attorney system provides



I just want to die

- Are you sure?
- Process request
- Message = you are right to think that you'd be better off dead
- *Stamp of medical beneficence*
- What is making today so terrible?
- What can we do to improve today?
- Message = you are worth me working hard to improve things

Laws and the social dynamic

Laws are more than just regulatory instruments.

Laws send social messages.

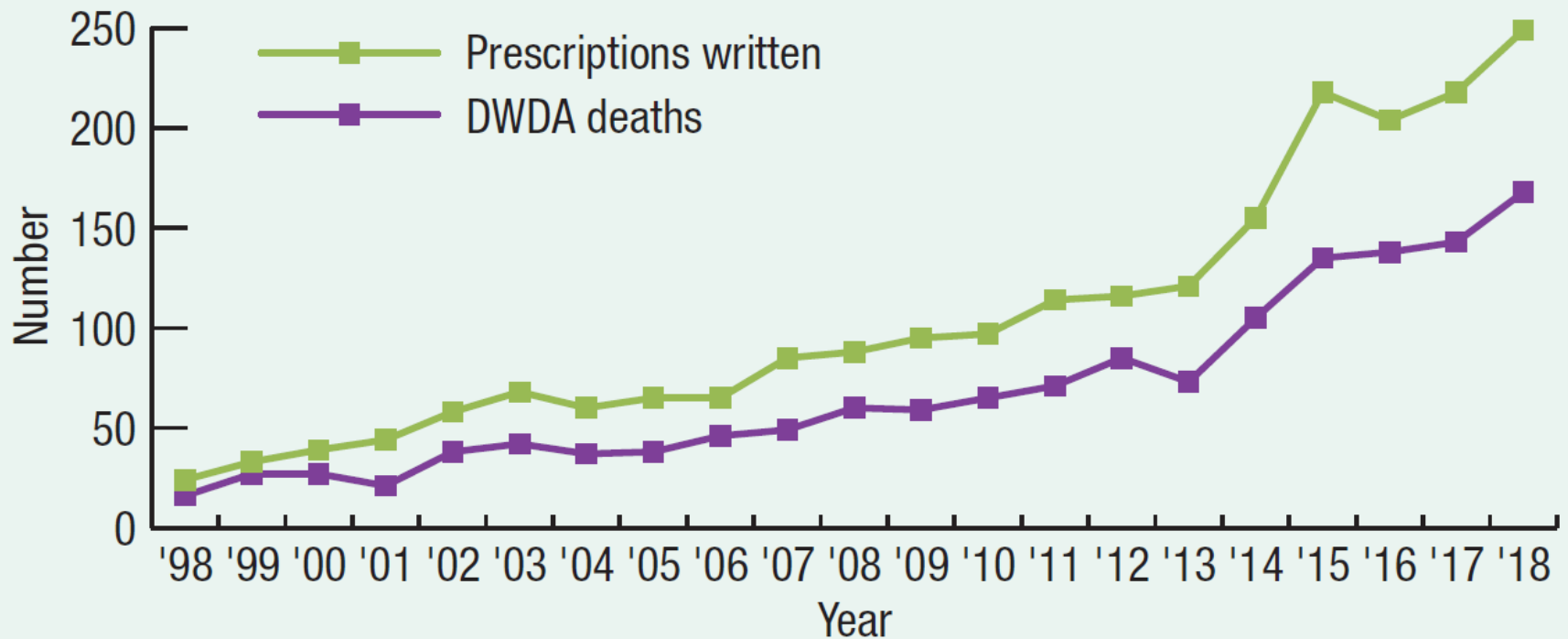
Embedded in medicine gives stamp of beneficence.

PAE makes patient passive recipient.

An 'assisted dying' law conveys the message that, if you are terminally ill, it is appropriate to consider ending your life.

Oregon

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2018



*As of January 22, 2019

The watertight Oregon model for assisted suicide is a leaky boat

- *Most diseases become terminal if patients refuse to take the medicine*
- 6-month prognosis is based on an assumption that the illness takes its course without further treatment



Fabian Stahle

>> Oregon Death with Dignity Act

2018 Data Summary

21 years data

Time to death 1 minute - 104 hours
(Average 97-439 mins depending on lethal cocktail)

8 awoke (21 yrs data)
1-35 prescriptions / doctor

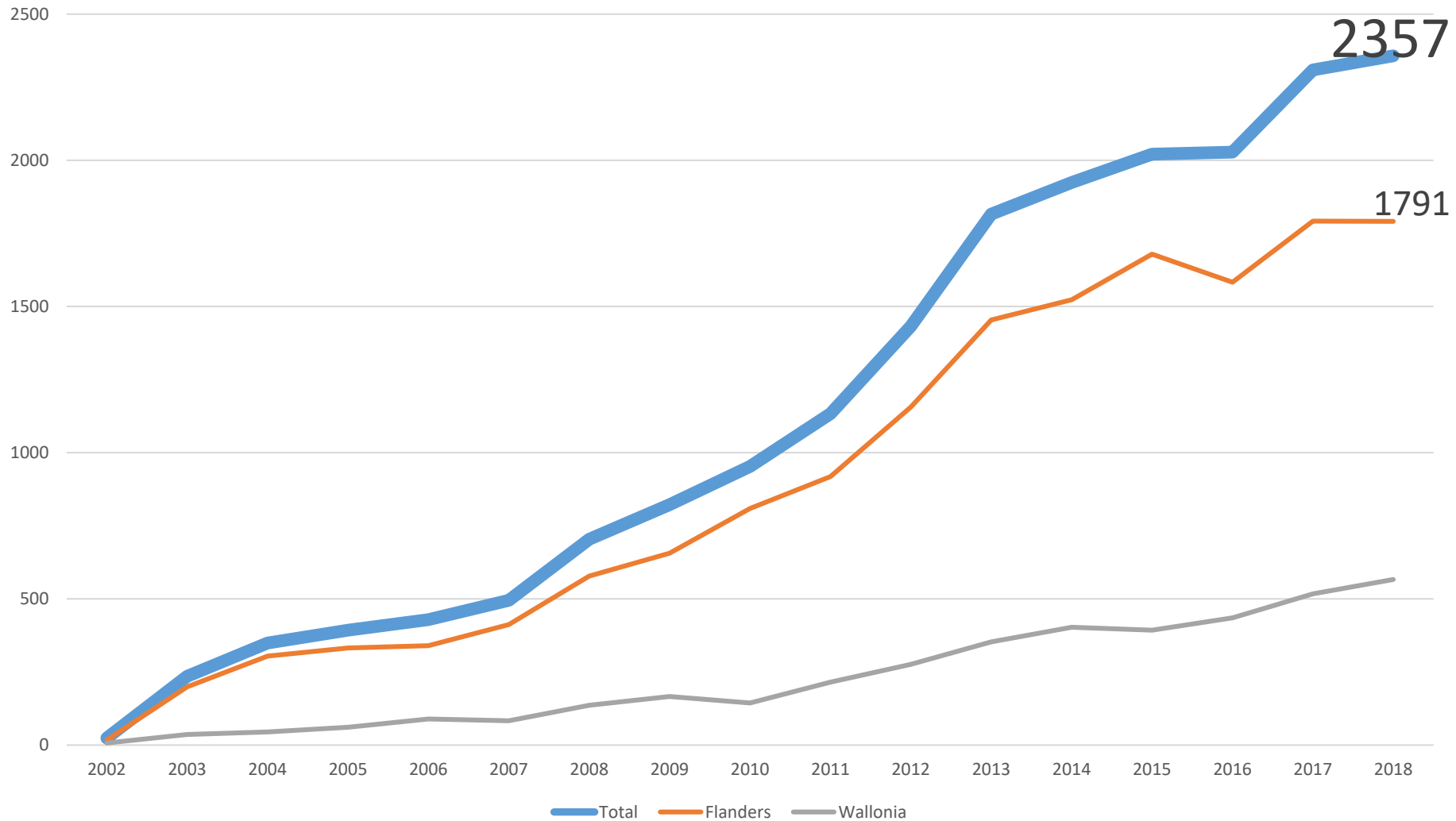
≈ 2,500 England & Wales

Barbara Wagner's Story

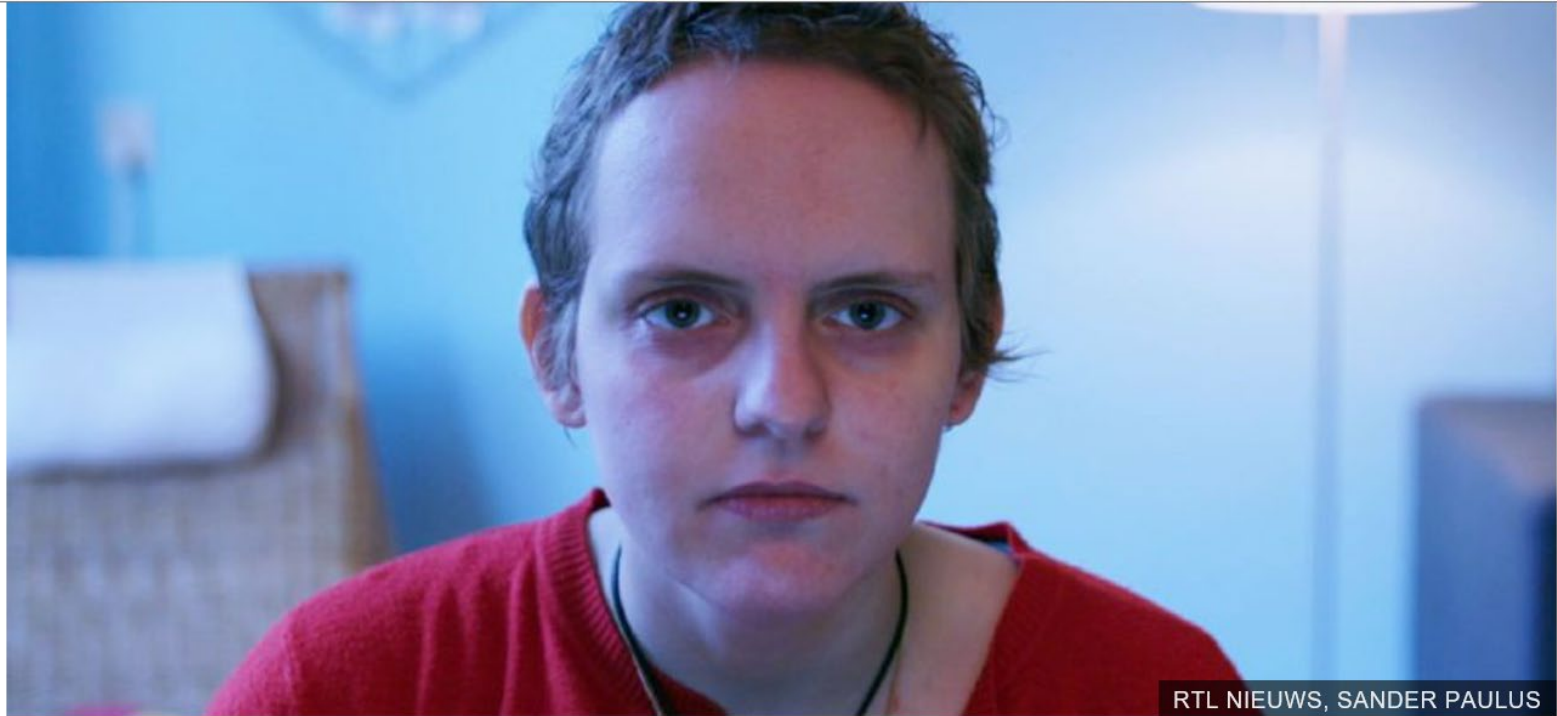


- 64 year old
- Oncologist prescribed palliative chemotherapy
- **Oregon Health Plan** stated chemotherapy is not covered, but... assisted suicide drugs are 100% covered as a “comfort care” measure
 - *Eugene Register-Guard* June 3, 2008

Reported euthanasia - Belgium 2002-18



Aurelia Brouwers 29 years old



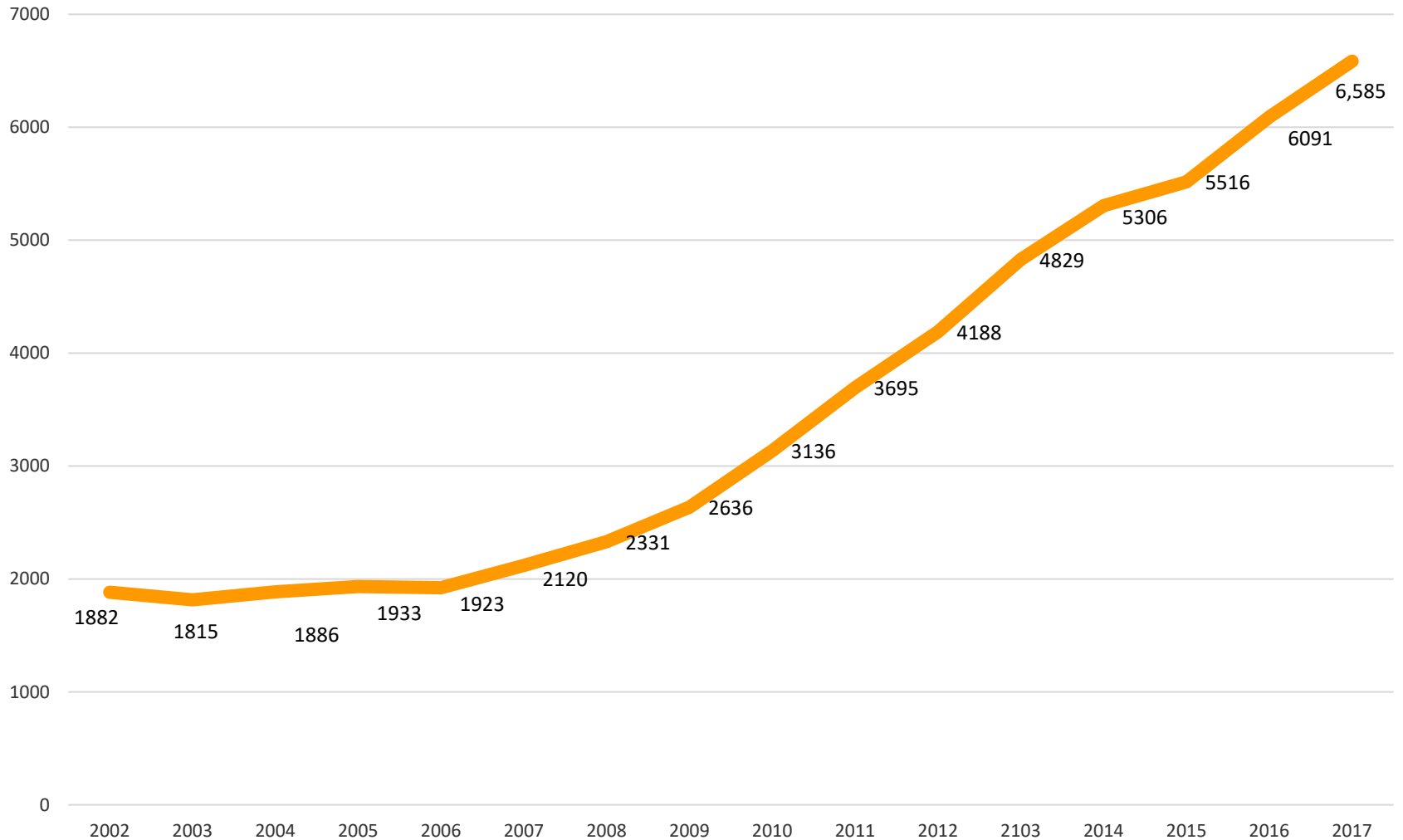
During her last two weeks of life, Aurelia was often distressed and had self-harmed.

"I'm stuck in my own body, my own head, and I just want to be free," she said. "I have never been happy - I don't know the concept of happiness."

83 people were euthanised on the grounds of psychiatric suffering in 2017

Netherlands - notifications (PAS + Euth.)

$\simeq 25,000$ in UK



Quits regulator committee

- Berna van Baarsen, a medical ethicist, said she could not support “a major shift” in the interpretation of her country’s euthanasia law to endorse lethal injections for increasing numbers of dementia patients.

1 Dutch case prosecution

- Alzheimer's woman
 - Coffee drugged
 - Restrained while drugs injected
 - Making plans to go out to eat with family that day
 - AD to be euthanized "whenever I think the time is right."
Later, said "But not just now, it's not so bad yet!"
- Fluctuating capacity
- "overruling the wishes of incompetent patients to live, because a will to live is your basic, fundamental right" Ghislaine van Thiel Utrecht

Canada 'Medical Aid In Dying' MAiD

<i>July 1 - Dec 31, 2017</i>	<i>1525</i>
Total MAiD deaths since Dec 10, 2015	3714

Already pressures to expand to mental illness,
mature minors, advance directives

Dr T Lau: Euthanasia in Canada: a cautionary tale

Costs saved on healthcare

- Canadian estimates \$35m-139m.

[Albaladejo A. *BMJ* 2019;364:1852 doi: 10.1136/bmj.l852](#)

- US > \$1000m today.
- “It is certainly plausible and perhaps even likely that budget-minded health care organization managers and their physician-employees would press their dying patients toward exercising [a right to receive a physician's assistance with suicide]”

[Ezekiel J, Battin MP. *NEJM*. 1998;339:167-72](#)

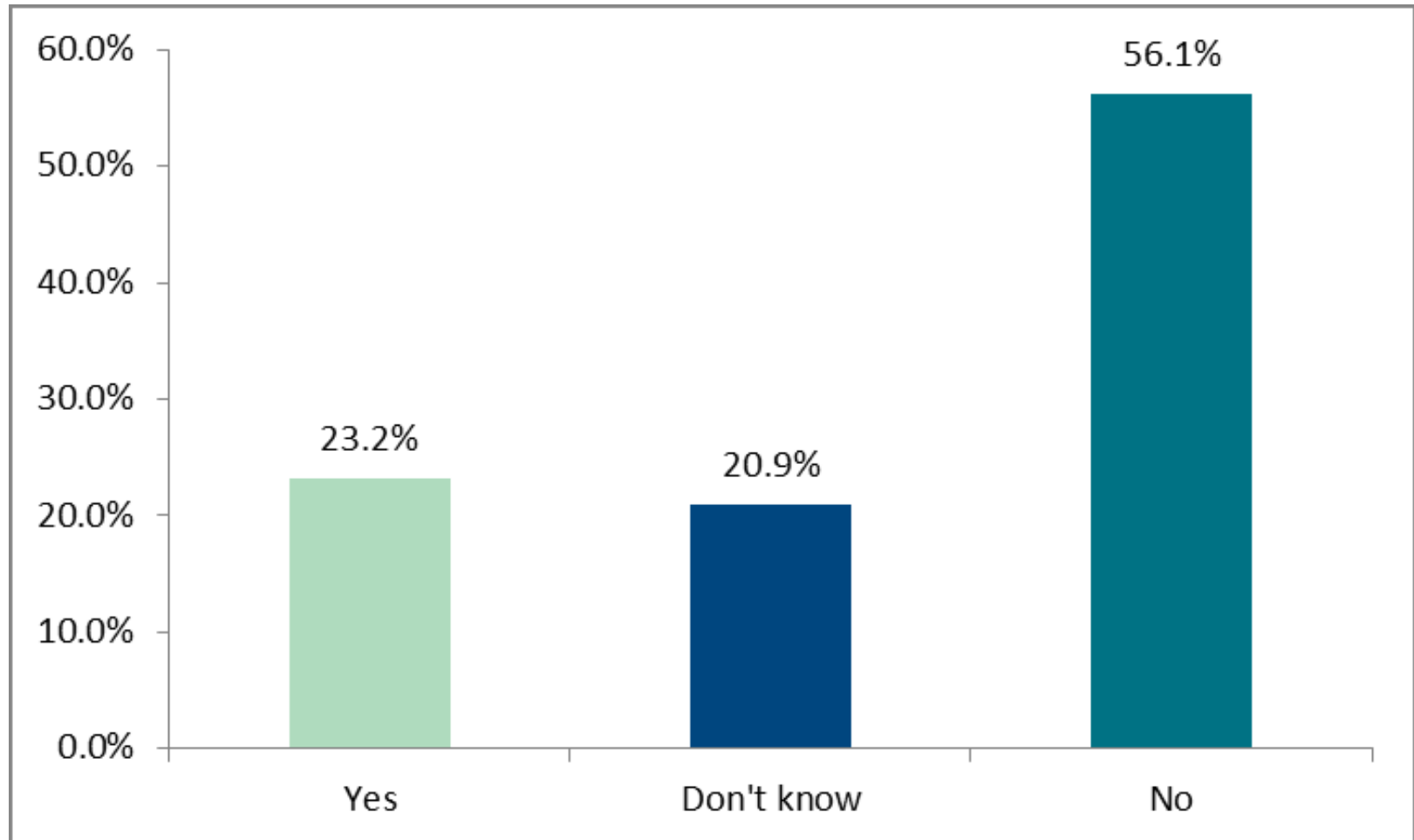
Canada – the lived experience

- **Roger Foley** – disability support arrangements denied but free to pursue medically assisted death

Vulnerable Persons Standard 2008:

- **“we can have little confidence that MAiD-related decisions are being appropriately grounded in effective communication especially for patients who have disabilities that affect their communication”**

Regardless of your support or opposition to change, if the law were changed to permit assisted dying, would you be prepared to participate actively? RCR 2019 - 34% response rate



The law?

- Law is to protect the vulnerable
- Where is the Rubicon re mental illness, suicide prevention, dementia, post-abuse, chronic illness?
- Societal issue, not a medical issue

PAS rejected by 330 votes to 118

(11/9/2015)

- Laws are for public safety
- **Send social messages**
- Can have unintended consequences





NO COMMITMENT

WEAK SURVEILLANCE

POOR DRUG QUALITY

IRRATIONAL DRUG USE

LACK OF RESEARCH

LACK OF INFECTION CONTROL

DRUG RESISTANCE

Infections

The screenshot shows a web browser window displaying the homepage of The UK Sepsis Trust. The browser's address bar shows the URL <https://sepsistrust.org>. The website features a dark background with a large, bold headline: "SEPSIS AFFECTS 25,000 CHILDREN EACH YEAR IN THE UK". Below this headline, a sub-headline reads: "Layla Astley was just 13 weeks old when she nearly died of sepsis after suffering a water infection." A button labeled "READ PATIENTS' STORIES" is positioned below the sub-headline. To the right of the text, there is a black and white photograph of a young girl, Layla Astley, standing on a beach with her arms raised in a 'V' shape. The word "SEPSIS" is written in large, dark letters on the sand in front of her. The website's navigation menu includes links for "ABOUT", "FUNDRAISE", "VOLUNTEER", "GET SUPPORT", "PROFESSIONAL RESOURCES", "SHOP", and "CONTACT". A "DONATE TODAY" button is located in the top left corner. The browser's taskbar at the bottom shows various application icons, including Windows, Edge, Word, Excel, and Chrome, along with the system clock indicating 18:23 on 02/03/2019.

THE UK SEPSIS TRUST

DONATE TODAY

SEPSIS AFFECTS 25,000 CHILDREN EACH YEAR IN THE UK

Layla Astley was just 13 weeks old when she nearly died of sepsis after suffering a water infection.

READ PATIENTS' STORIES

SEPSIS

SCROLL

Sepsis kills 5 people an hour in the UK

HOW TO SPOT SEPSIS IN ADULTS

Seek medical help urgently if you (or another adult) develop any of these signs:

Slurred speech or confusion

Extrême shivering or muscle pain

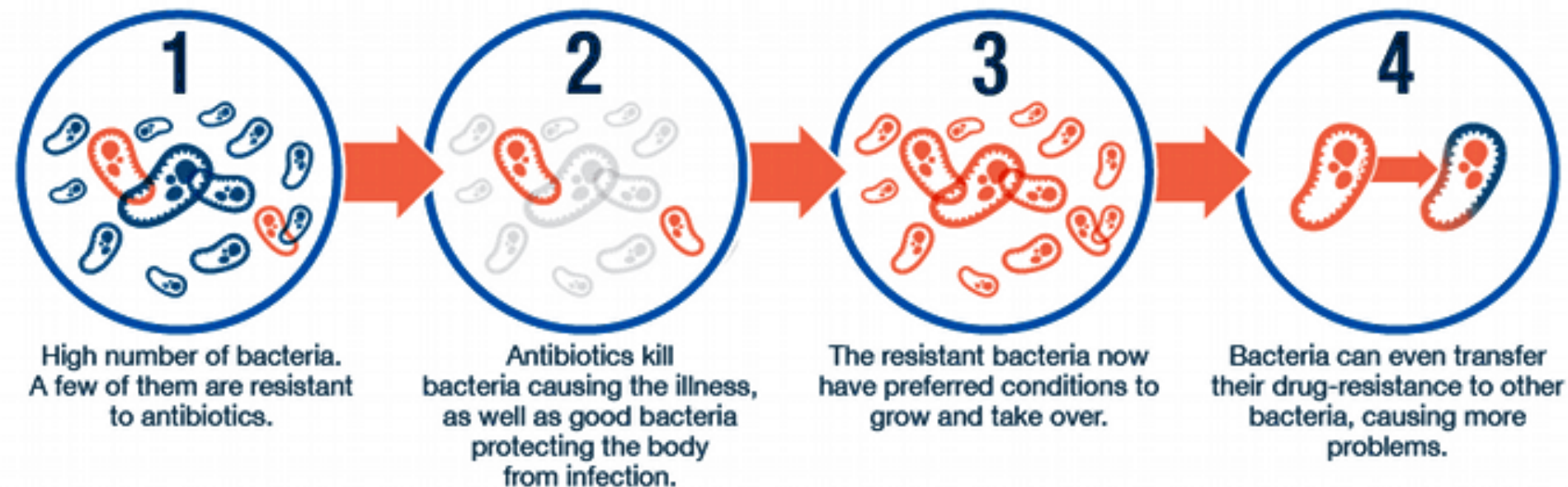
Passing no urine (in a day)

Severe breathlessness

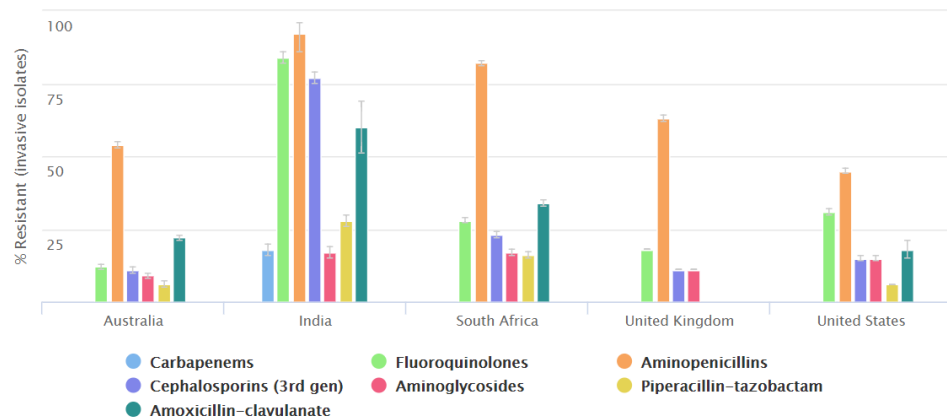
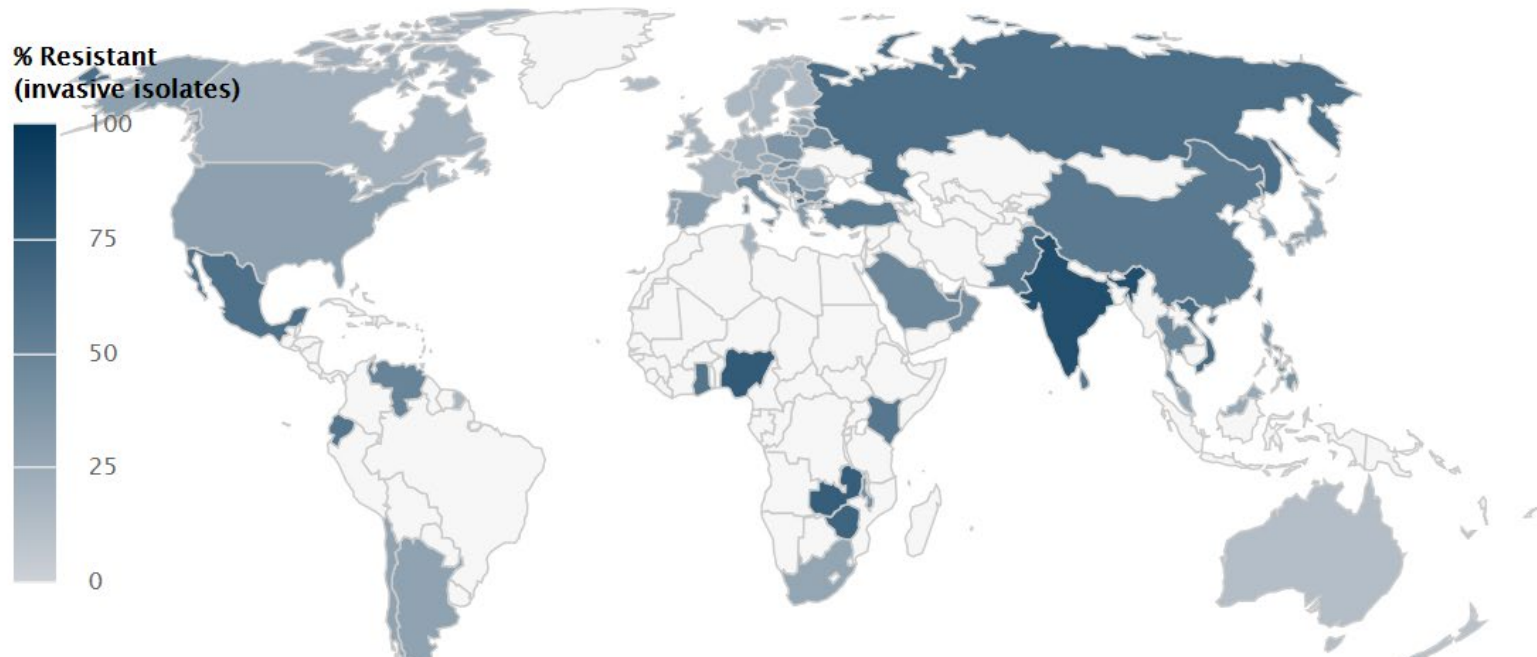
It feels like you're going to die

Skin mottled or discoloured

How does antibiotic resistance occur?



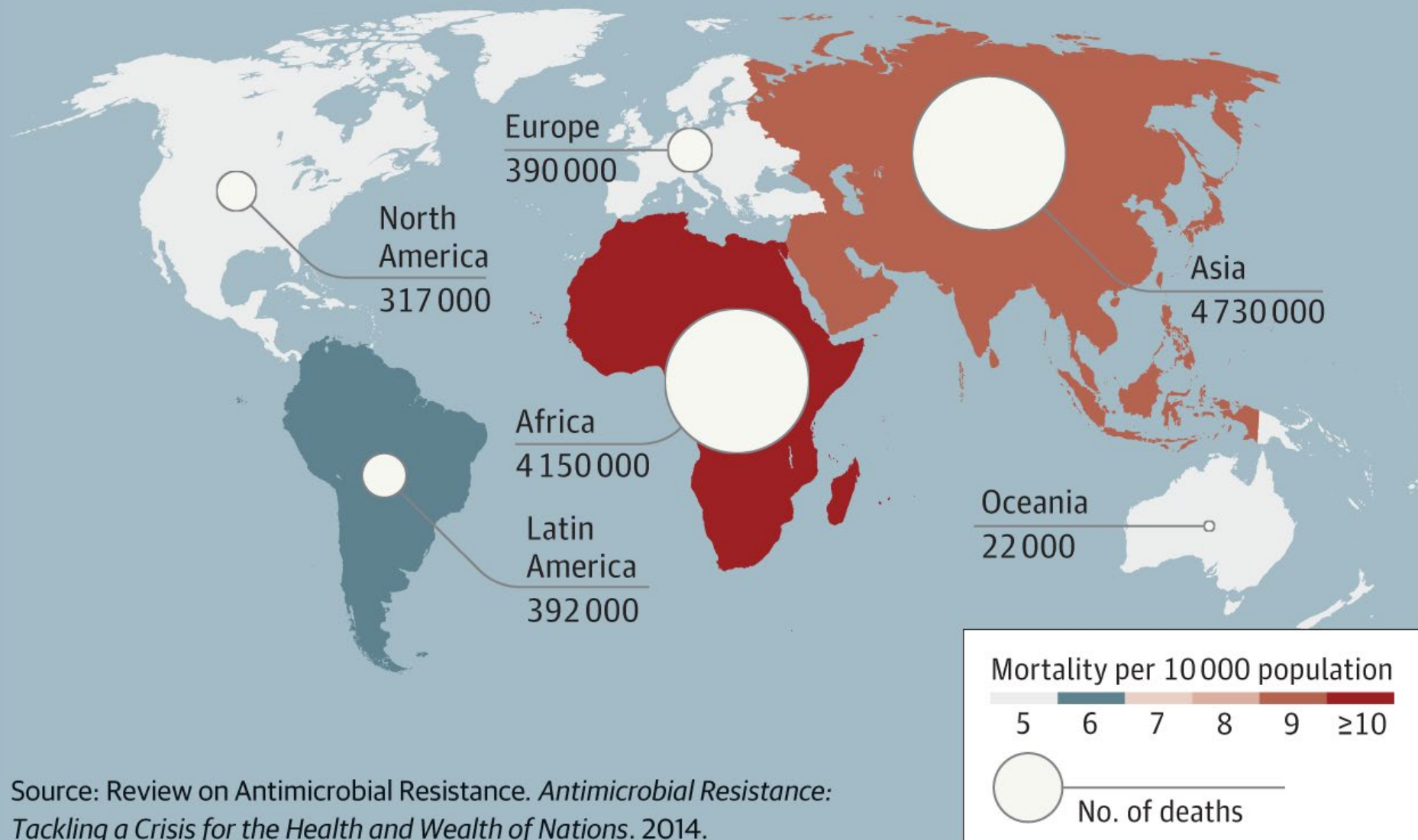
Resistance of E Coli to fluoroquinolones



India



Deaths Attributable to Antimicrobial Resistance Every Year by 2050



Source: Review on Antimicrobial Resistance. *Antimicrobial Resistance: Tackling a Crisis for the Health and Wealth of Nations*. 2014.