Achieving Policy Change in Palliative Care

Prof. Ilora Baroness Finlay of Llandaff

Marie Curie
Care and support through terminal illness

hospice UK

Comisiwn Bevan Commission

Cardiff University
Prifysgol Caerdydd

ldw
living and dying well

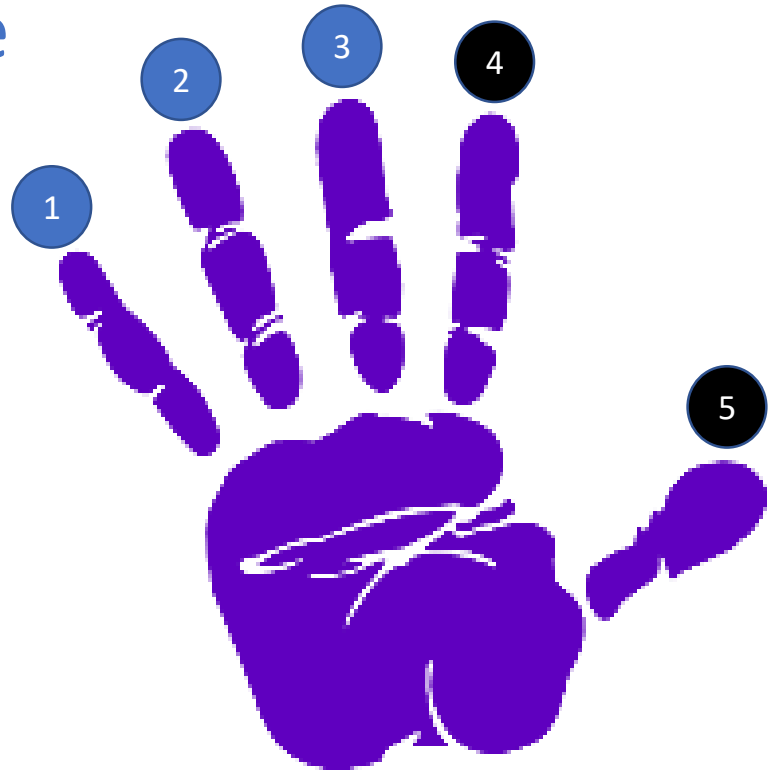
The role of evidence

- Previous law – MCA
- Previous experience – Wales
- The Health and Care Act 2022
- ‘AD’ likely to be presented in UK – what we can learn from each other

- Where we need more evidence – much more!

Mental Capacity Act 2005 – FIVE principles – What are they?

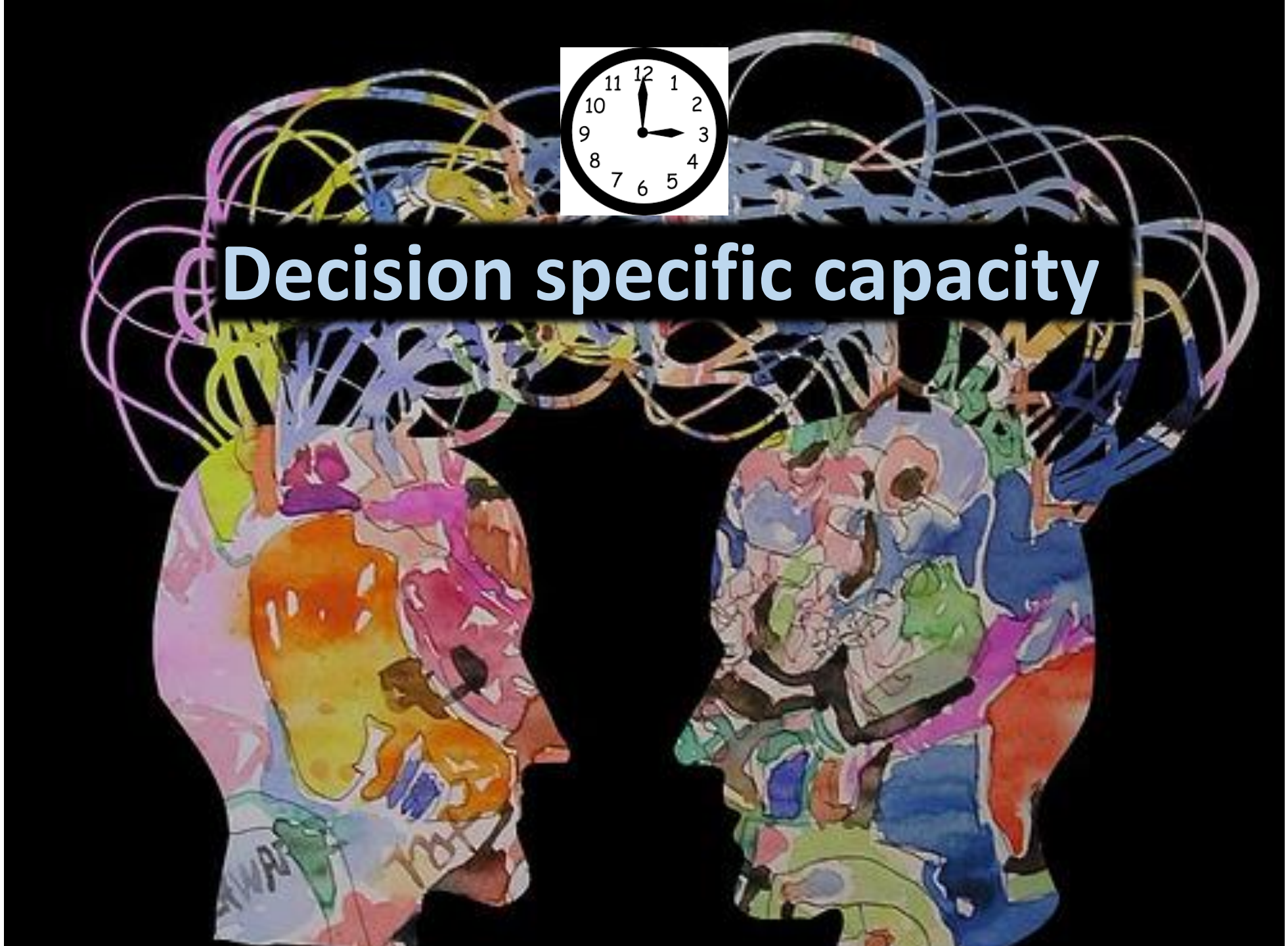
1. A presumption of capacity
2. Individuals **supported** to make their own decision
3. Unwise decisions
4. Best interests
5. Less restrictive option



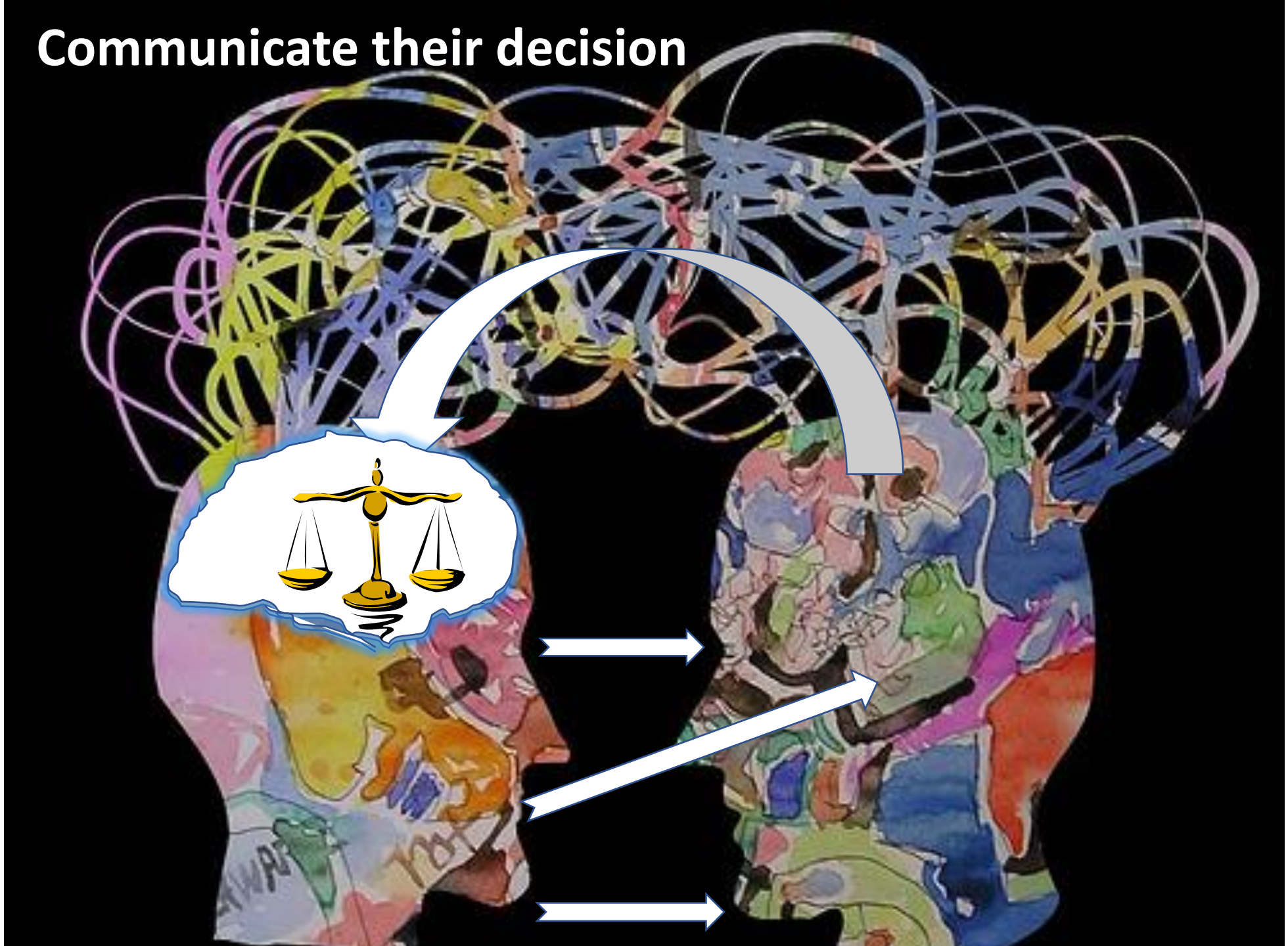
After Shropshire Council

Mental Capacity Act 2005

- Dilemmas – difficult decisions
- Is it treatable?
- Best interests decision making
- Supporting decision making
- Lasting Power of Attorney
- Advance Decisions to Refuse Treatment
- Advance Statement of Wishes


Decision specific capacity

Communicate their decision



How was the person supported?

- Information?
- Options?
- Using P's strengths?

- **Why didn't the support work**?

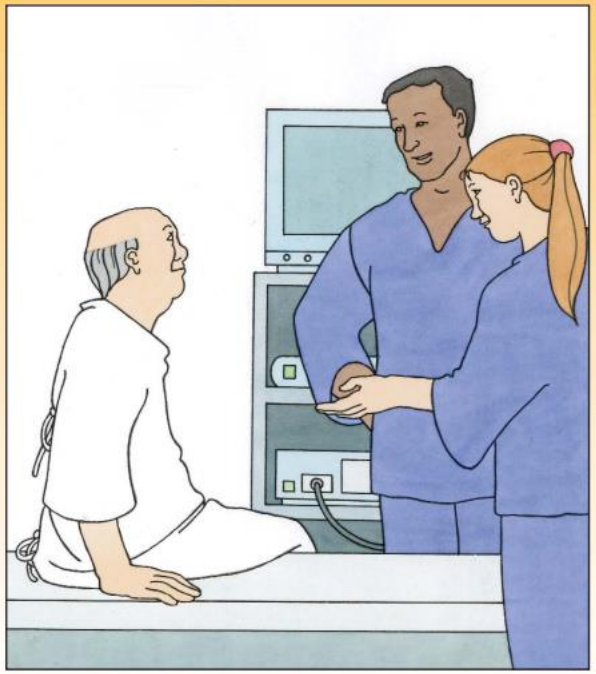
THEN

- Assess capacity for that decision at that time

Beyond Words
empowering people through pictures

NHS
Cancer Screening Programmes

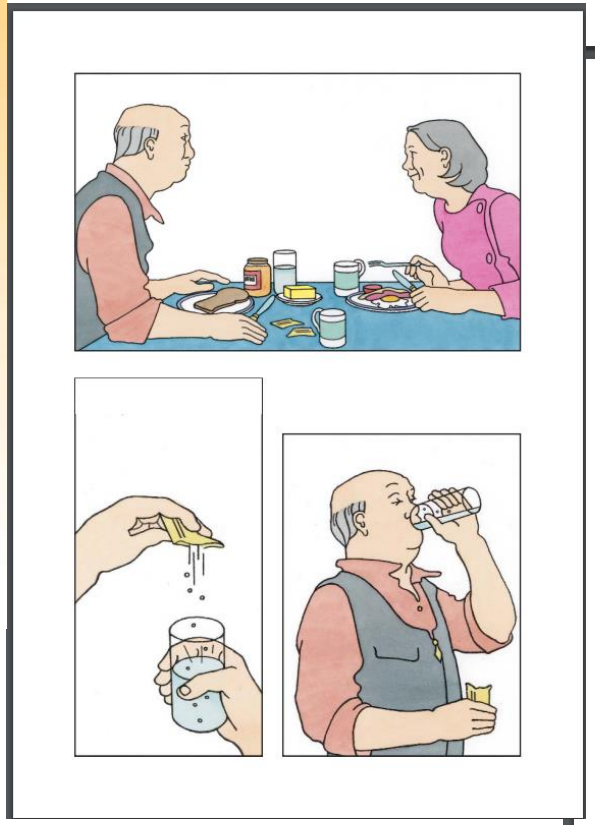
An Easy Guide to Having a Colonoscopy

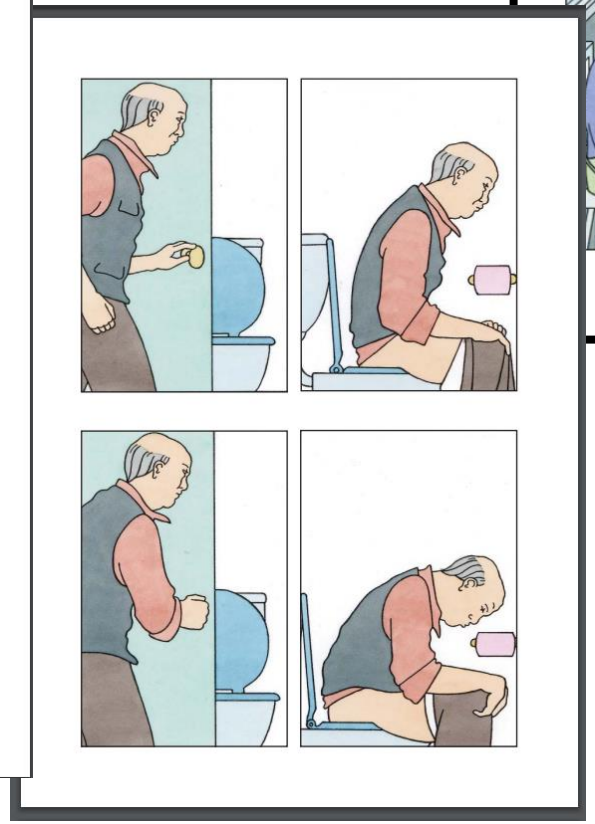


A leaflet by and for men and women with learning disabilities

Beyond Words

empowering people through pictures





First hand information – beware of unconscious bias

Do you know about what mattered to the person?

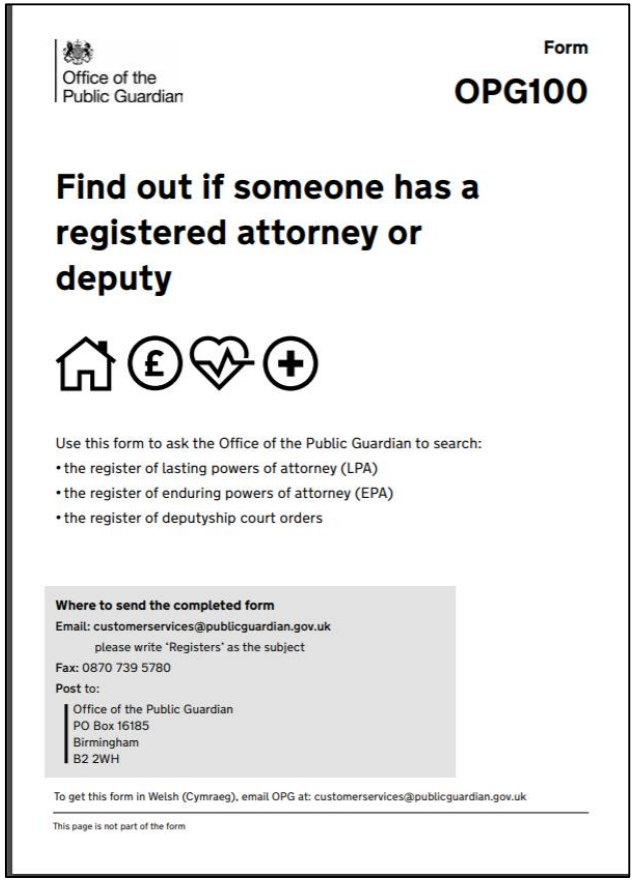
Do you listen actively?

Are you on their territory?

Best interests decision?

What would the patient have done in the circumstances if they had been able to make their own decision?

- Regain capacity?
- Person's **wishes and feelings**, **values and beliefs**?
- Permit and encourage participation



Office of the Public Guardian

Form
OPG100

Find out if someone has a registered attorney or deputy

Use this form to ask the Office of the Public Guardian to search:
- the register of lasting powers of attorney (LPA)
- the register of enduring powers of attorney (EPA)
- the register of deputyship court orders

Where to send the completed form
Email: customerservices@publicguardian.gov.uk
please write 'Registers' as the subject
Fax: 0870 739 5780
Post to:
Office of the Public Guardian
PO Box 16185
Birmingham
B2 2WH

To get this form in Welsh (Cymraeg), email OPG at: customerservices@publicguardian.gov.uk

This page is not part of the form

The MCA - Best interests

An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

Section 4 (5)
Where the determination relates to **life-sustaining** treatment he **must not**, in considering whether the treatment is in the best interests of the person concerned, **be motivated by a desire to bring about his death.**

Pitfalls in decision making

- Diagnosis
- Prognosis
- Detecting coercion
  - Behind closed doors
  - Internal – being a burden etc
  - Doctor patient power differential
- Status of Advance Decision to Refuse Treatment – DNACPR etc
- Advance care planning = Advance Statement of Wishes

Coercive pressures

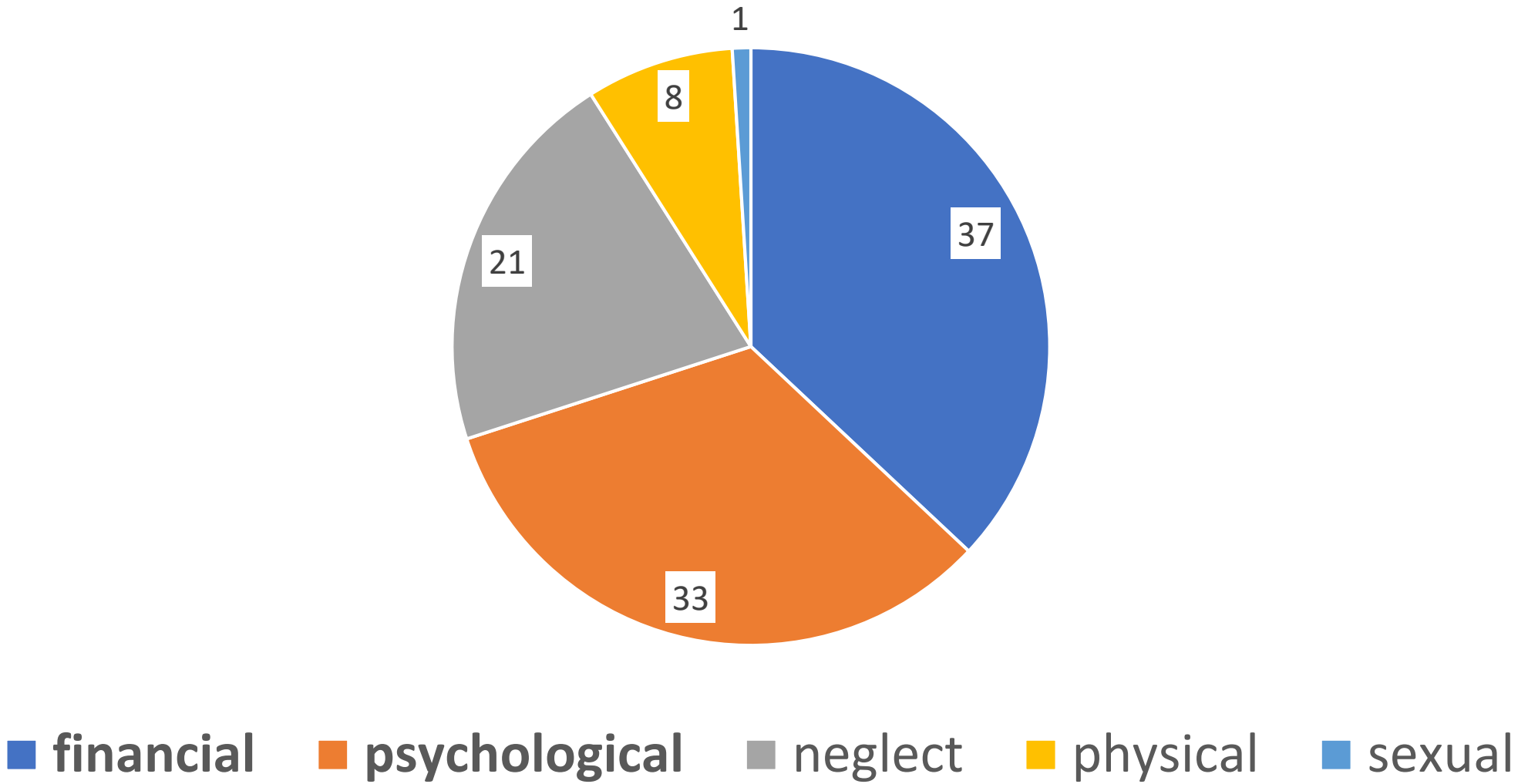
Internal pressures:

- Hope and despair fluctuate
- Burden on the family

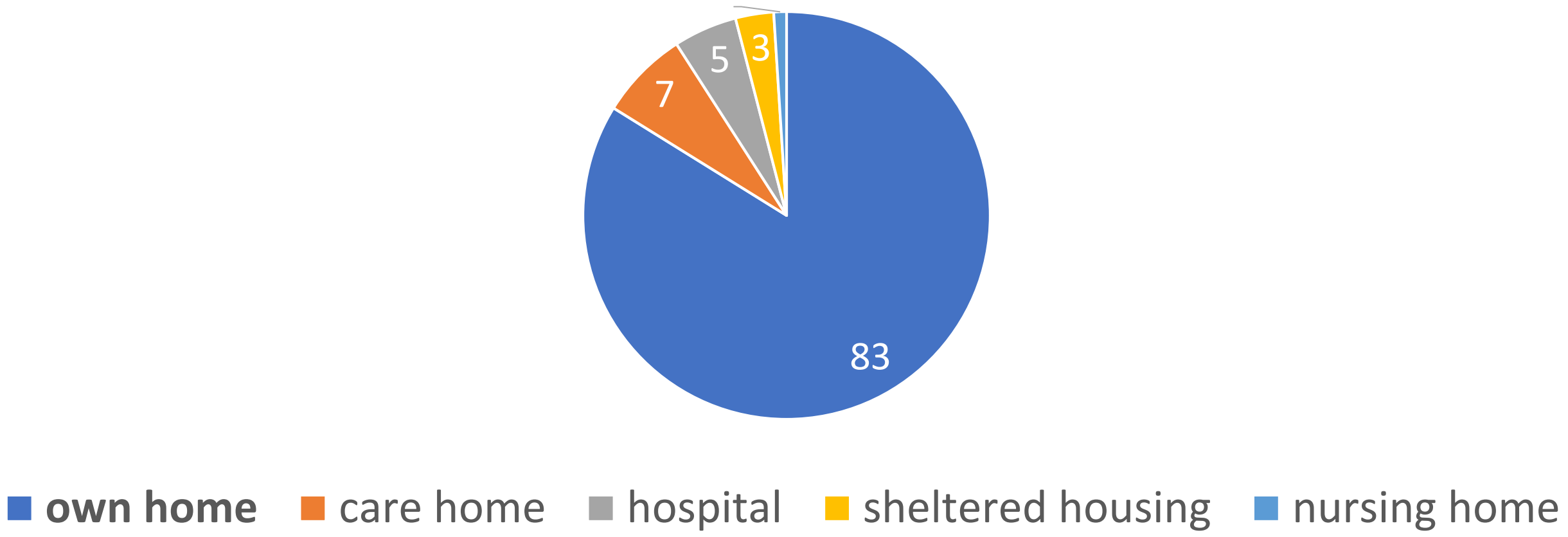
External pressures:

- Detecting coercion in families - not necessarily malicious
- Financial pressures
- **Abuse** - 1 in 5 respondents = 2.7 million older people (Hourglass)
- Exploitation by ‘befrienders’

Abuse of elderly 1 in 5 = 2.7 million affected



Where? Average 75 yr old female victims

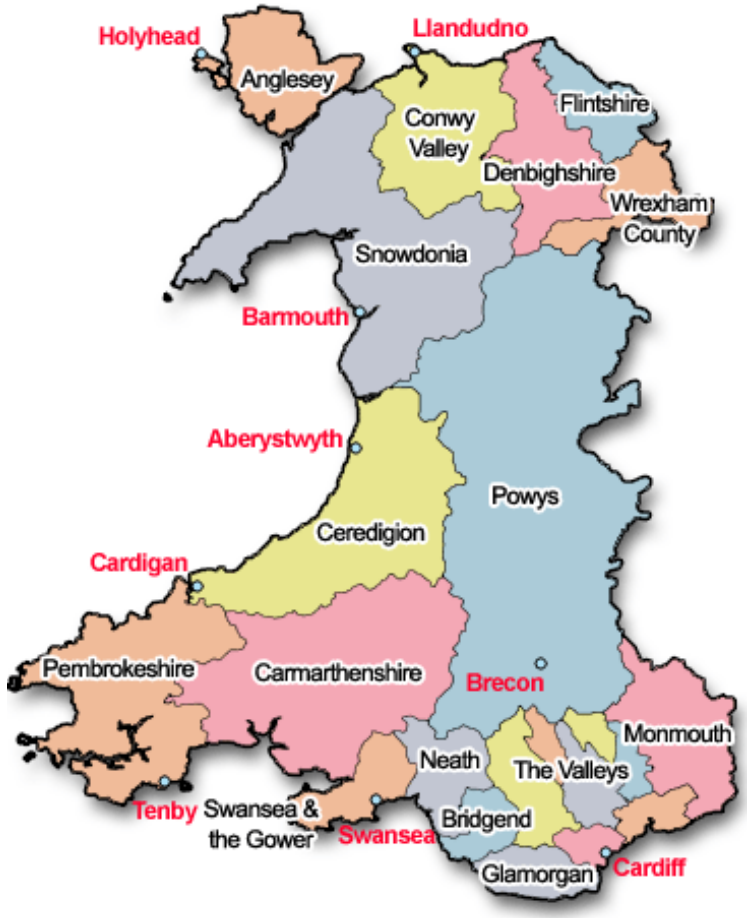


Palliative Care - Facing the future

- The legislation and its implications
- Integration needs
- The risks
  - The economy
  - Virtual wards
  - Disability

2008 – Sugar report and strategy

bwrdd gweithredol gofal lliniarol cymru
palliative care cymru implementation board

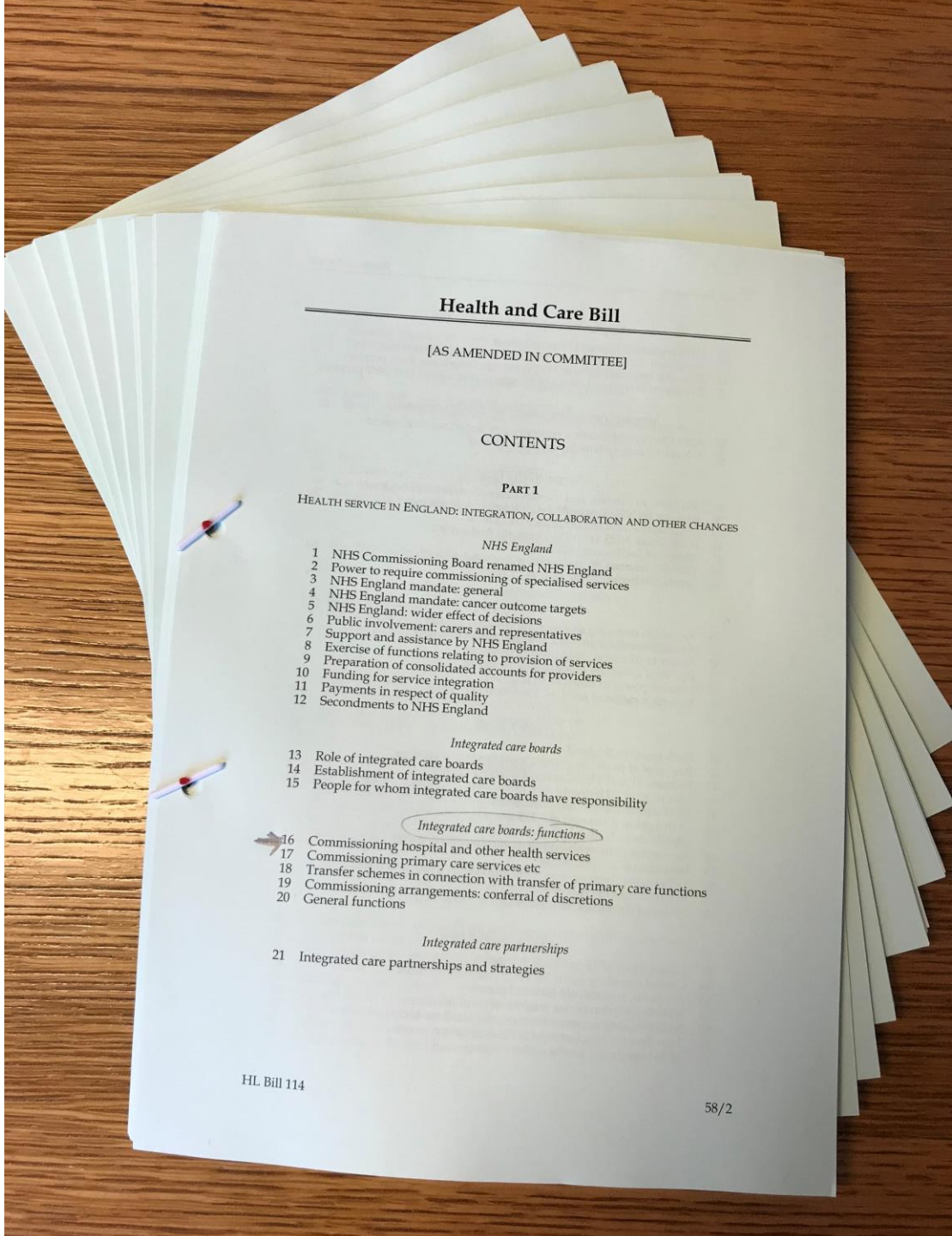


- Fair access
- Palliative care is core
- Specialist Palliative Care 7 days/wk – advice 24/7
- Patient Information System
- Standards & Quality measures
- Patient focused
- Research
- Funding formula to underpin fairness

Clause 16

- Integrated care boards: functions

- 23rd March 2022 – amended



NOW: An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—

(a) hospital accommodation,

(b) other accommodation for the purpose of any service provided under this Act,

(c) medical services other than primary medical services,

(d) dental services other than primary dental services,

(e) ophthalmic services other than primary ophthalmic services,

(f) nursing and ambulance services,

(g) such other services or facilities for the care of pregnant women, women who are breastfeeding and young children as the board considers are appropriate as part of the health service,

"(ga) such other services or facilities for palliative care as the board considers are appropriate as part of the health service,"

(h) such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as the board considers are appropriate as part of the health service, and

(i) such other services or facilities as are required for the diagnosis and treatment of illness.

Clause 16 – Government 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.

Clause 16 - *continued*

LORD KAMALL

16 Page 13, line 42, at end 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.

BARONESS FINLAY OF LLANDAFF
BARONESS FRASER OF CRAIGMADDIE
THE LORD BISHOP OF CARLISLE
BARONESS BRINTON

17 Page 14, line 23, at end insert—

"(5) For the purposes of this section "specialist multi-professional palliative care services" must include the provision of—

(a) specialist support in every setting, including private homes, care homes, hospitals, hospices and other community settings, working with local clinical teams,

(b) specialist level in-patient palliative care beds when required, including admission on an urgent basis,

(c) specialist palliative care advice, available at all times of day every day, to support health and social care professionals who are providing care to the person and their family,

(d) support to ensure the right, skilled workforce, equipment and medication is available to deliver this care,

(e) a point of contact, available for people with palliative care needs if their usual source of support is not accessible,

(f) appropriate systems to share information about the person's needs with all professionals involved in their care, provided they give consent for this,

(g) support to ensure patients and their families are able to have open conversations about what matters to them,

(h) support for the education and training of the health and social care workforce, and

(i) support to enable staff to participate in relevant research and disseminate evidence-based innovations in palliative care."

"specialist multi-professional palliative care services" must include the provision of support

in **every setting** - private homes, care homes, hospitals, hospices, community settings (w. local clinical teams)

in-patient pall. care **beds** when required, including **urgent** admission

advice at **all times of day every day**,

skilled **workforce, equipment and medication** available,

a **point of contact**, for people with palliative care needs if their usual source of support is not accessible,

systems to share information about the person's needs,

patients and their families can have **open conversations about what matters** to them,

education and training of workforce,

participate in **relevant research and disseminate evidence-based** innovations."

“specialist multi-professional ive care services” must include th f support

in **every setting** - private homes, car munity settings (w. local clinical teams)

in-patient pall. care **beds** w

advice at **all times of d**

skilled **workforce**,

a **point of contact**, ual source of support is not accessible,

systems to share inform

patients and their families **tions about what matters** to them,

education and training of wo

participate in **relevant research eminate evidence-based** innovations.”

24/7
7 days
Rapidly responsive
Person centred

Disease does not respect the clock or the calendar

Palliative care / end-of-life care / supportive care

Specialist	Generalist
Cardiology	heart disease
Dermatology	rashes galore
Gastroenterology	bowel problems
	etc.

Palliative care includes end-of-life care

Specialist palliative and end of life care services

Adult service specification

18 January 2023

Universal palliative and end of life care

Interventions

Personalised approaches

Shared decision-making; identification of people likely to be in their last year of life; personalised care and support planning; social prescribing, self-management; personal health budgets; compassionate communities, including wellbeing interventions and bereavement support.

Specialist (plus targeted and universal)

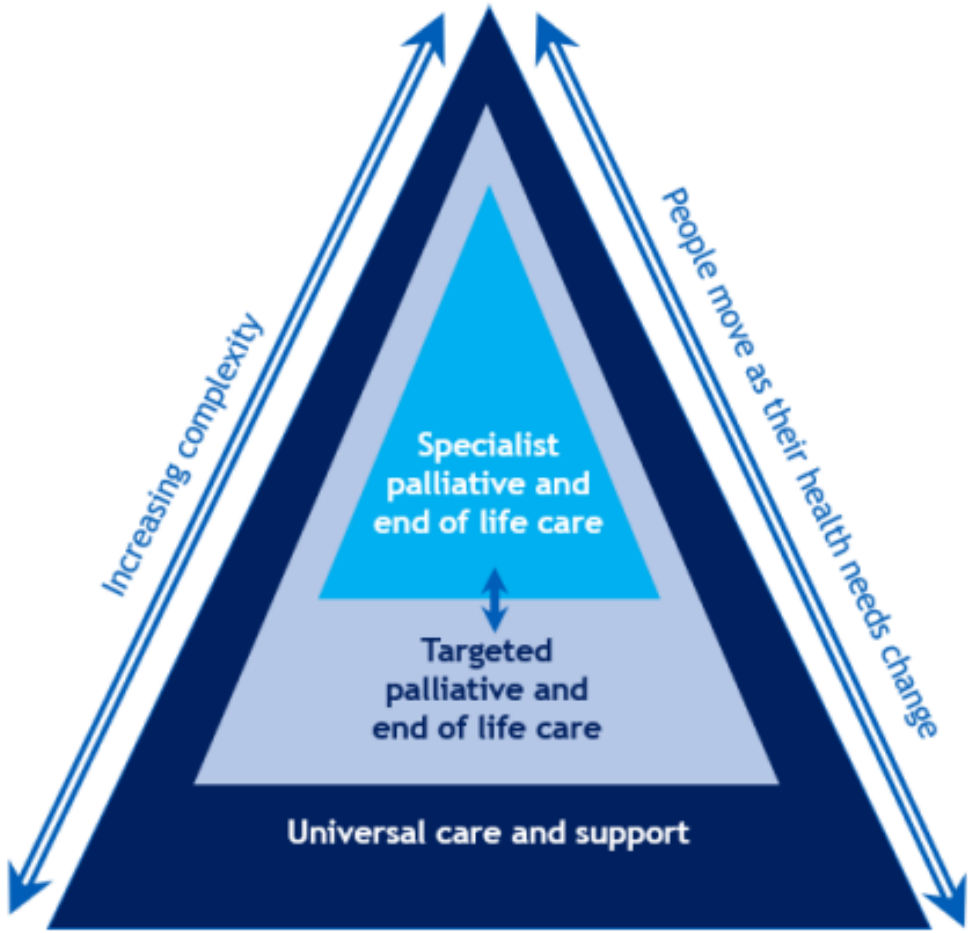
Tertiary or specialist palliative care services in hospices, community and hospital: 24/7 advice or care, complex symptom management and specialist equipment

Targeted (plus universal)

Non-specialist palliative care delivered in hospitals; hospice at home, respite care and hospice day services (may be generalist and/or specialist level)

Universal

Non-specialist palliative care delivered by primary, community, acute and urgent care services



Outcomes

I am treated with dignity and respect

I have a personalised care and support plan that records my preferences, wants and needs

My pain and symptoms are proactively managed

I am seen as an individual

I have fair access to care

My care is co-ordinated and seamless

I can expect my carer/family have their needs recognised and are given the support they need

Living and dying well

What do people want?

- Continuity of care – direct contact
- Integrated/ coordinated care systems
- Someone who is there when it is difficult
- Not to wait, not to be pushed from pillar to post, no answerphones
- To be listened to
- It’s their data

Funding formula – *minimums* specialist palliative care (SPC)

- Community advice – 2 spc doctors + 6 sp. nurses /300,000 population
- Hospital support teams – 2 spc doctors + 3 sp. nurses / 300 beds (approx)
  higher for specialist centres / teaching hospitals / A&Es etc
- Hospices – approx 11 beds minimum
  hospice at home teams
- PLUS AHPs etc

- All specialist staff in pooled flexible rotas
- NHS employed - move around
- Allocated links to care homes

Is it good enough for your relative?

- A service that is only there when everyone else is around, is not essential.
- An essential service is there when others aren’t – it’s there when needed.

Family Reported Outcome Measure (FROM-16)©

Because of my family member's condition... *Not at all* *A little* *A lot*

Part 1 Emotional – how you feel

- Worried
- Angry
- Sad
- Frustrated
- Difficult to talk about my thoughts
- Caring is difficult

Part 2: Personal and Social Life – affected

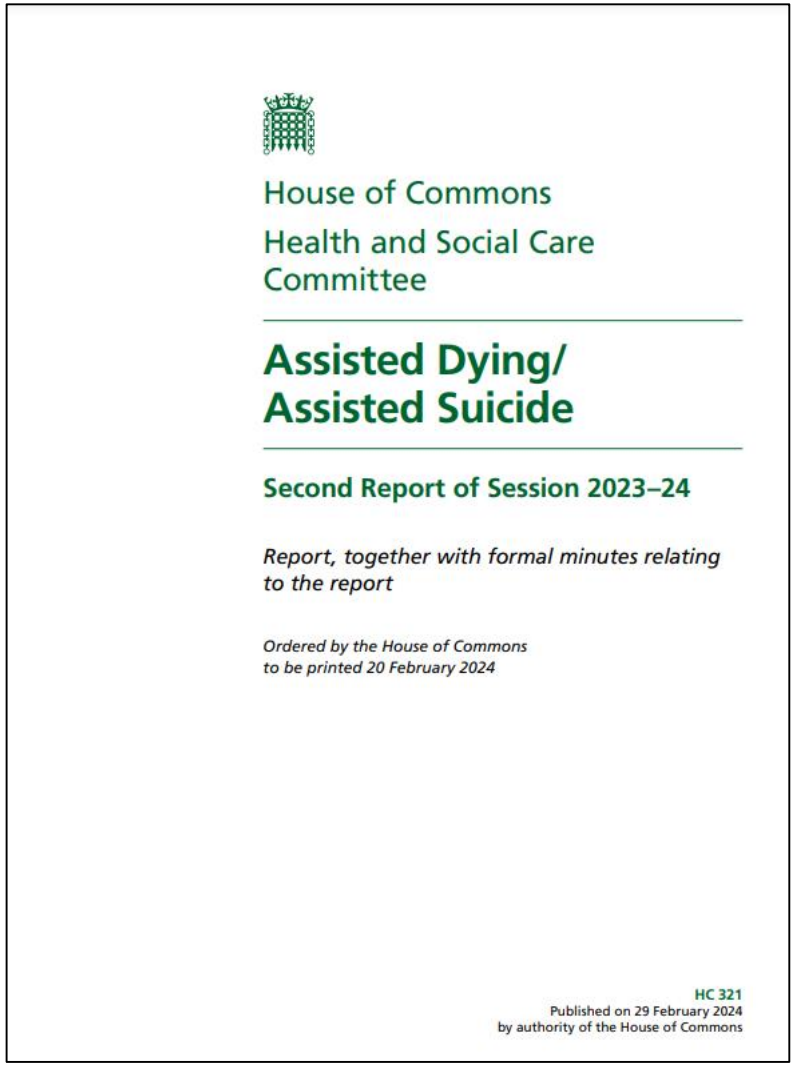
- Hard to find time for myself
- Every day travel
- Eating
- Family activities
- Problems going on holiday
- Sex life
- Work or study
- Relationships with others in family
- Family expenses
- Sleep

Election: a game-changing opportunity

Comisiwn Bevan Commission

1. Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production
    - Support other disciplines – single shot radiotherapy, spinal/epidural NO SILOS
2. Care for those with the greatest health need first, making most effective use of all skills and resources.
    - Rapidly responsive NO WASTE
3. Do what is needed – no more, no less – and do no harm.
    - Patients before processes NO SILLY RULES
4. Reduce inappropriate variation using evidence-based practices consistently and transparently EXCELLENCE
    - Data

Key points palliative care



PEoLC patchy in UK – **bad** deaths

Better commissioning needed – **funding** uplift

Suicides

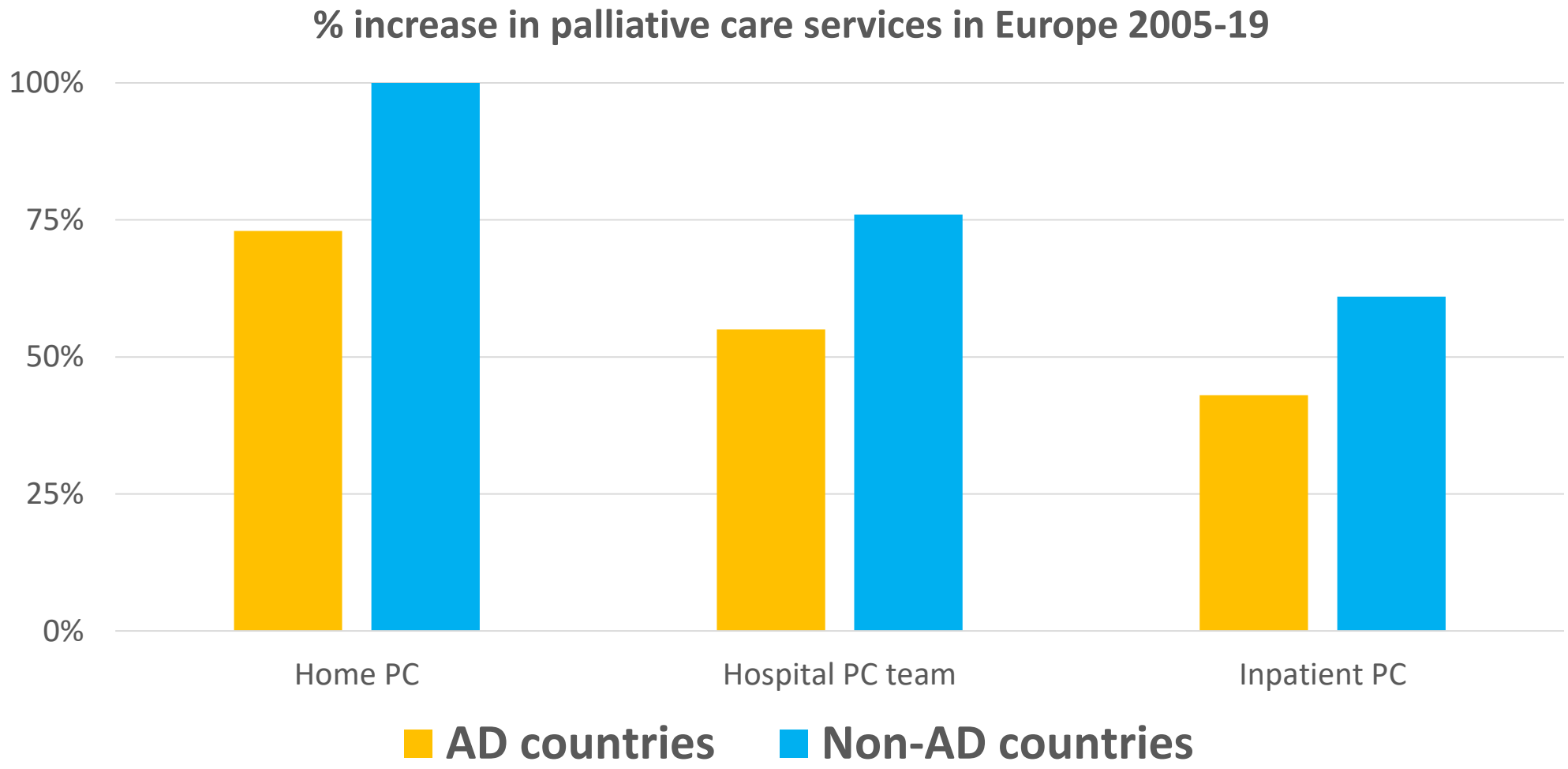
- Mental Health support
- Death literacy strategy

[saw no indication of worsening PEoLC in AD/AS]

Health and Social Care Committee

- *The UK has long been a **world leader** in palliative and end of life care, but access to and provision of palliative and end of life care is **patchy**. The Government must ensure universal coverage of palliative and end of life services, including hospice **care at home**.*
- *It is important that everyone is able to choose what type of support they need at the end of their life, and that their advanced care plan is honoured where possible.*

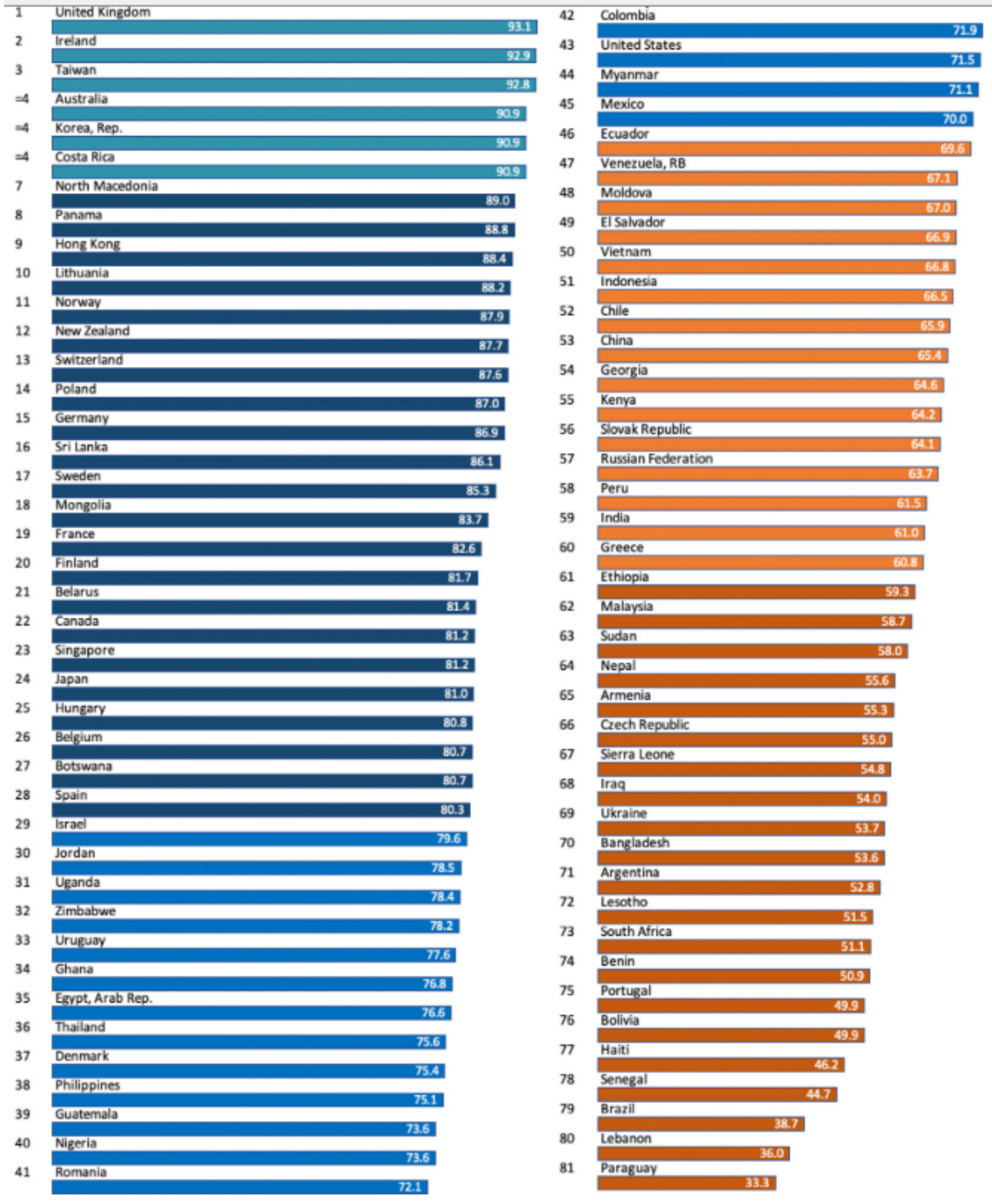
Have “law change and improvements to palliative care have gone hand in hand”?



Arias-Casais N, *et al* *Palliative Medicine*, 2020; **34**(8): 1044-56.

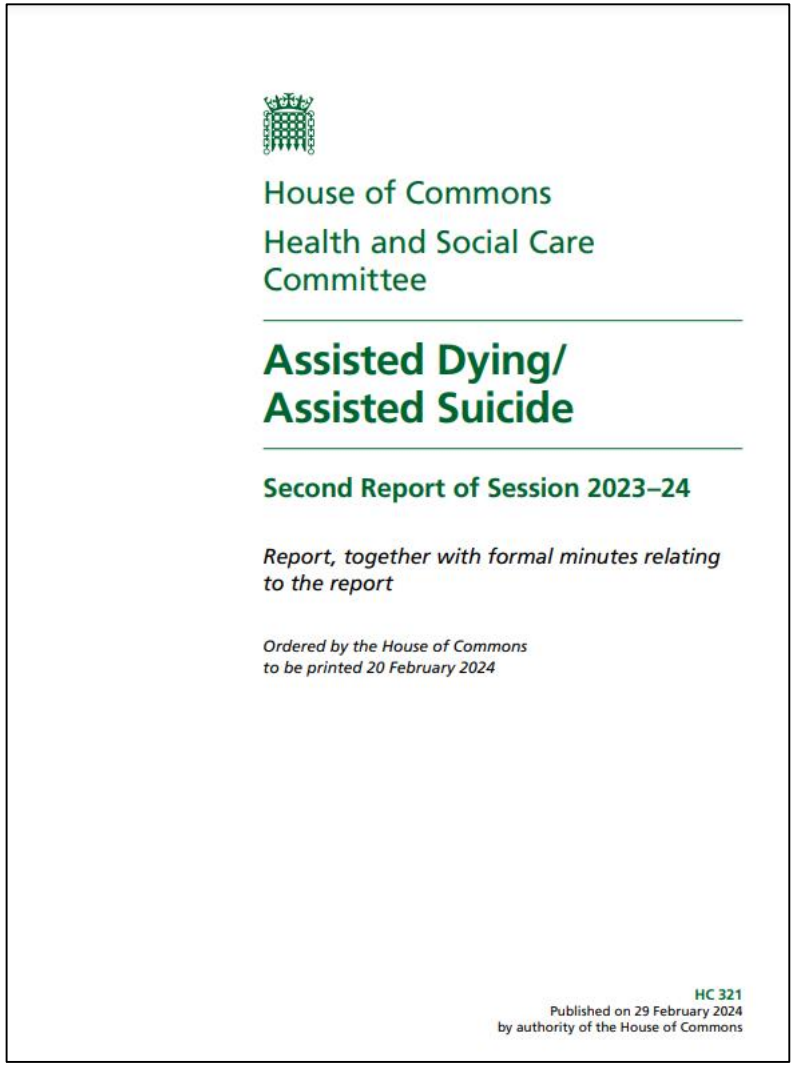
Impact of AD on quality of EoLC (2015 to 2022 change)

Australia	4th (↓2 places)
Netherlands	*8th (only 2015 data)*
New Zealand	12th (↓ 8 places)
Switzerland	13th (↑ 2 places)
Canada	22nd (↓ 11 places)
Belgium	26th (↓ 21 places)



Finkelstein EA, et al.. *Journal of Pain and Symptom Management*, 2022; 63(4); e419-e429; The 2015 Quality of Death Index: ranking palliative care across the world. London: Economist Intelligence Unit, 2015.

Key points AS/AD


House of Commons
Health and Social Care Committee

Assisted Dying/ Assisted Suicide

Second Report of Session 2023–24

Report, together with formal minutes relating to the report

Ordered by the House of Commons to be printed 20 February 2024

HC 321
Published on 29 February 2024
by authority of the House of Commons

- GMC & BMA guidance - doctors' medical reports
- Divergence if in Scotland/Crown Dependency
- Terminally ill v unbearable suffering
- Complexity
- Better data – much still to learn
- HCP participate freely – never imposed on them
- ?capacity ?safeguard the person in every case

Access to Palliative Care

In 23 countries, palliative care involvement was less than 19 days for cancer, and 6 days for non-cancer

Jordan RI *et al. BMC Medicine* 2020; 18: 368.

Canada: Ottawa study MAiD requests

MAiD deaths had more physical suffering. Less than half of assisted death patients had seen hospital specialist palliative care team. Before MAiD request <60% had PC involved.

Munro C, *et al Canadian Family Physician*, 2020; 66: 833-42.
Access to Palliative Care in Canada. Ottowa: Canadian Institute for Health Information, 2018

Is an assisted death better than a non-assisted one?

- 149 Oregon bereaved families interviewed after death
  - 52 had lethal drugs prescription,
  - 32 requested but didn't get one,
  - 63 did not pursue
- No difference in quality of death
- Smith KA *et al* J Pall Med. 2011; 14(4): 445-50

- Australia – bereavement different

Is there a ‘Right to Die’?

- Karsai v ECHR June 2024 – Hungarian lawyer MND. Right to life, right to refuse treatment upheld. Articles 8 & 14 not violated.

‘A British Law made in Britain making what we consider to be appropriate for the terminally ill in Britain, not a Belgian or a Canadian one’

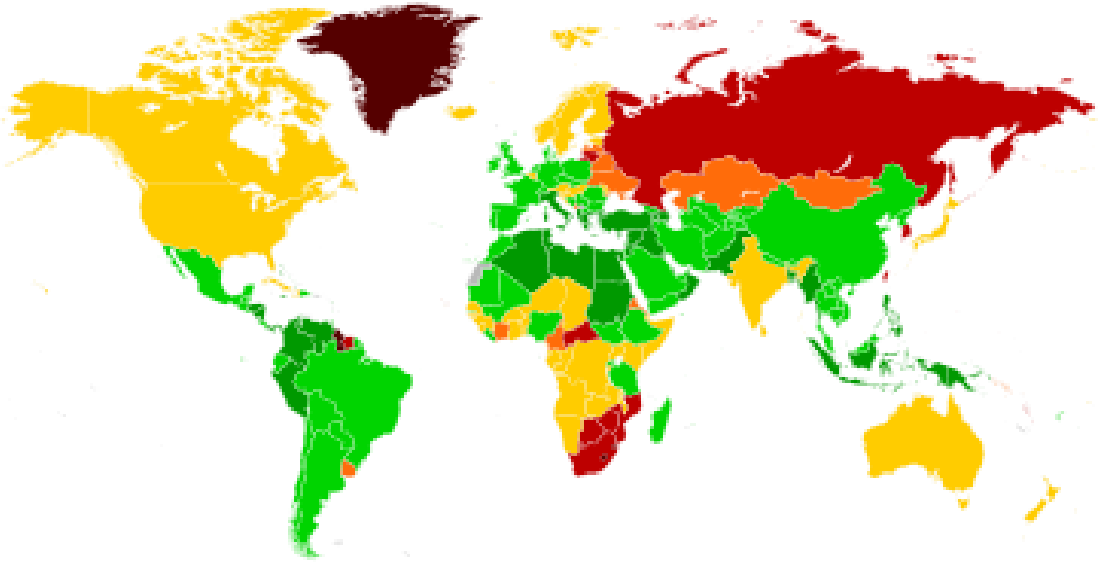
- Proposals in Scotland and Jersey mimic extended-Oregon and Canada
- Disagreement amongst advocates – ‘My Death My Decision’
- Falconer commission – ‘baby-steps’

What are ‘appropriate safeguards’

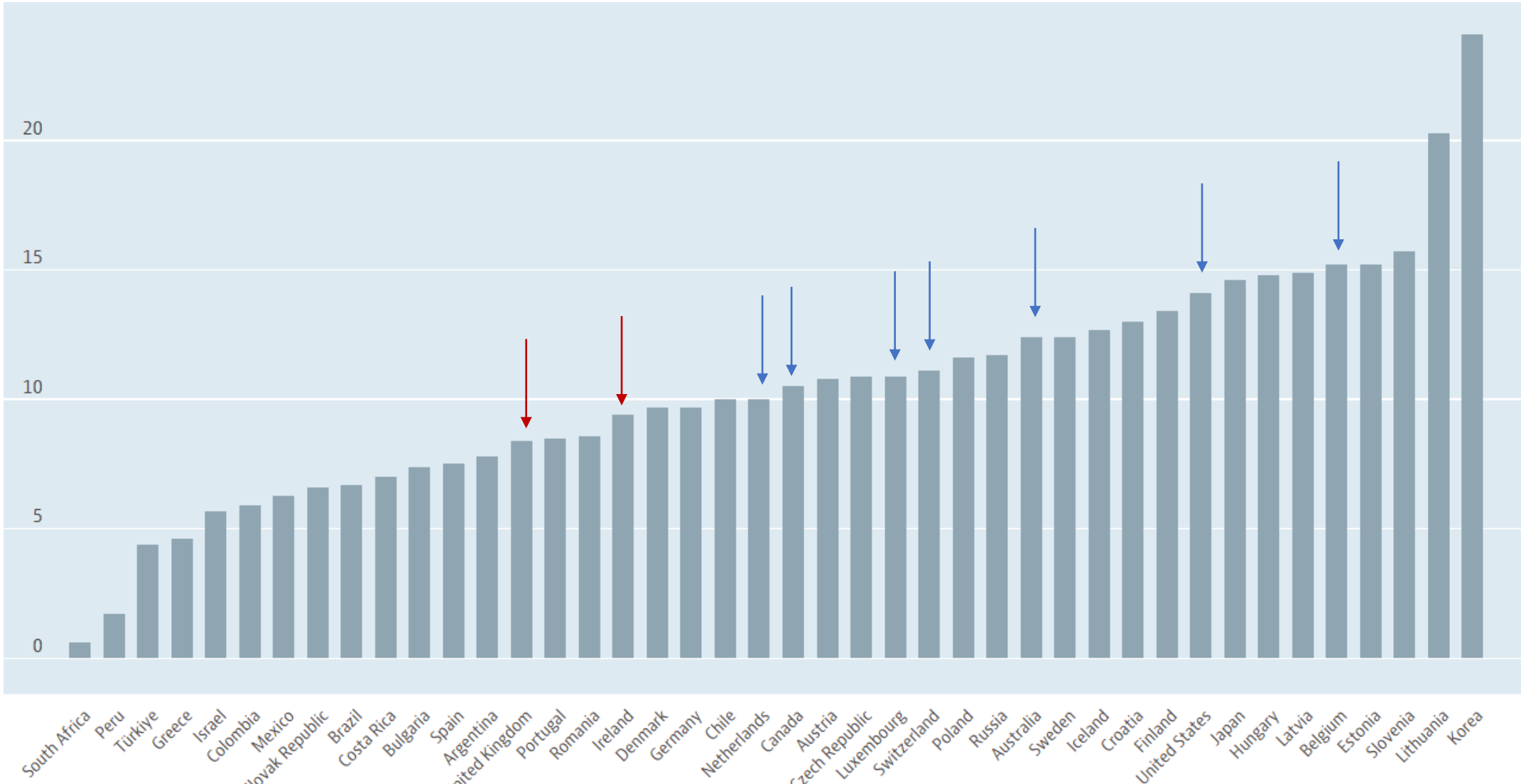
- How safe is safe enough?
- ‘No law can be 100% safe but we should not stand in the way of such legislation due to a minority of cases of exploitation or misdemeanour’ Polly Toynbee 28th Feb 2023
- Paulette Leonard (Deputy PM and Health Minister Luxembourg) Cambridge debate ‘a law by nature is never perfect’ 9th March 2023
- Lord Falconer - Today Programme ‘can’t have a system that is watertight’6th Jan 2012

Suicide rates 2022 per 100,000

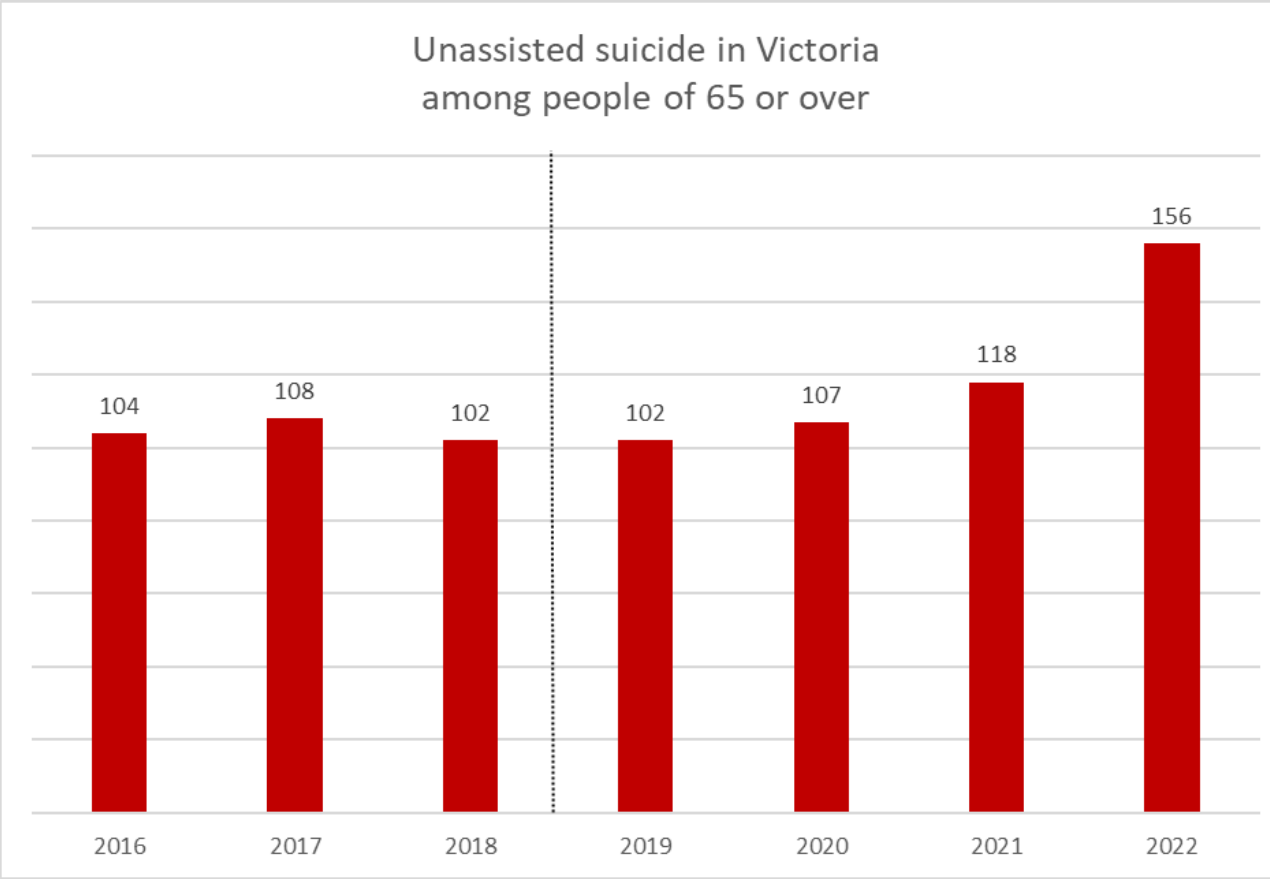
- Belgium 15.2
- Australia 12.4
- Switzerland 11.1
- Luxembourg 10.9
- Canada 10.5
- Netherlands 10.0
- **UK** **8.4**

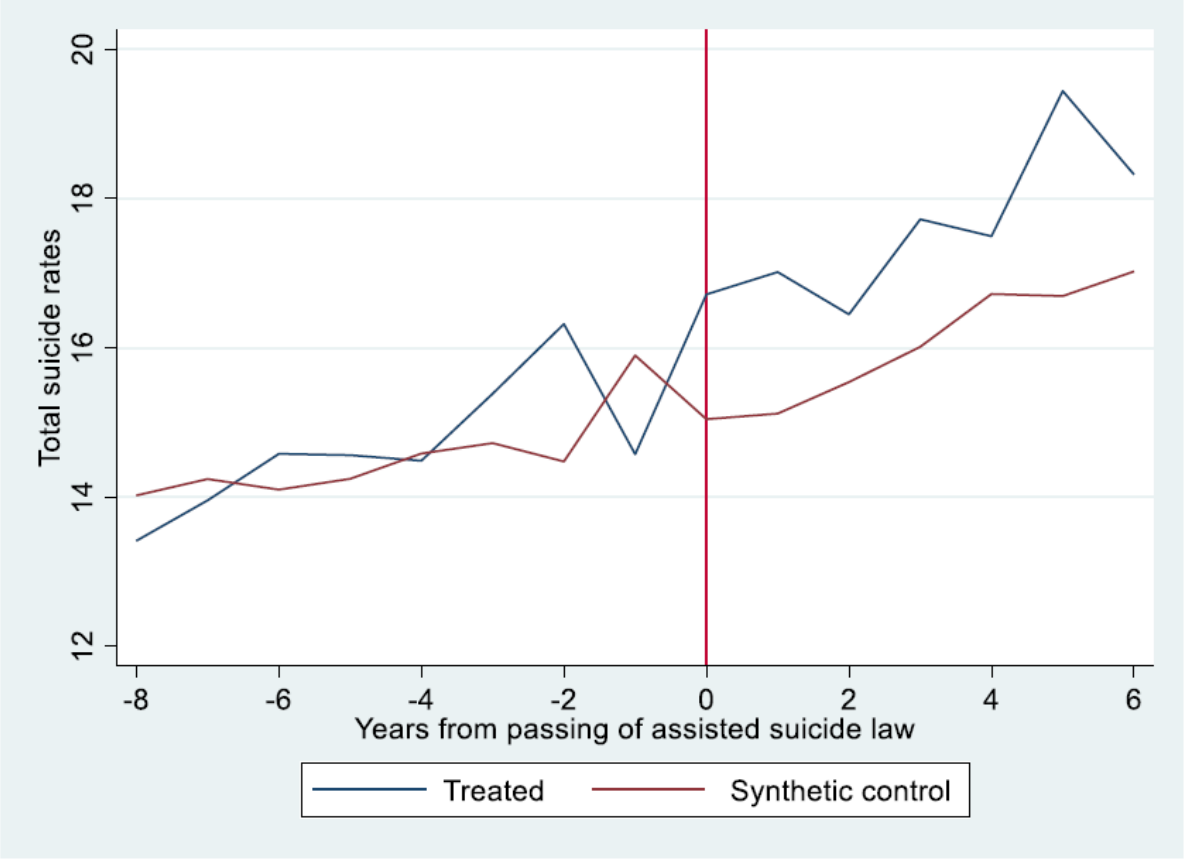


suicide rates/100,000 (not-assisted) 2022



Is suicides prevention affected?





- Jones, D.A (2023) 'Did the Voluntary Assisted Dying Act 2017 prevent "at least one suicide every week"'? . *J. Ethics Ment. Health*, Open Volume 11:1-20
- Girma, S., & Paton, D. (2022). Is assisted suicide a substitute for unassisted suicide? Eur. Econ. Rev., 145, 104113.

Does AD prevent suffering?

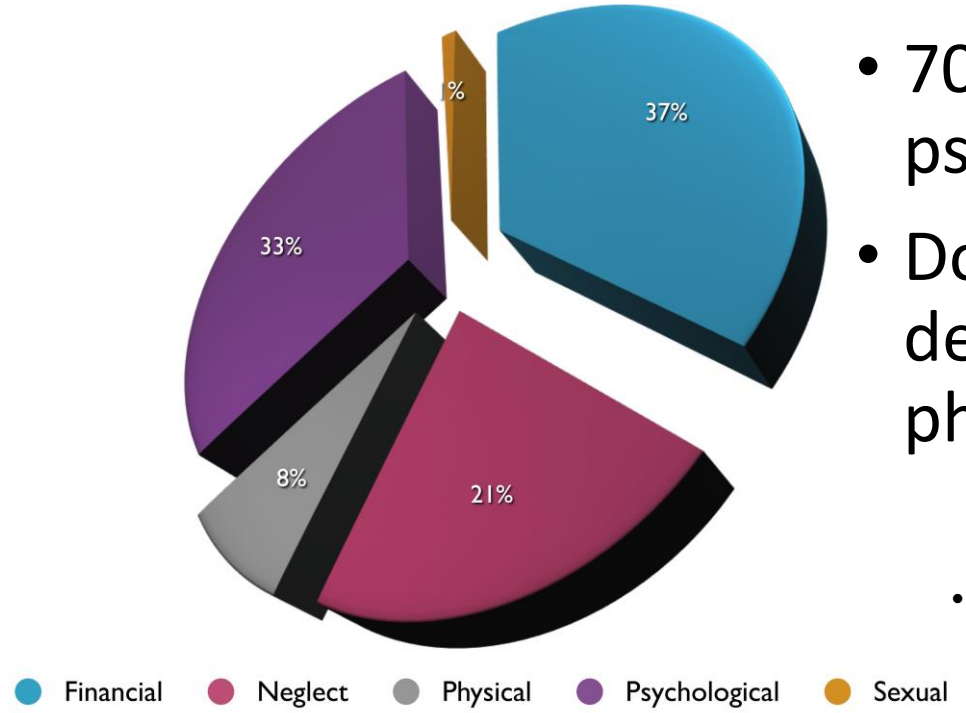
The Dutch have the most liberal AD laws anywhere

…and yet… up to 43% of Dutch dying patients have at least one unresolved symptom

Heijltjes MT. Symptom evolution in the dying. BMJ Supp Pall Care, 2022. doi:10.1136/bmjspcare-2022-003718

Abuse

Jersey carer jailed for 'appalling' treatment of vulnerable disabled teenager in landmark court case



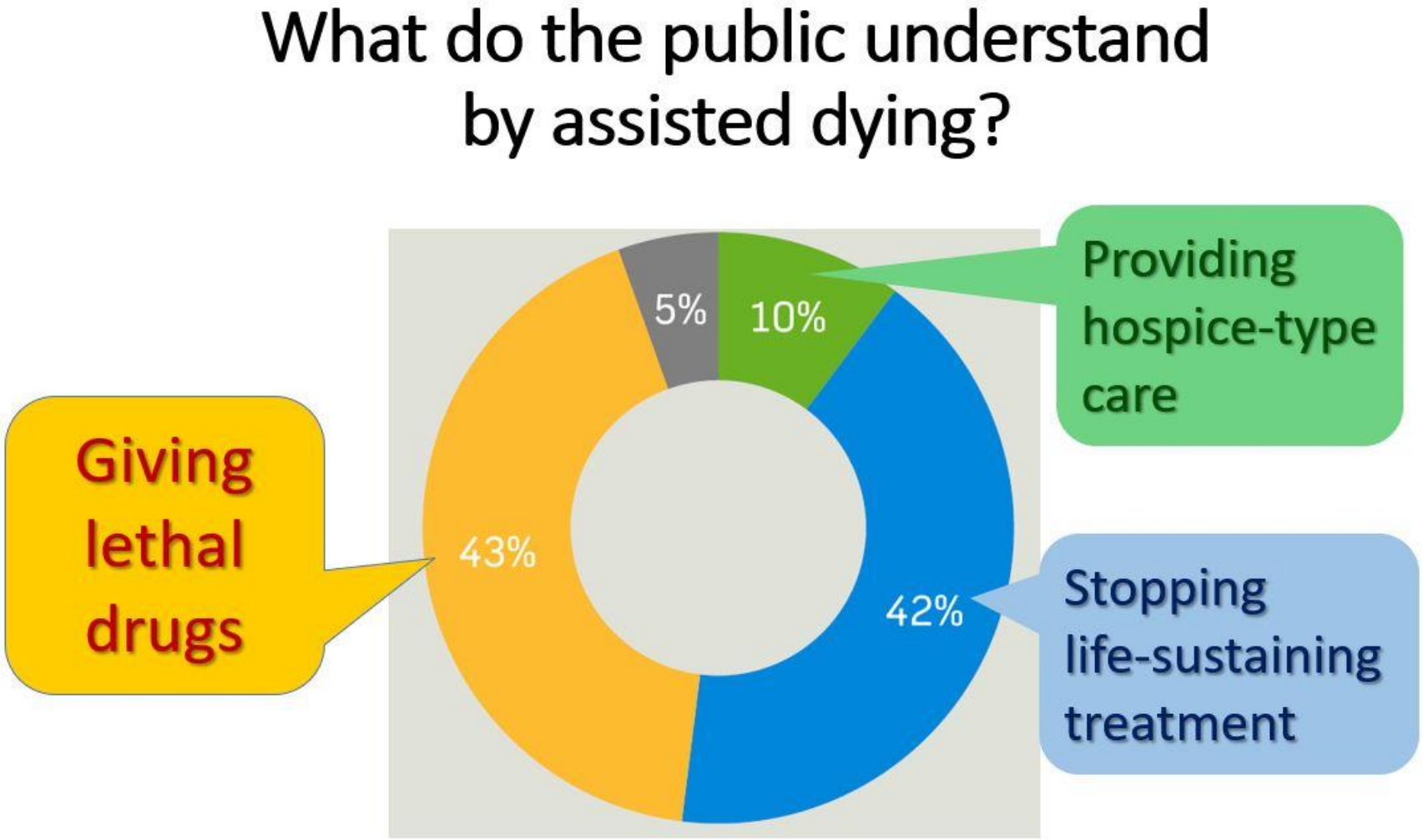
- 83% in own home
- 1 in 5 over 65yrs affected by abuse
- 70% financial or psychological
- Doctors poor at detecting non-physical abuse

- Hourglass data

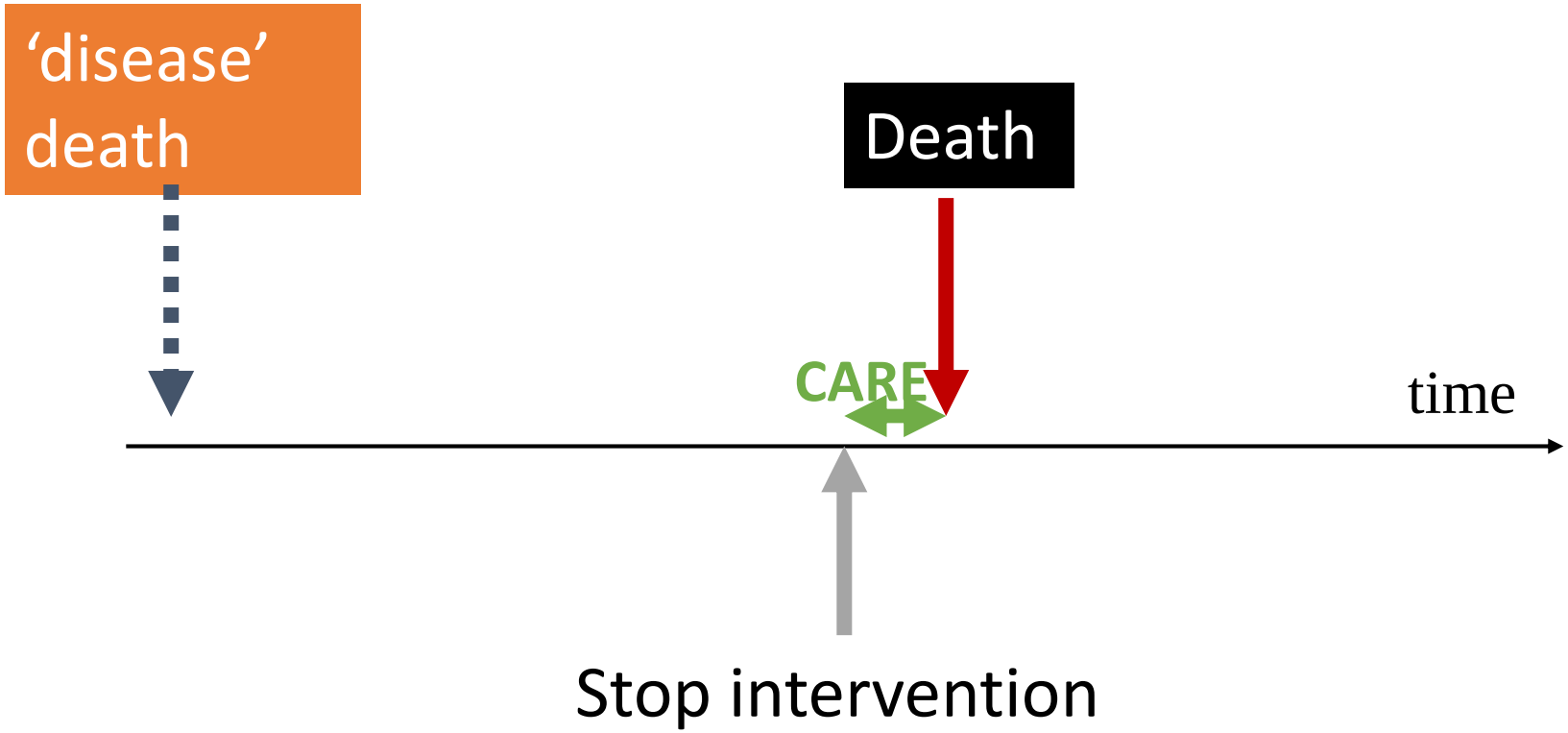
A SAFER AGEING SOCIETY BY 2050

FREE FROM ABUSE, HARM, EXPLOITATION AND NEGLECT.

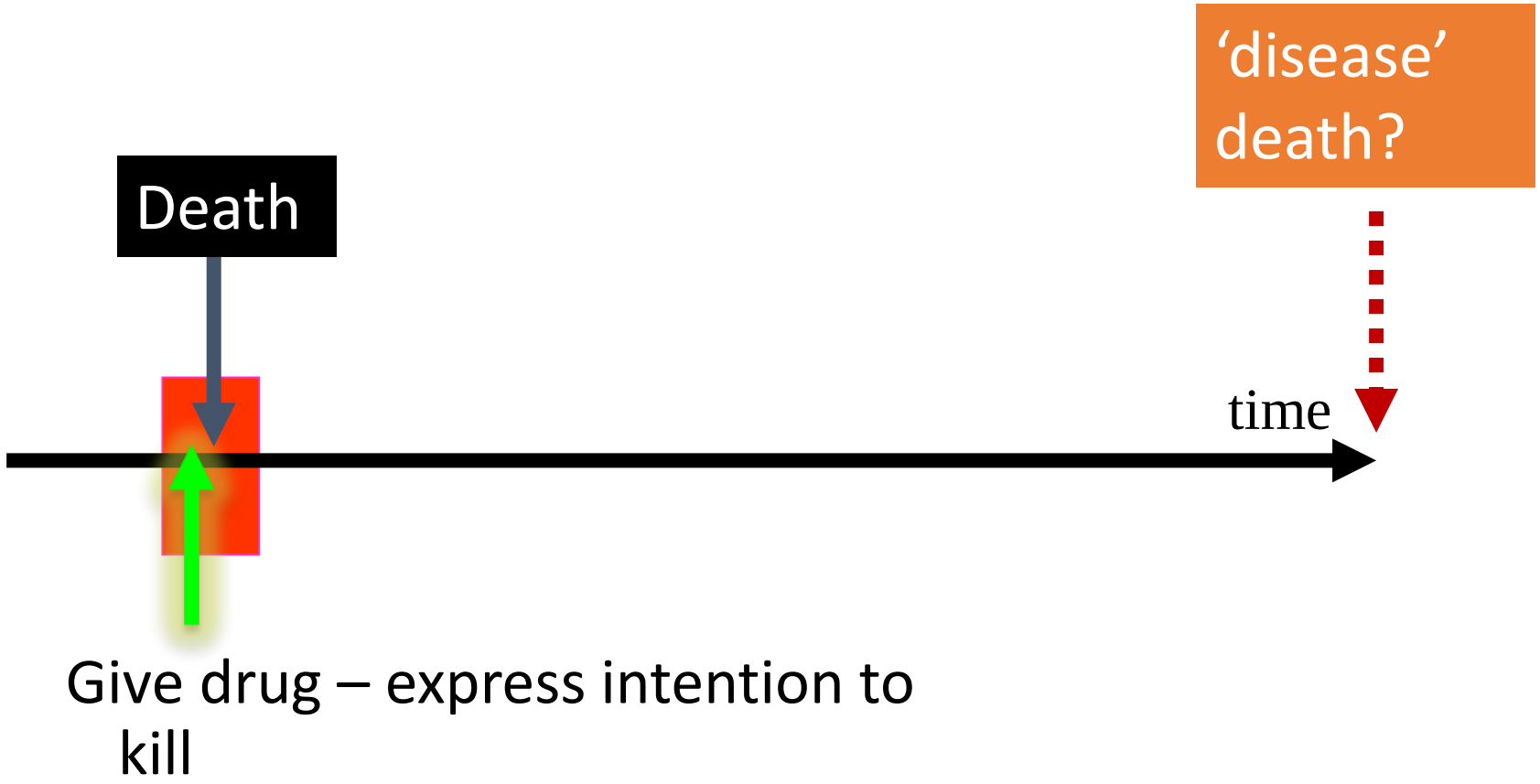
2021 Survation Survey on ‘assisted dying’



Stopping treatment / withdrawal of consent



Euthanasia / physician assisted suicide / assisted suicide (outside clinical care)



Canada – unintended consequences of MAiD

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**”

What does assisted suicide involve?

Secobarbital:

‘Just before ingestion dissolve the powder from 100 capsules in a warm liquid and drink as a single dose’

Mixtures

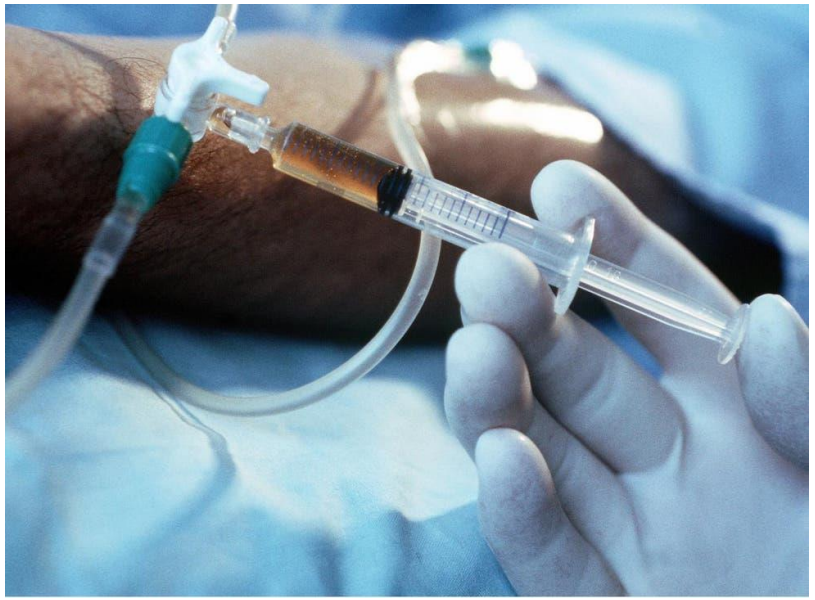
DDMA (diazepam, digoxin, morphine sulfate, amitriptyline)

Oregon: 2159 deaths in 24 yrs

6.4% complication rate (n=904)

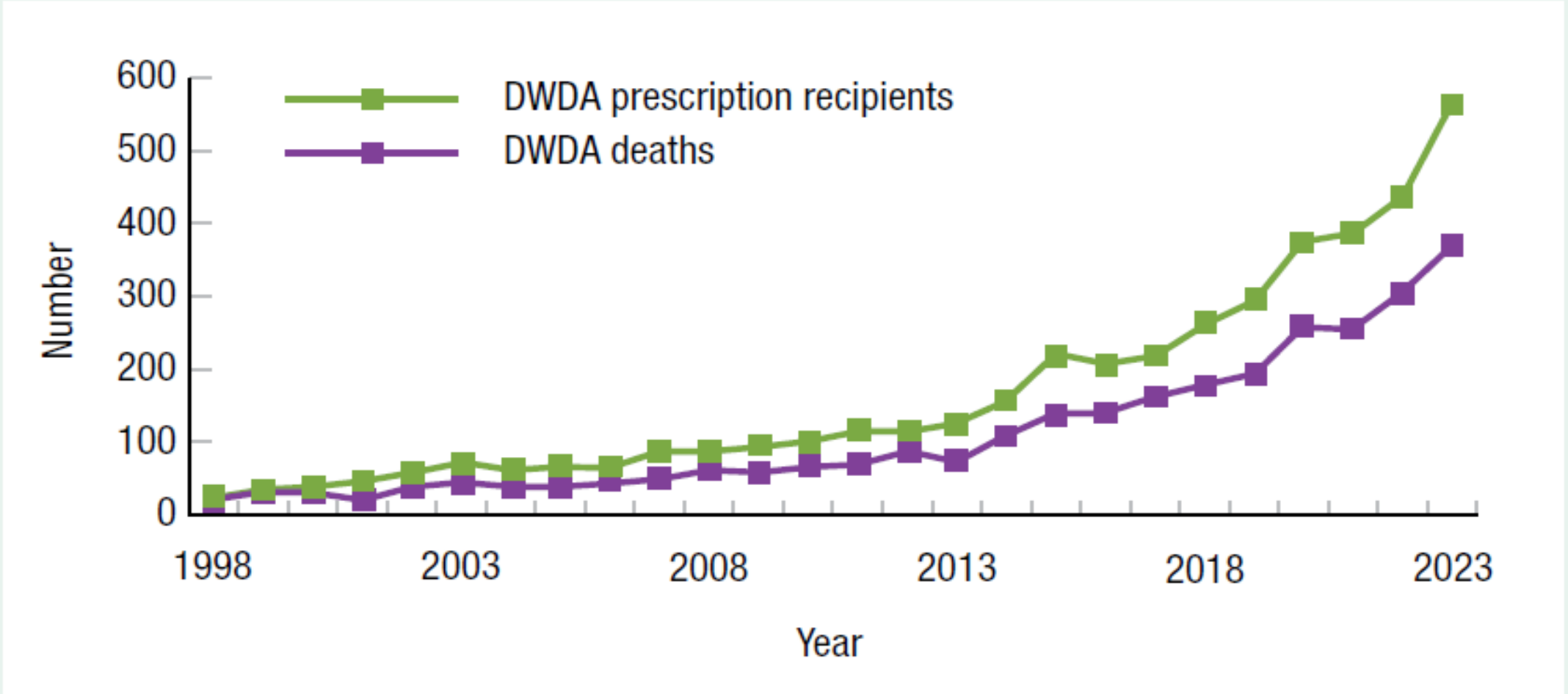
Half took 30 mins-104 hours to die (n=1198)

Euthanasia



Belgium 2022 official report	Nos.	%
Thiopental + paralysant neuromusculaire i.v.	1844	62.2
Thiopental i.v.	936	31,6
Propofol + paralysant neuromusculaire i.v.	148	5
Barbiturates orally (=PAS)	16	0.5
Morphine and/or anxiolytic + paralysant neuromusculaire i.v.	11	0.4
Other	11	0,4
Total paralysant neuromusculaire		**67.6**

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998–2023



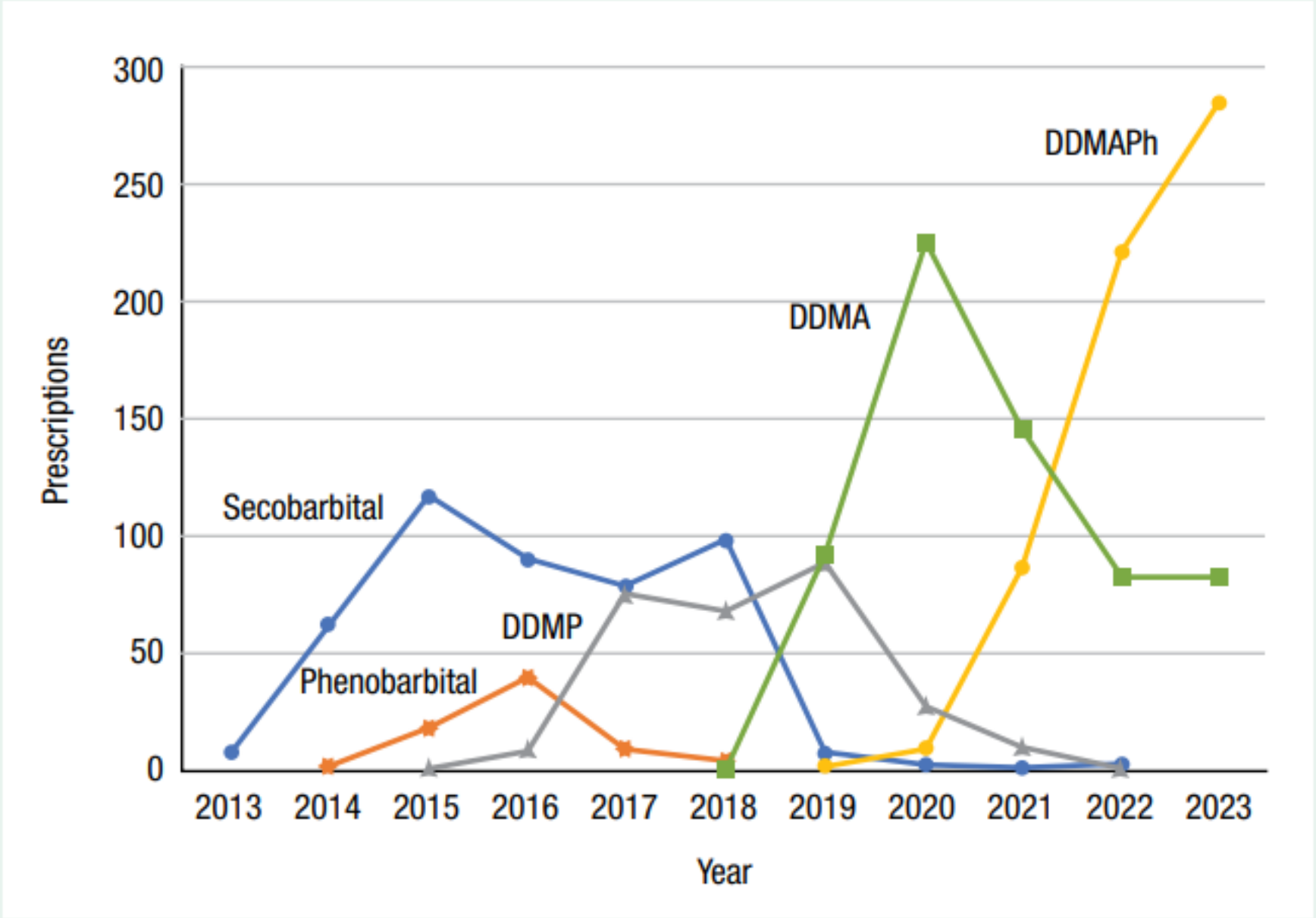
*As of January 26, 2024

See Table 2 for detailed information

Since 2023, non-residents can also receive prescriptions.

1-76 Rx / physician

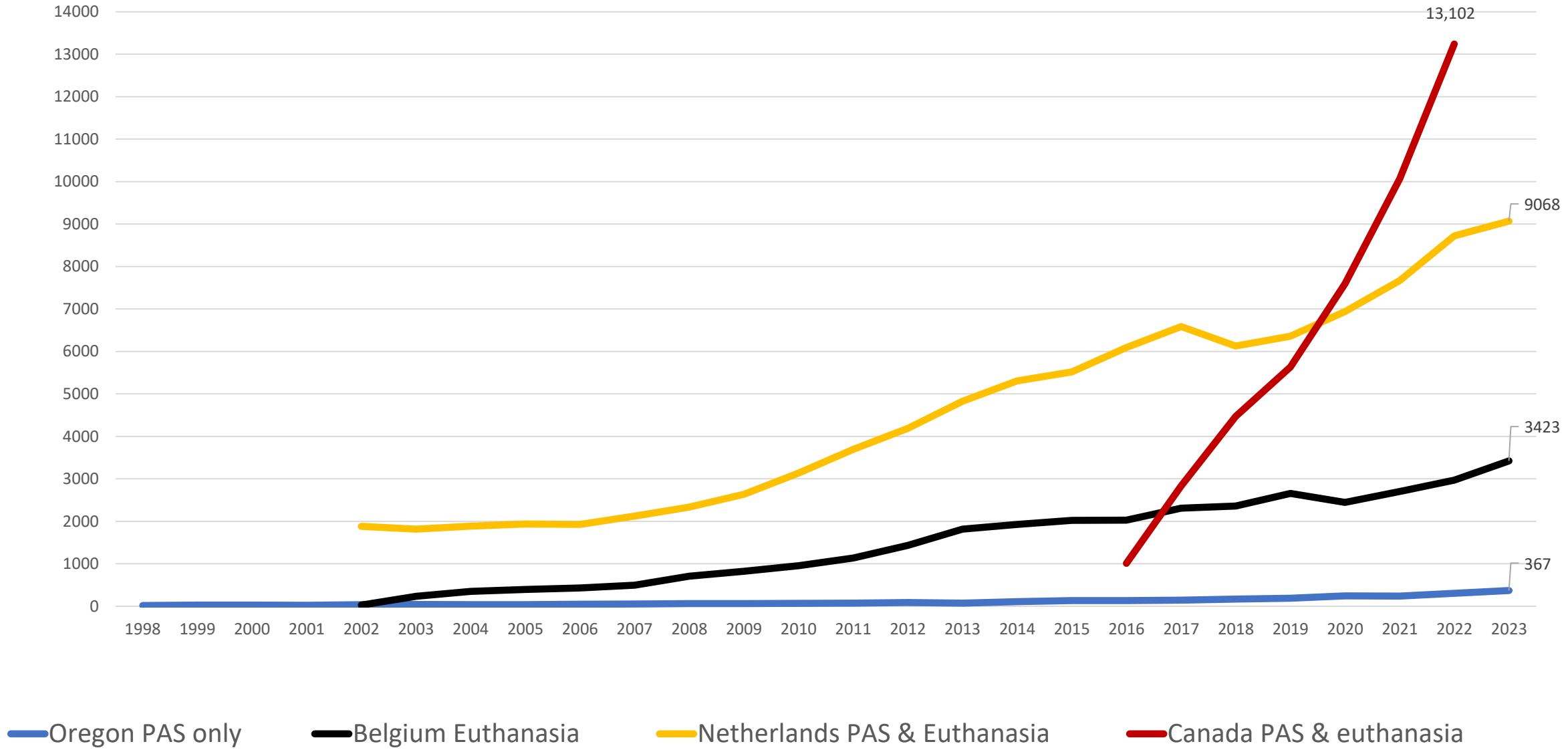
Figure 3: Medication used in DWDA ingestions, 2013-2023



75% of ingestions in 2023
DDMAPh,
diazepam, digoxin, morphine sulfate, amitriptyline, and phenobarbital

DDMA,
diazepam, digoxin, morphine sulfate, and amitriptyline,

Reported assited deaths each year (jurisdicition health department data)



Protecting People – mental distress

- In June 2023, Kathryn Mentler was experiencing suicidal ideation and went to the Vancouver General Hospital for help.
- She was told by a counsellor that there were no available beds and the earliest that she could talk to psychiatrist was November.
- She was then asked if she had ever considered a medically assisted suicide?

Canada

Proponents said “it couldn’t happen here” re Netherlands

Claim: nearly all have palliative care

Reality: In 2022, only 23% of MAiD patients had seen a palliative care specialist

Access to palliative care increased by 6% in 5 years

but MAiD increased by 550%

Current discussions

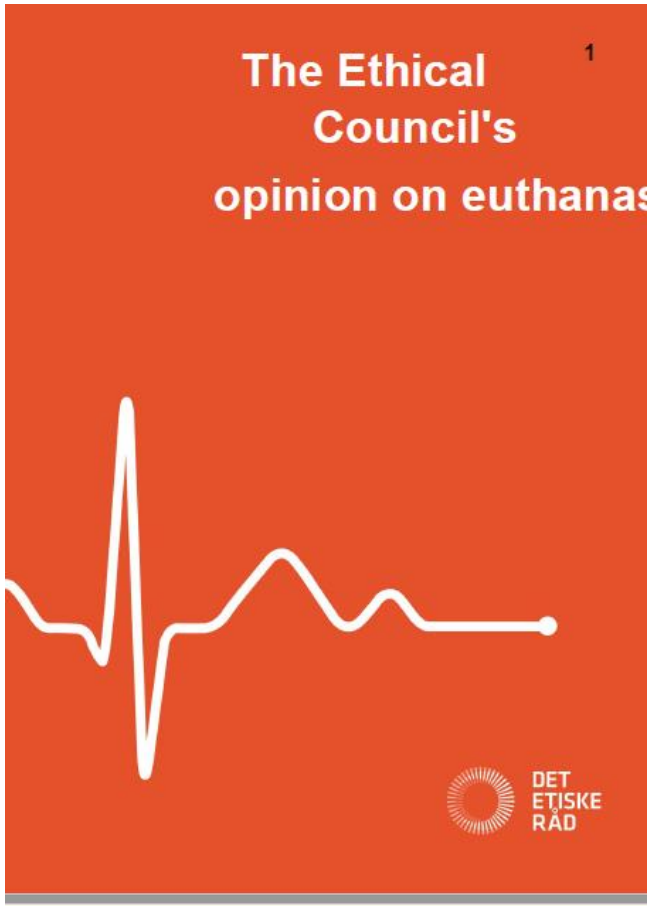
- Opt in or opt out for doctors – conscience?
- Must be offered to all who might be eligible
- Must refer?
- Discriminatory to exclude those who aren’t already dying
- All ages
- Stay with patient throughout
- 60 hours to do thoroughly
- How to assess capacity? Coercion?
- Post event reporting v monitoring assessments

Danish Ethical Council – for Danish Parliament

21 Sep 2023

The Ethics Council concluded that neither the Oregon nor the Dutch models were:

“sufficiently clear in their delineations,
fair in their justifications for access,
or sound in terms of control mechanisms”



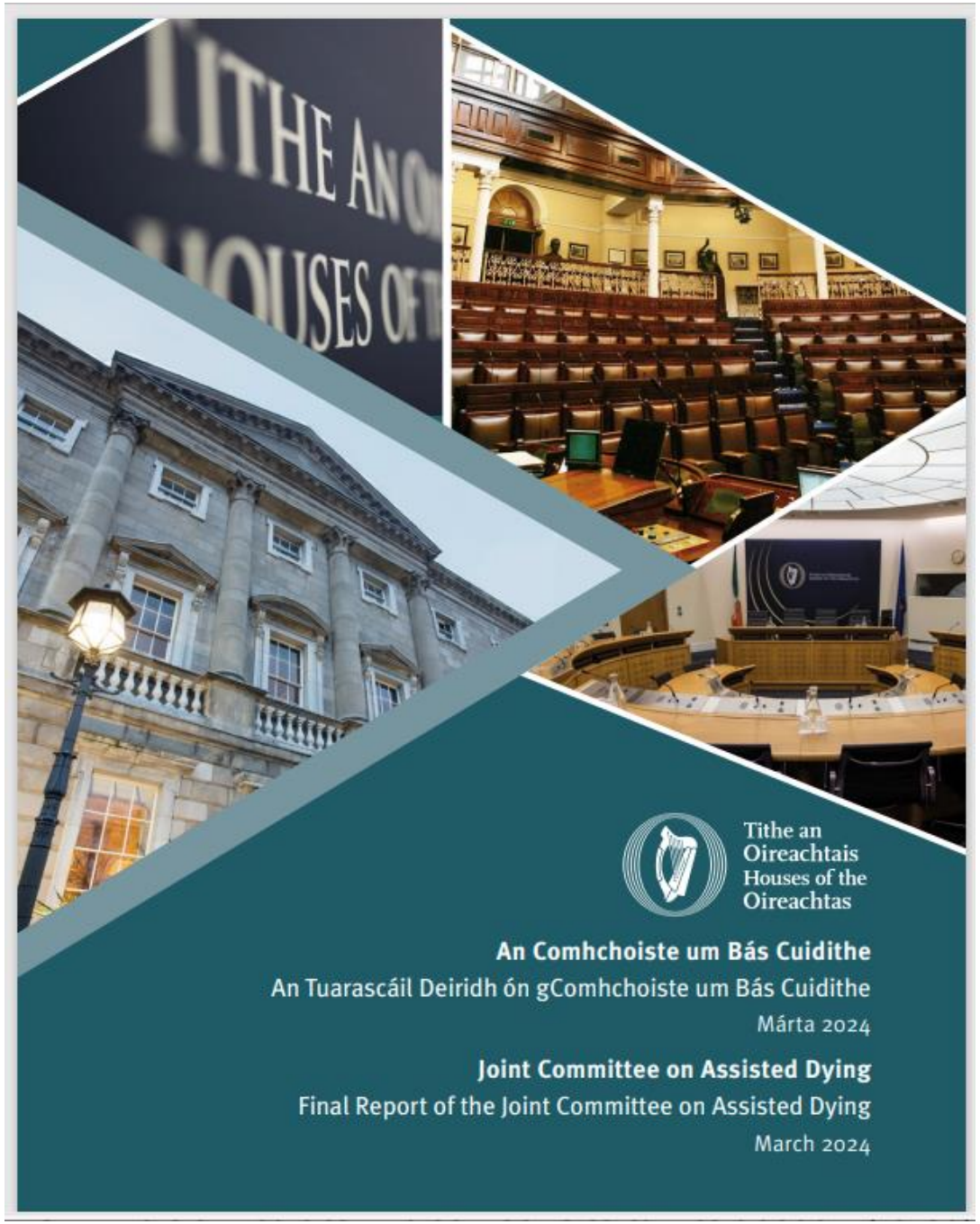
Danish Ethical Council

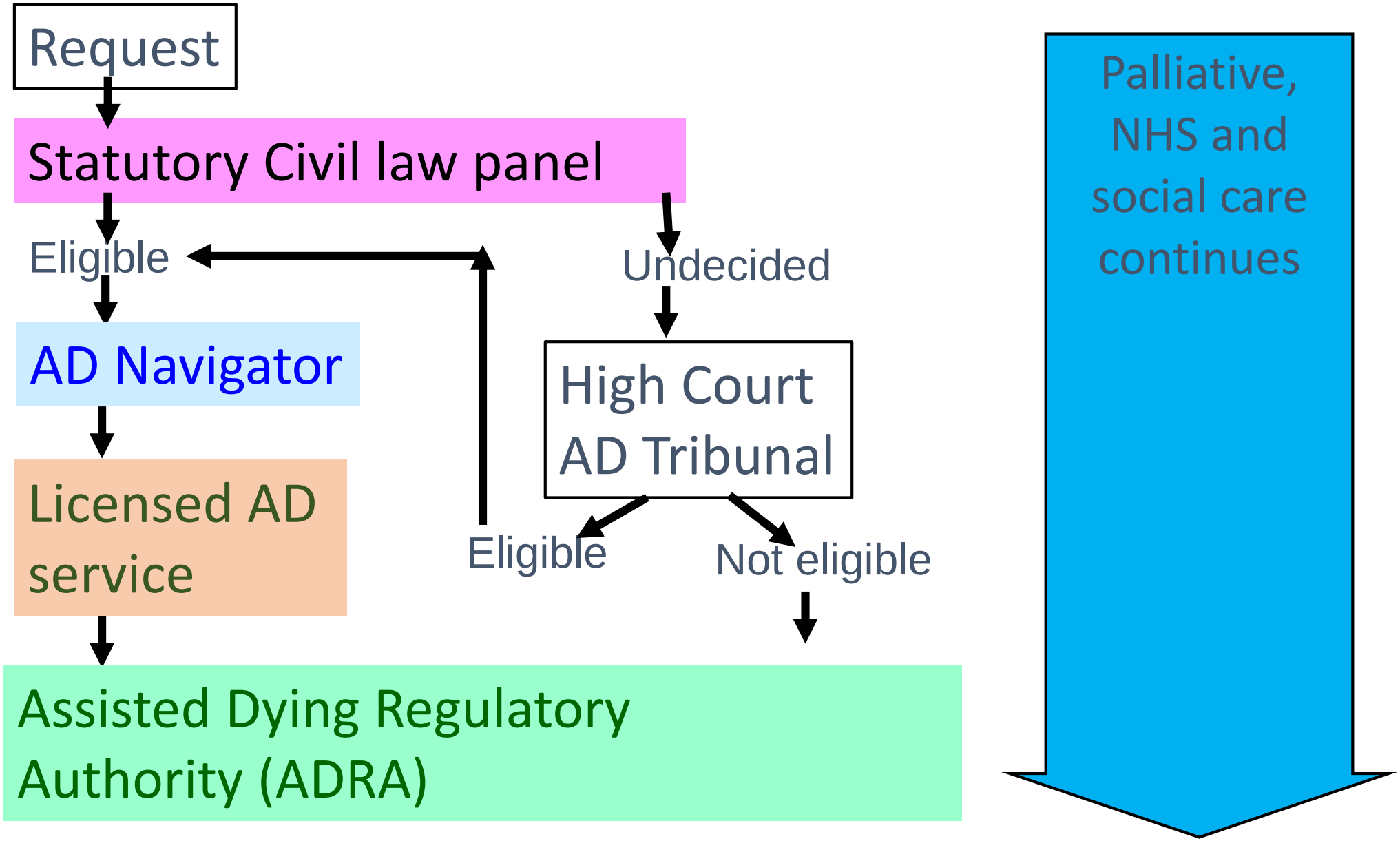
21 Sep 2023

- **“The members consider euthanasia to be in conflict with palliative care and are therefore against the legalization of euthanasia as long as we as a society have not exhausted the possibilities for relief.”**
- “If euthanasia becomes an option, there is too great a risk that it will become an expectation aimed at special groups in society.”

Recommendation 13

The Committee recommends that palliative care and the operation of assisted dying should operate completely separately and independently of each other.




Request
Statutory Civil law panel
Eligible
Undecided
AD Navigator
High Court
AD Tribunal
Licensed AD
service
Eligible
Not eligible
Assisted Dying Regulatory
Authority (ADRA)
Palliative,
NHS and
social care
continues

What happens to funding when Assisted Suicide is introduced?

- The budget line is crucial
- Need to keep palliative care completely separate from any AS budget

How well does an opt in system work?

What about moral injury to other patients and to staff?

Will people keep giving money to hospices?

Should hospices have 100% core clinical service funded?

Keep the patient at the centre of all we do

Questions?