Assisted dying in Belgium in the 21st century

Developments and complexities

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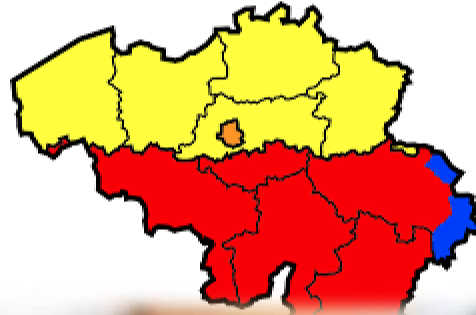
Belgium



Euthanasia in Belgium: 2002 law

General requirements:

- Person is in a medically futile state causing constant and unbearable physical or mental suffering that cannot be alleviated, and suffering is the result of a serious and incurable condition caused by illness or accident
- Oral request + in writing
- Durable nature of the person's request (repeated)
- Person is conscious & legally competent at request and performance
- Person given essential information (diagnosis, prognosis, treatment options)
- Peer consultation with an independent physician
- Reporting (a posteriori) to Federal Control and Evaluation Committee Euthanasia

Additional requirements when death not expected in the foreseeable future:

- Second consultation with an independent psychiatrist or specialist in the person's condition
- One month waiting period between the person's written request and the provision of euthanasia

- Interpretive “leeway” in legislation
  - Eg “accident”, “repeated” request
  - Eg “serious” condition
  - Eg suffering > primarily subjectively assessed, by the patient
- Silence on some counts
  - Eg assessment legal criteria
  - Eg family role/involvement
- Starting assumptions
  - No regulation is perfect (macro vs micro: framework vs practice)
  - Regulation cannot realistically cover every detail of practice
  - Regulation evolves under unfolding practice
  - Practice evolves under regulation

‘Regulation’

- Limits to legislative policy
  - Defer to professionals
- Additional governing sources with goal to ensure:
  - Adequate access
  - Patient safety
  - Feasibility for system
  - Protection for engaging physicians
- Not just operationalizing, but also adding content, eg palliative filter

Table 4. Overview of the Sources of Regulation, Indicating Source Sub-types and Giving Examples for Each (Archer et al., 2023).

Source of regulation and sub-types	Example
Law	
Legislation, amendments to the law	*The Act*
Royal decrees	*Royal Decree of 2 Apr 2003* establishing the procedures for drawing up, reconfirming, revising or withdrawing the advance declaration on euthanasia
Case law	Constitutional court judgement 14 Jan 2004 – Judgement number 4/2004
Policy	
Organisation-level policies	Caritas Flanders policy: Caring for a dignified End of Life (Zorg voor een menswaardig levenseinde), 2005
Institution-level policies	Ghent University procedure concerning euthanasia and psychological suffering, 2009
Public policy	Federal Health department Circular addressed to physicians, “Advance requests for euthanasia – electronic consultation by physicians” 4 Sep 2008
Professional standards	
Written standards (medical, psychiatric, general practice, pharmaceutical)	Order of physicians Advice of Mar 2003 regarding palliative care, euthanasia, and other medical decisions at the end of life
Disciplinary proceedings	Decision 24 Oct 2007 Provincial Council of West Flanders (Order of Physicians)
Training programs	
Tertiary education	Vrije Universiteit Brussel undergraduate core curriculum
Non-mandatory training	Life End Information Forum (LEIF) training on euthanasia
Advisory documents	
Produced by independent statutory bodies (the CFCEE and the National Bioethics Committee)	CFCEE biannual reports on euthanasia practice
Academic articles	Beatrice Figa, ‘L’euthanasie: Considérations <practiques>’ [2006] 230 La Revue de la Médecine Générale 82
System infrastructure	
Pre-existing system infrastructure	Office of the public prosecutor
Created pursuant to the Act	CFCEE registration document
Developed independently of the Act	End-of-life consultation and advice centres (LEIF, Forum End of Life, ULTeam)

Legislative evolutions in Belgium

Law extension to minors (no age limit) in 2014

- General requirements apply
- Additional requirements:
  - Only somatic illness + death expected in the foreseeable future
  - Thorough psych assessment of capacity of discernment
  - Parents' consent

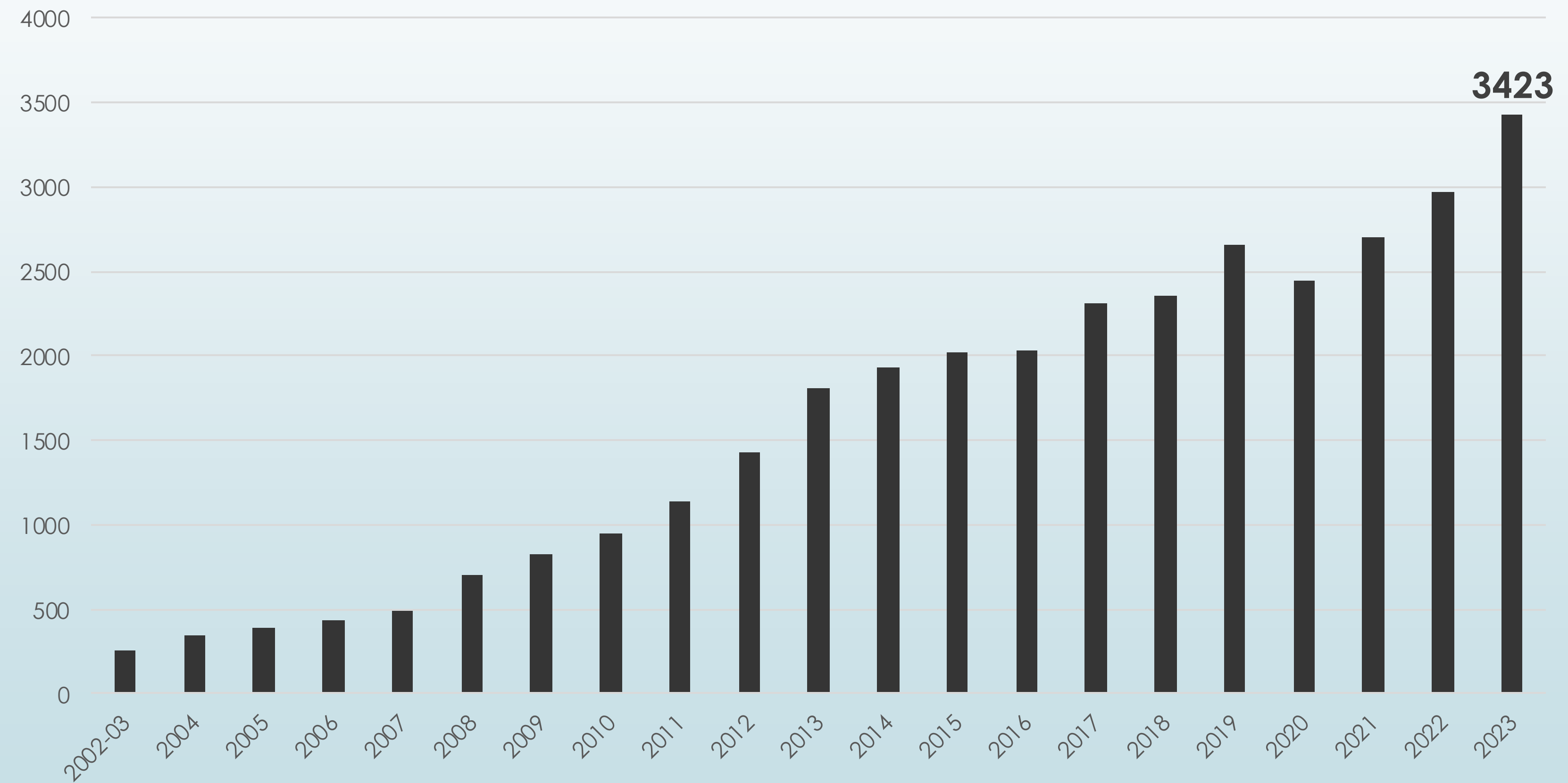
To date (2014-2023), just 7 cases reported

➔ question of principle (equity) rather than need

Small law amendments, eg obligation to refer (2020), penalty system (2024)

Developments last 20 years

- Gradual expansion year after year



Sources: Fed Control & Evaluation Committee Euthanasia reports

Developments last 20 years

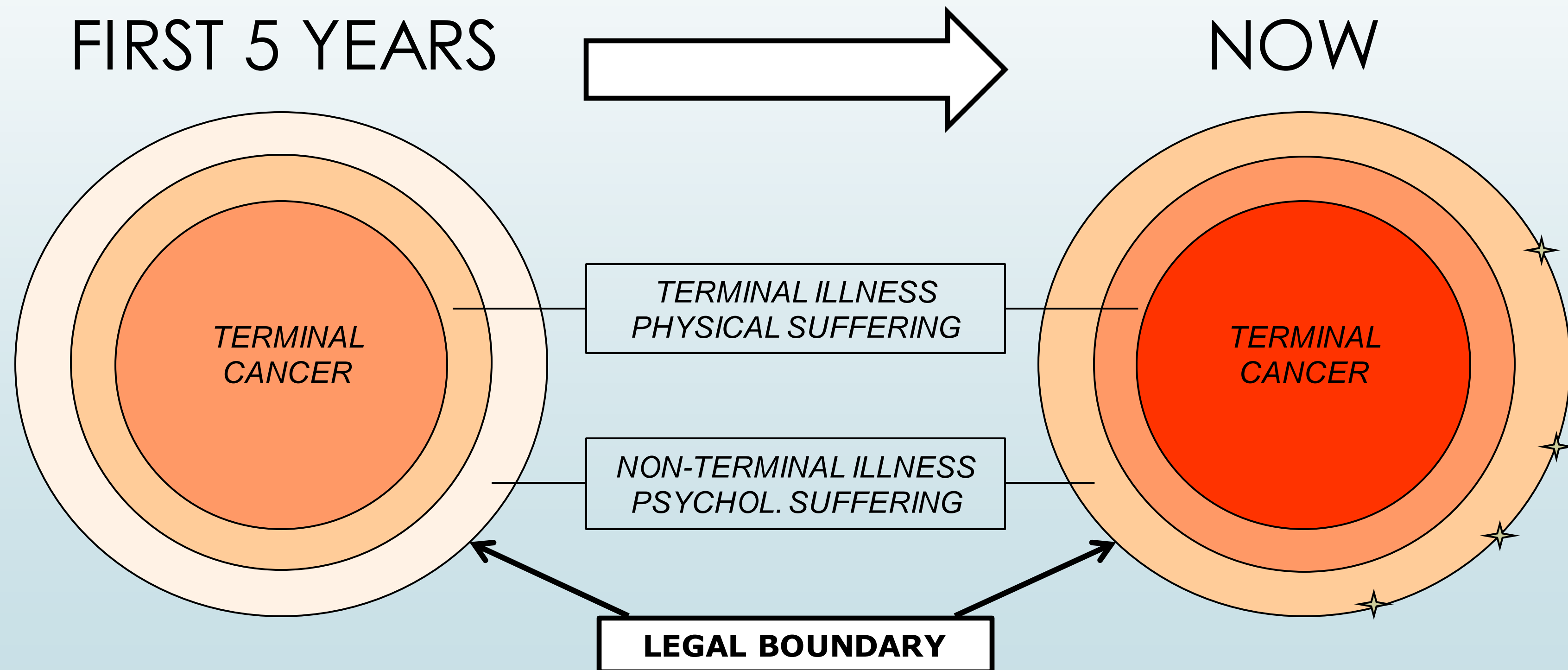
- Expansion = increasing 'diversity' of clinical profiles
- Shifts in age profile → toward parity

	Reported 2002-2007 (n=1925)	Reported 2023 (n=3423)
Malignant cancer	**83%**	**56%**
Progressive neuromuscular disease	7%	10%
Cardiovascular disease	2%	3%
Multiple pathologies	**2%**	**23%**
Neuropsychiatric disease	1%	3%
Other (renal, pulmonary, digestive, AIDS,…)	5%	5%
Non-terminal illness	***7%***	***21%***
Aged over 80 years	***18%***	***42%***

Sources: Fed Control & Evaluation Committee Euthanasia reports

“Expanded” acceptance

Full *scope* of the euthanasia law now used



Developments last 20 years

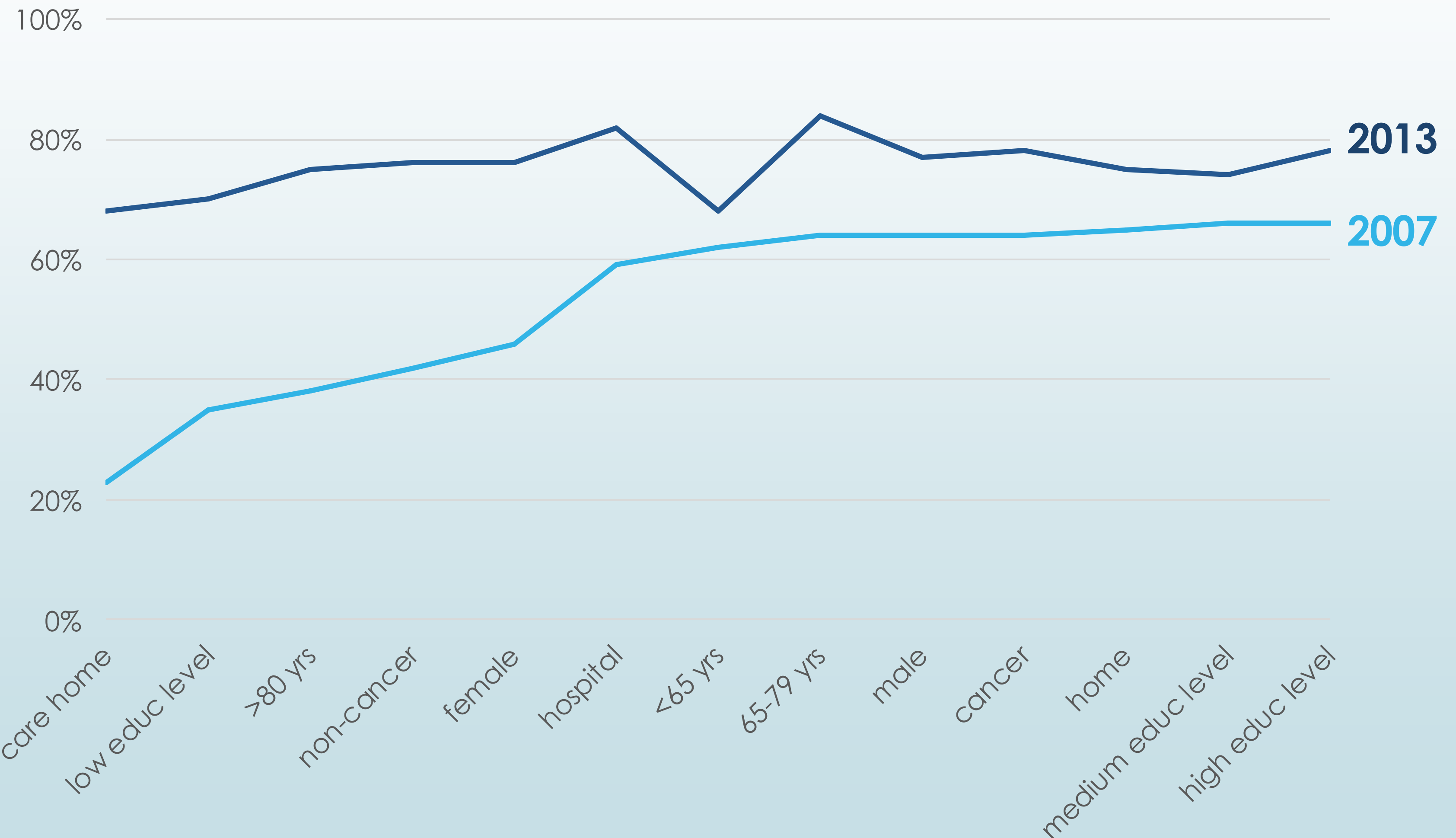
- Gradual expansion year after year
- Both in terms of number of requests and in granting rate

- **Increasing number of requests (3.4% → 6.0% of deaths)**
  - Cultural/attitudinal shift: focus on quality of dying, control
  - Higher awareness of euthanasia as end-of-life option
  - Generational shift (secularisation)

- **Increasing granting rates (56% → 77%)**
  - Less reluctance: less conscientious objection, more trust, positive experiences
  - Less resistance in care institutions (eg in nursing homes)
  - “Non-traditional” cases more often considered eligible

Source: Dierickx S et al, JAMA Intern Med 2015

Increasing granting rates



Source: Dierickx S et al, JAMA Intern Med 2015

Adherence to legal criteria?

- Adherence to eligibility criteria
  - Occasionally cases heavily debated, eg
    - Verbessem twins, progressive deafness & blindness
    - Nathan Verhelst, failed sex change operations
  - Individual cases of transgressions, eg
    - Simona De Moor, 'reactive depression' or tiredness of life? (case referred, physician reprimanded)
    - Tine Nys, clinical depression: 'refractory'? (murder trial, physicians acquitted)

(Micro vs macro level: individuals vs population)

Adherence to legal criteria?

- Adherence to procedural safeguards
  - A few documented transgressions (see previous slide)
  - **Reporting rates**: increased but still 1/3 not reported

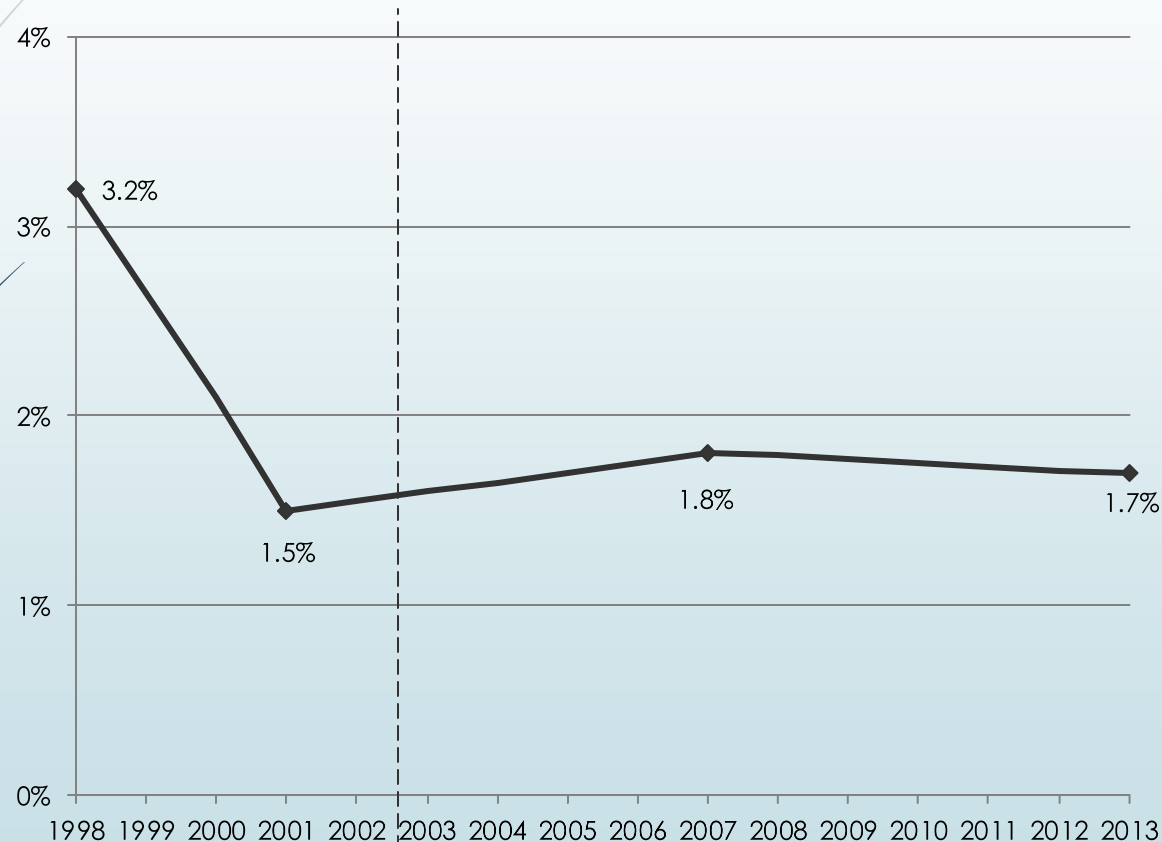
	Benzodiazepines and/or opioids	Barbiturate +/- muscle relaxant
Reported to Federal Control and Evaluation Committee Euthanasia	6%	**95%**
Not willing to report	3%	3%
Not euthanasia according to physician	**91%**	2%
Request in writing	22%	**97%**
Only oral request	**78%**	3%
Drugs administered only by physician	31%	**96%**
Also by nurse	**35%**	3%
Only by nurse	**34%**	1%
2nd physician consulted	**82%**	**98%**
Euthanasia best term according to physician	3%	**96%**
Palliative sedation best term	**82%**	3%
Other term better	15%	1%

Source: Dierickx S et al, J Pain Symptom Manage 2018

"Grey zone" sedation

- Palliative sedation:
  - reported use for hastening death (few days at most) – see previous slide
  - deep sedation (not according to int’l guidelines; cf. proportionality)
  - seen as a choice for patients *(Robijn L et al, Pall Med 2018)*
- Life-ending acts without request
- More openness on end of life, death and individual preferences (advance care planning integrated)
- Palliative care

Life ending acts without explicit request



Source: Chambaere K et al, NEJM 2015

Found in research

BUT

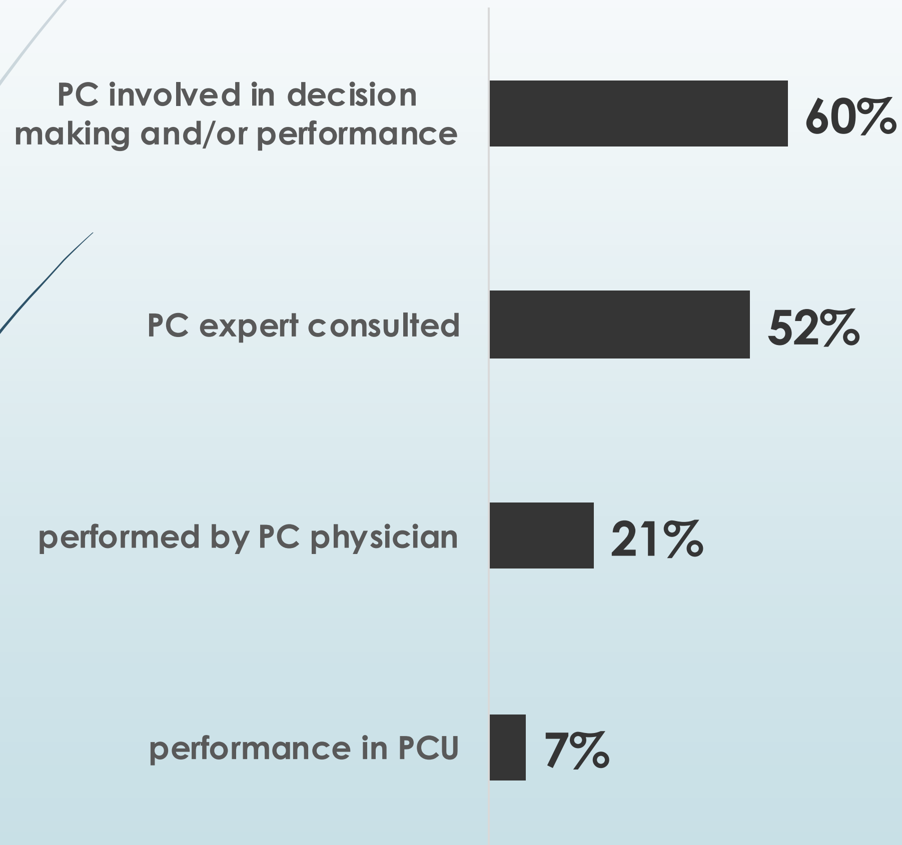
1. Occurred *before* the enactment of the euthanasia law in Belgium
2. Did *not increase* after the enactment of the law
3. Also occurs in *countries without assisted dying* law

Palliative care & euthanasia in Flanders

- Twin law: law on palliative care in 2002
  - Recognition that euthanasia should not be performed for lack of the best possible (palliative) care at the end of life
  - Structural embedding of palliative care in health care organisation: palliative function in all care settings
  - Universal access to palliative care (=patient right)
  - Reimbursement through health care insurance system (palliative status, lump sum, palliative leave)
- Position Palliative Care Flanders
  - 2003: "No polarisation, but dialogue and respect", "Palliative care involvement in euthanasia requests"
  - 2011: "Palliative care can guarantee that euthanasia requests will be dealt with in a careful and caring way"
  - 2013: "Euthanasia embedded in pallliative care" (Vanden Berghe P et al, 2013)

= UNIQUE IN THE WORLD!

Palliative care & euthanasia in Flanders



Source: Dierickx S et al. Pall Med 2017

Current ‘pressure points’: older persons

- **Old age-related multimorbidity** (polypathology)
  - Incl. deafness, blindness, immobility, incontinence, arthritis, heart problems, etc
  - Social dimensions in suffering and in motives for requests: loss of relationships, being a burden, isolation, loneliness (‘social death’)
  - Tiredness of life / completed life – very recently media discussion
- **Dementia**
  - Early dementia: widely accepted but heavily discussed (‘going earlier than necessary’)
  - Advanced dementia: bill proposals but issues with incompetence at administration
- Risk of **ageist reasoning** in assessment of requests?

Current ‘pressure points’: psychiatry

Extremely sensitive, ‘line in the sand’ debate, the ‘canary in the mine’

- Eligibility difficult to assess
  - Incurable illness? No prospect of improvement? (here also: socio-economic dimensions of suffering)
  - Competence?
  - Ambivalence, suicidal ideation (Verhofstadt et al, 2022)
- Fear for lack of uniformity & consistency
  - Proliferation of policies, differences & inequality
  - Physician “shopping”
- Involvement, role and impact on social circle (family)? ‘Relational autonomy’
- Relinquish single-physician ‘absolutism’?
  - ‘Colloque singulier’ eroding (times changed since 2002 legislation)
  - Current policy: multiple physicians + positive advices (=above & beyond legal requirements)
  - Team involvement in decision making

Expertise centres for euthanasia?

Ideal: concentration of expertise

- Support service for professionals
- Independent & quality advice
- Transparency

In practice: **not ideal & criticised**

- Patient "dumping"
  - Passing the buck?
  - Patient-physician relationship?
- Lack of resources, staffing
- Suspicion: "closed community", overly permissive

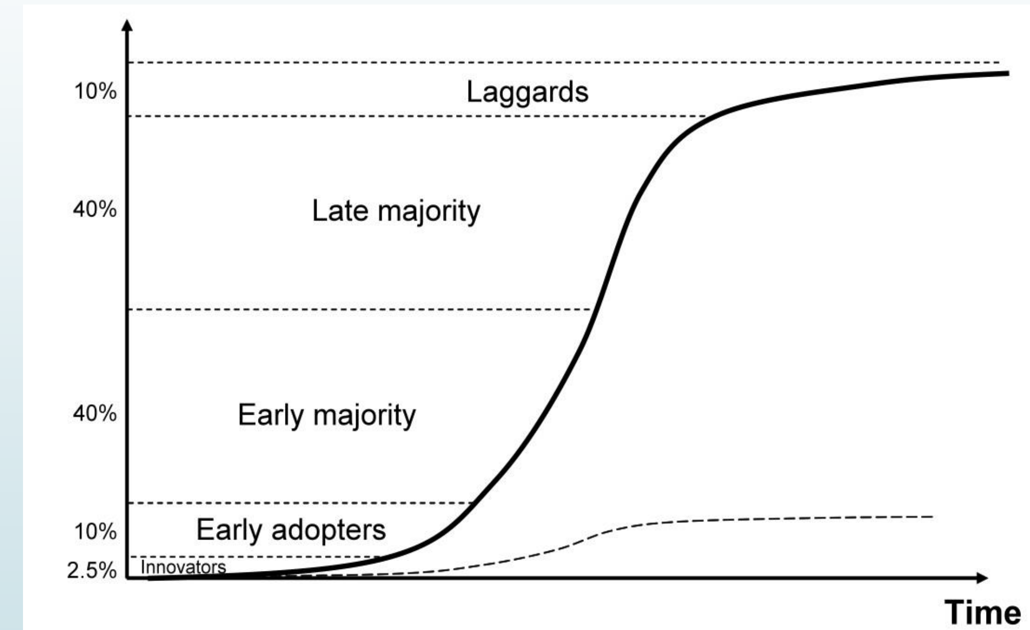
- **'Slippery slope'** ever present in academic debate
  - Unequivocal 'bad' situation at the end of the slope: what is that situation? (Mass extermination?) Many versions. Do away with it?
  - More fundamentally: what is its philosophical validity? It implies universal and timeless morality, but morality evolves with time (empirical fact). Should we decide today what the situation should always/never be for our societies?
- Rising euthanasia figures, in general, in more 'complex' cases, in 80+ age group
  - Sign of shifts in morality? Is this problematic per se? Shifts might be positive
  - 'Normalisation': bad per se? 'Culture of death'?
  - Tells us little as such about moral acceptability, appreciation in the eye of the beholder
- No widespread abuse, occasional cases of transgressions (cf. cases vs populations)
  - Question of 'quantity' → how much is problematic? Every transgression is a tragedy? Reason to tighten legislation?

A sociological lens on developments

Diffusion of Innovations theory (Rogers)

- Applied in a wide range of fields; assisted dying not special
- Stages of adoption, each with unique challenges
- Diffusion continues as long as
  - Experienced as useful and beneficial
  - No undesirable developments

  ON POPULATION LEVEL!



- Dynamic view on morality needed
- Puts ‘normalisation’ & ‘slippery slope’ in perspective
- Continued need for monitoring of evolutions: macro & micro

Prime undesirable development

Request free of ‘external pressure’? Socio-economic motives for requesting assistance in dying

- ‘Duty to die’? Nudging?
- Socio-economic context amenable to improvement?
- (Subtle) family pressures
- Sufficient access to (mental) health system?
- Sufficient integration in society?
- May be excuse for government and policy to forgo investments in healthcare and support of those in precarious health

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