Legalising assisted dying: cross-purposes and unintended consequences

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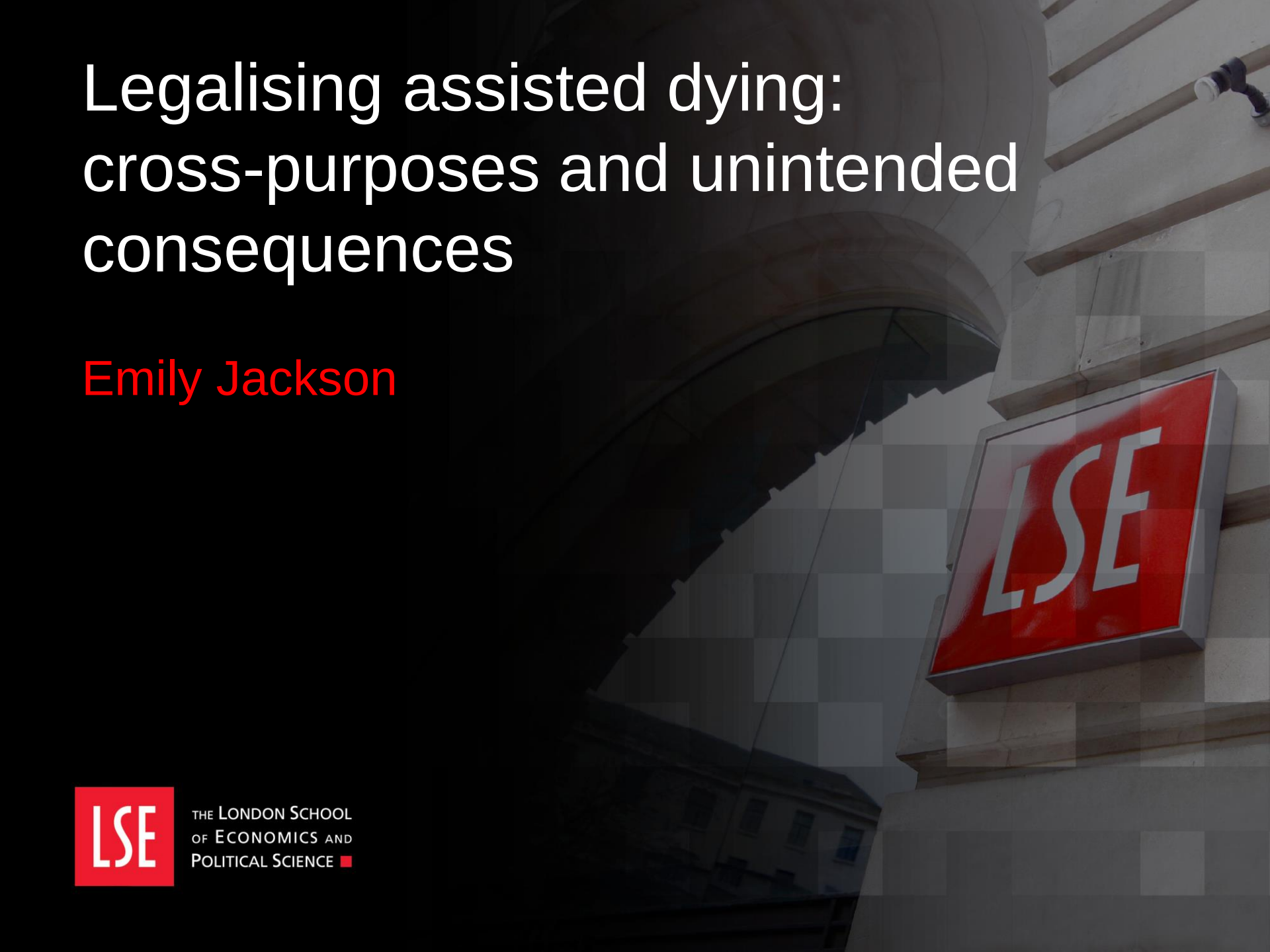

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UK pro-legalisation strategy 2001 to date

Judicial review actions

- Dianne Pretty (2001)
- Debbie Purdy (2009)
- Tony Nicklinson (2014)
- ‘Martin’ (2014)
- Paul Lamb (2014)
- Noel Conway (2017)
- Omid T (2017)

Parliamentary Reform

- Assisted Dying for the Terminally Ill Bill 2003 and 2004
- House of Lords Select Committee on Assisted Dying (2005)
- Demos/Falconer Commission (2012)
- Assisted Dying Bills 2014, 2015, 2016…

R (on the application of Pretty) v Director of Public Prosecutions [2001] UKHL 61

Lord Bingham: 'I would for my part accept the Secretary of State's submission that Mrs Pretty's rights under article 8 are not engaged at all.'

Lord Steyn: 'the guarantee under article 8 prohibits interference with the way in which an individual leads his life and it does not relate to the manner in which he wishes to die.'

Pretty v UK (2002) 35 EHRR 1.

ECtHR: 'The applicant in this case is prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life. The Court is not prepared to exclude that this constitutes an interference with her right to respect for private life as guaranteed under Article 8(1) of the Convention.'

R (on the application of Purdy) v Director of Public Prosecutions [2009] UKHL 45.

Lord Hope: '… I would therefore depart from the decision in [Pretty] and hold that the right to respect for private life in article 8(1) is engaged in this case.'

Lord Brown: 'What to my mind is needed is a custom-built policy statement indicating the various factors for and against prosecution.'

Lord Neuberger: '… a sensible and clear policy document would be of great legal and practical value, as well as being, I suspect, of some moral and emotional comfort, to Ms Purdy and others in a similar tragic situation.

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Lord Brown: '… suppose, say, a loved one, in desperate and deteriorating circumstances, who regards the future with dread and has made a fully informed, voluntary and fixed decision to die, needing another's compassionate help and support to accomplish that end (or at any rate to achieve it in the least distressing way), is assistance in *those* circumstances necessarily to be deprecated? Are there not cases in which (although no actual defence of necessity could ever arise) many might regard such conduct as if anything to be commended rather than condemned?'

R (Nicklinson and Another) v Ministry of Justice, [2014] UKSC 38.

Lord Neuberger: 'Parliament now has the opportunity to address the issue of whether section 2 should be relaxed or modified, and if so how, in the knowledge that, if it is not satisfactorily addressed, there is a real prospect that a further, and successful, application for a declaration of incompatibility may be made.'

Lord Wilson: 'Were Parliament for whatever reason, to fail satisfactorily to address the issue whether to amend the subsection to permit assistance to be given to persons in the situation of Mr Nicklinson and Mr Lamb, the issue of a fresh claim for a declaration is to be anticipated. … the court would, I hope, receive the focussed evidence and submissions which this court has lacked. While the conclusion of the proceedings can in no way be prejudged, there is a real prospect of their success.'

Lord Neuberger: '…there is force in the point that difficult or unpopular decisions which need to be taken, are on some occasions more easily grasped by judges than by the legislature. Although judges are not directly accountable to the electorate, there are occasions when their relative freedom from pressures of the moment enables them to take a more detached view….

'A system whereby a judge or other independent assessor is satisfied in advance that someone has a voluntary, clear, settled, and informed wish to die and for his suicide then to be organised in an open and professional way, would, at least in my current view, provide greater and more satisfactory protection for the weak and vulnerable, than a system which involves a lawyer from the DPP's office inquiring, after the event, whether the person who had killed himself had such a wish.'

'

Assisted Dying Bill 2016

1 Assisted dying

(1) Subject to the consent of the High Court (Family Division) pursuant to subsection (2), a person who is terminally ill may request and lawfully be provided with assistance to end his or her own life.

(2) Subsection (1) applies only if the High Court (Family Division), by order, confirms that it is satisfied that the person—

(a) has a voluntary, clear, settled and informed wish to end his or her own life;

(b) has made a declaration to that effect in accordance with section 3; and

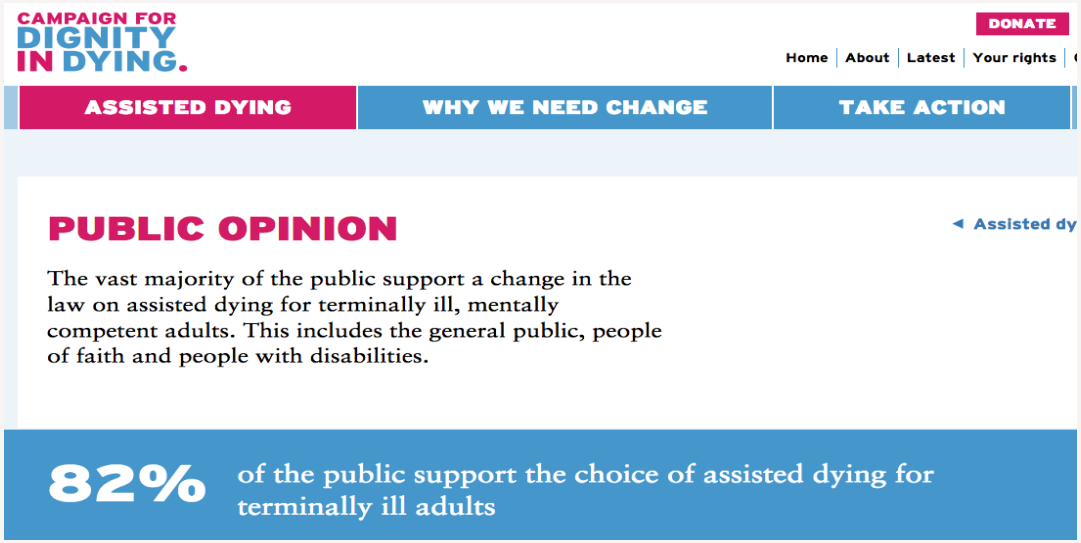
(c) on the day the declaration is made—

(i) is aged 18 or over;

(ii) has capacity to make the decision to end his or her own life; and

(iii) has been ordinarily resident in England and Wales for not less than one year.

Terminal illness?



Capacity requirement?

Rules out advance decisions for assisted dying.

Unintended consequences of earlier suicides/assisted suicides overseas.

To medicalise or not medicalise assisted dying?

Involvement of healthcare professionals in legalised assisted dying is mandatory and optional.

- Must confirm medicalised eligibility criteria.
- Must prescribe medicines.
- Where euthanasia is lawful, must also administer medicines.

Right to conscientiously object to participation.

Good reasons to involve doctors:

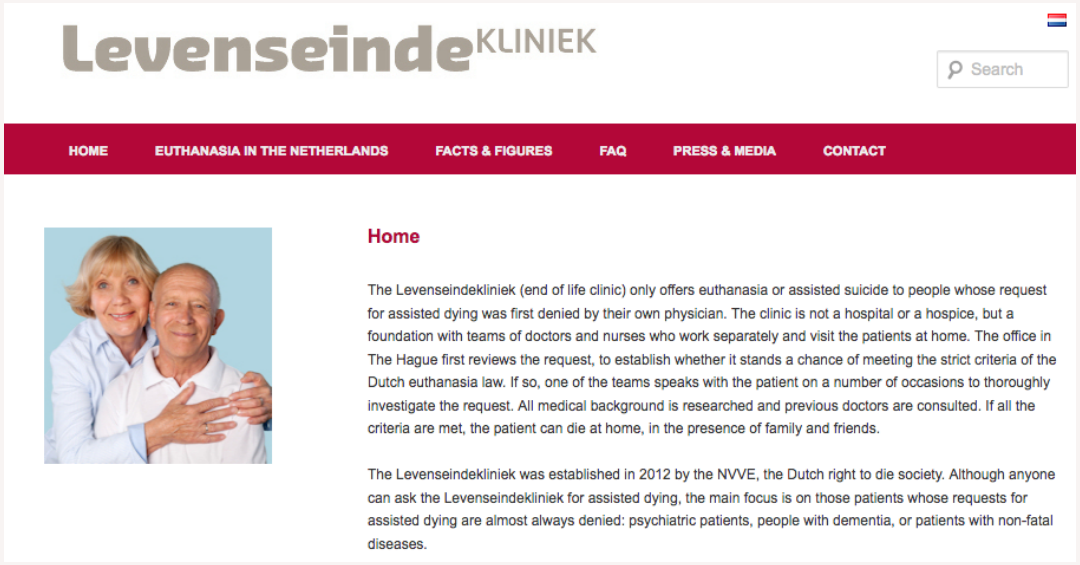
1. Necessary knowledge and skill to diagnose and confirm medical eligibility criteria.
2. Skills to end lives effectively and painlessly.
3. Evidence from Belgium that the integration of assisted dying and palliative care ensures continuity of care.
4. Broader purpose of legitimation.
5. Easier for relatives/loved ones?

And good reasons *not* to involve doctors:

1. Neutralise arguments grounded in the impact of legalisation upon medical profession?
2. Involvement in assisted dying is not easy for doctors.
3. Support for legalisation is generally lower among doctors than the general public.
4. Doctors find involvement in AD especially difficult when the patient's suffering is psychosocial or mental (easier if the patient is dying from cancer).
5. Advance decisions are difficult (and rare).

Evidence from Europe

1. Increasing number of requests where there is no underlying medical condition.
2. Voluntarily stopping eating and drinking is not uncommon.
3. ‘Of free will’ movement
4. ‘End life now’ clinics.



Less medicalised in Switzerland? But…

1. Only doctors can prescribe sodium pentobarbital.
2. Swiss Academy of Medical Sciences:
   - The patient's disease justifies the assumption that he is approaching the end of life.
   - Alternative possibilities for providing assistance have been discussed and, if desired, have been implemented.
   - The patient is capable of making the decision, his wish has been well thought out, without external pressure, and he persists in this wish. This has been checked by a third person, who is not necessarily a physician.
   - The final action in the process leading to death must always be taken by the patient himself.

Vulnerable or not vulnerable?

- House of Lords Select Committee on Assisted Dying: ‘We were also concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death’.
- Lady Hale (in *Nicklinson)*: ‘The only legitimate aim which has been advanced for this interference is the protection of vulnerable people, those who feel that their lives are worthless or that they are a burden to others and therefore that they ought to end their own lives even though they do not really want to.’
- Rob Marris MP (House of Commons, 11 Sep 2015): ‘coercion of the vulnerable is the most difficult issue, for me and many people in the House and outside’

Evidence from Europe?

Requests come more frequently from those who:

- have no religious affiliation
- are well-educated and middle class
- live alone
- live in urban rather than rural areas, and in more affluent neighbourhoods.

‘I offer a new conception of vulnerability, one that demonstrates how rich, educated, white males … are just as, if not more, vulnerable to threats posed by PAS/VAE’ (Erik Krag, ‘Rich, White, and Vulnerable: Rethinking Oppressive Socialization in the Euthanasia Debate’ (2014) 39 *Journal of Medicine and Philosophy* 406–429.

Interest in assisted dying more generally:

‘A shared theme seems to be that those who support assistance in dying value control’. They are ‘not prepared to accept paternalistic attitudes on the part of health staff’, and see access to assisted dying ‘as a way of rising above one’s circumstances’. (Natasja J H Raijmakers et al, ‘Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross-sectional survey’ (2015) 41 Journal of Medical Ethics 145-150.

Smith et al found that requesters of assisted dying had ‘dismissive styles of attachment’, that is they prioritise ‘self-reliance, autonomy and independence’, and are interested in AD to ‘maintain an ultimate sense of control and autonomy within a process that allows very little opportunity for either’. (Kathryn A Smith et al, ‘Predictors of pursuit of physician-assisted death’ (2015) 49 *Journal of pain and symptom management* 555-561.)

Talking about assisted dying as an end in itself?

- Desire to talk about hastening death is common.
- It may have multiple meanings.
- And it can be 'dynamic and interactive' (Kathrin Ohnsorge, Heike Gudat, and Christoph Rehmann-Sutter, 'Intentions in wishes to die: analysis and a typology–A report of 30 qualitative case studies of terminally ill cancer patients in palliative care' (2014) 23 *Psycho-Oncology* 1021-6).

Why do people want to talk about hastening death?

- Asking for reassurance?
- Cry for help?
- Test others' reactions?
- Recognition of what lies ahead?
- Letting loved ones know one has accepted that one is dying?
- Expression of despair?
- Attempt to regain agency?

Legal status of assisted dying may shape response

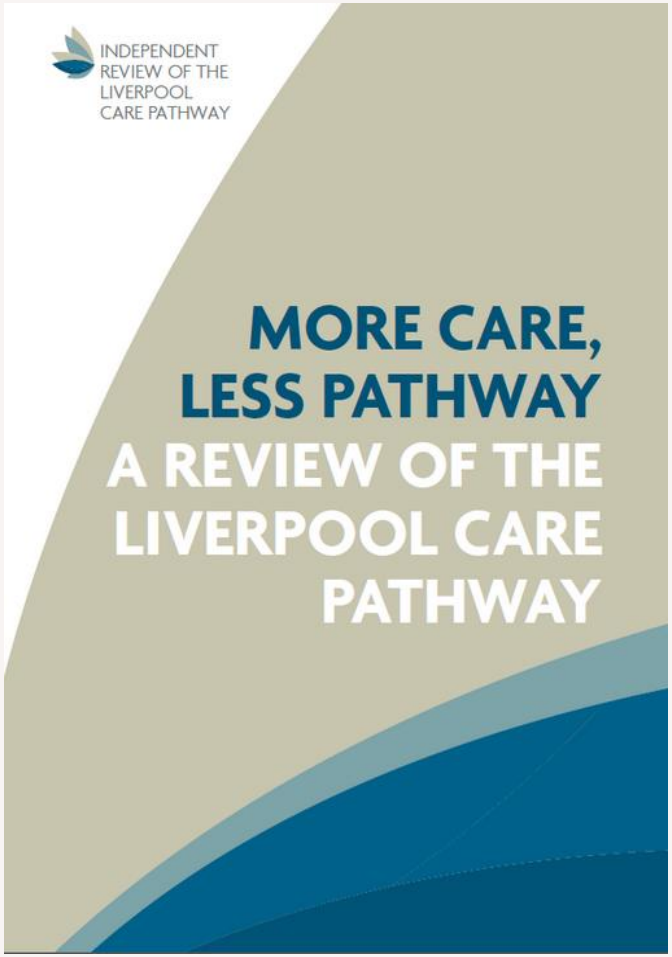
- Eg ‘I can’t help you with that’.
- ‘... all patients claimed that both health and family caregivers tended to ignore or deny their desire to die’. (Martina Pestinger et al, ‘The desire to hasten death: Using Grounded Theory for a better understanding “When perception of time tends to be a slippery slope”’ (2015) 29 Palliative Medicine 711-719.)

Difficulty of proactively raising question of assisted dying:

- Signal endoresment or loss of hope?
- Cf only available to the privileged?
- Cf organ donation following assisted dying in Belgium and the Netherlands.

- *But* open conversations about death and dying are associated with better outcomes, for patients and for the bereaved.

Improving care at the end of life



- Fear of dying and fear of indignity of care.
- Inadequate communication.
- Open discussion of death and dying must be a priority.