

# Developing the assisted dying debate: a focus on implementation

Professors Nancy Preston and Suzanne Ost

## **Policy Context**

There is increasing momentum behind legal reform to permit assisted dying (AD) in England and Wales, but <u>nearly half of doctors</u> do not want to participate in AD in any way.

This is a rare policy case where *how* we do it matters more than *should* we do it. The potential future implementation of AD will be highly complex and contested. Yet the debate is so focused on changing the law that delivery of AD is at real risk of being overlooked.

### Key research findings

The experience of countries that have implemented AD shows that its delivery is extremely complex and has not had sufficient scrutiny in England and Wales. Considering the significant implications for health, palliative care and social care, we want policymakers to consider a system of AD delivered outside of the healthcare sector.

- Our research in the Netherlands, Washington State and Switzerland, informed by interviews with health care professionals and bereaved family members, reveals first-hand accounts of those assisted death experiences.
- When healthcare practitioners help, they sometimes struggle to cope: <u>'For me, it</u> really takes a year before I get over it and think: "Ok, now I'm ready for a new trajectory."
- In countries where AD is legal, patients and their families struggle to navigate the system to identify those who are willing to assist them.

- With so few doctors willing to be involved, there would be serious ramifications for healthcare practitioners if AD is placed within the NHS. Legal issues could also arise for healthcare practitioners if AD is integrated into the NHS without a clear delivery plan. A de-medicalised model outside healthcare could mitigate this risk.
- The costs of integrating AD in an NHS system, already at melting point, must be considered urgently. We are working on these costs, which should inform policy decisions.
- The alternative system outside of health care that <a href="weepropose">weepropose</a> would involve right to die organisations to help patients and families through the AD process and panels of experts to scrutinise the process before and after death.
- Patients would be offered support, have had a requisite palliative care assessment and, crucially, a pharmacist would be identified to dispense the drugs.



### Policy recommendations

- Work must be done on how to implement and deliver an AD model **before** the law changes, in parallel with discussion on whether AD should be legalised, to avoid a situation akin to the implementation of the <a href="Liverpool Care Pathway"><u>Liverpool Care Pathway</u></a> policy (inconsistent implementation; unclear terminology; poor understanding of guidance).
- Policymakers must consider the key questions: Who will be directly involved in AD, and how will an AD system support patients and their families through the process?
- The views, experiences and concerns of professionals in health and social care who might be involved with the delivery of AD must be taken into account in deciding how a lawful AD model should be implemented and delivered.
- The implementation model needs to recognise that, internationally, most doctors do not want to be directly involved in AD even if they agree with a change in the law.

- Government should be wary of committing to an AD model delivered by the NHS before it has considered the implications. As the majority of palliative care is provided through charities, it could risk sending the wrong message if AD is placed within the NHS.
- Consider the advantages of a demedicalised AD model delivered outside of healthcare, including prospective and retrospective review by a Panel of experts, allowing for greater scrutiny both before and after death.
- The financial costs of a de-medicalised system outside the NHS versus the costs of including AD within NHS provision, and the impact on healthcare professionals, must be considered.
- Please see our short film on assisted dying <u>On My Terms</u> or this summary of first hand experiences of assisted dying in The Conversation

#### Work with us

Professor Nancy Preston is Professor of the International Observatory on End of Life Care in the Faculty of Health and Medicine and Professor Suzanne Ost is in the Law School at Lancaster University. Nancy is a world leading researcher on the impact of assisted dying on families and healthcare workers through her international research. She gave evidence to both the Health and Social Care Committees on assisted dying for the British and Irish Governments. Suzanne was Expert Adviser and Friend to the <a href="Jersey">Jersey</a> and <a href="Nuffield Council's Citizens">Nuffield Council's Citizens</a> Juries on Assisted Dying. She has written extensively on assisted dying and her assisted dying research has been <a href="AHRC funded">AHRC funded</a>.

Contact Professors Preston and Ost at <a href="mailto:n.j.preston@lancaster.ac.uk">n.j.preston@lancaster.ac.uk</a> and <a href="mailto:s.ost@lancaster.ac.uk">s.ost@lancaster.ac.uk</a> if you would like to learn more about their research, invite them to speak at your event, or collaborate with them to improve or evaluate policy research.