



# Terminally Ill Adults (End of Life Care) Bill

Assisted dying is an important and complex area from a political, legal and clinical standpoint, and above all, for patients and their families. As the representative body for the UK's 23 medical royal colleges and faculties, the Academy of Medical Royal Colleges [the Academy] believes that this is a societal decision which can only be properly determined by parliament. Should parliament pass the [Terminally Ill Adults \(End of Life Care\) Bill](#) [the Bill], the Academy and our members will then implement the legislation that emerges.

To this end, the Academy has consciously adopted no position in relation to the current Bill, so that we can best support politicians to explore all of the key issues that are pertinent to the Bill. This document is intended to aid parliamentarians as they consider and revise the Bill. It sets out a series of issues from a clinical standpoint, which our members believe should be thought through during the next stage of parliamentary scrutiny.

To be clear, it is not suggested that everything set out below should be included on the face of the Bill and set out in primary legislation, as many of the issues can be covered in any resulting secondary legislation.

## Considering the legislation

When developing the Bill, parliamentarians should consider the following factors, questions and issues. For ease, we have grouped these under distinct headings on the following pages.

## The evidence base — Parliamentarians should consider:

- An international review of the evidence from jurisdictions where assisted dying has already been introduced, considering what differences between healthcare systems and legal frameworks might mean for organisation and delivery.
- Gaps in current evidence and data gathering.
- Any equality, diversity and inclusion gaps or implications identified by an assessment of equality impacts.

## Person-centred delivery — Parliamentarians should consider:

- Patient protection, including 'choice', 'coercion' and 'capacity'.
- Provision of advice and support for individuals and families including mediation when a family is not in agreement with a patient's wishes.
- Provision of counselling support, including capacity and funding.
- The legal definitions of a terminal illness and reliability of estimates of timescales for particular terminal diagnoses.
- Whether there are any conditions and diseases which will be specifically excluded, and what this might mean for people who have multiple (physical and mental health) conditions?
- Mechanisms for ensuring that all information on options are made available to the patient.
- People with particular conditions who may ultimately be unable to self-administer their medication.
- What public education campaigns will be needed to outline scope, practice and to manage patient and public expectations.
- What the process for assessment of coercion should be, who will assess this, and what should the burden of evidence be?
- Support for those who fall outside the time-limited scope of any legislation (i.e. those not in the last six months of life).
- The position and role of those holding health and welfare power of attorney and how they would be supported.
- How should deaths be recorded on the death certificate, and whether assisted dying be referenced?

## Consistency — Parliamentarians should consider:

- The degree of alignment of approaches across all four jurisdictions of the United Kingdom, plus Isle of Man, Jersey and Guernsey.
- Geographical spread of any provision, including remote and rural areas and those with limited numbers of appropriate staff.
- Alignment of standards of mental capacity with those set out in the Mental Capacity Act 2005.
- Alignment regarding standards of measuring and/or agreeing the last six months of life.

## Service design — Parliamentarians should consider:

- What form the service will take, will it be part of the NHS or a stand-alone/contracted service?
- What role might independent sector provision play?
- Which clinical specialties and roles will deliver the service?
- Would those professionals charged with delivering the service be independent of other NHS teams providing treatment?
- Will any specialties or professional groups be excluded from the organisation and delivery of the service?
- What role might medical examiners or other independent professionals play?
- Whether the service will be built around self-administration (with doctors' prescribing), or administration by a particular set of clinicians?
- What frameworks will be needed to govern the use of approved substances, including dosage, drug combinations, route of administration, quality assurance, and liability issues for prescribers and manufacturers.
- How will the use of approved substances be monitored, taking account of outcomes, failures, and unintended effects, including idiosyncratic drug reactions.
- Issues relating to the supply chain in light of global medicines shortages.
- Would assisted dying be considered a medical treatment option which can be raised by clinicians with patients directly?
- Where the service be delivered and whether this will enable patients to die where they want to – at home, in hospital or another healthcare setting?
- How all relevant third party (individuals in addition to the patient who are involved in the process) information might be collected?

- Whether where the service is to be delivered might impact subsequent health behaviours of families by making them less willing to use particular health settings in the future?
- Relationships with medicine and services for older people.
- Relationships with palliative care, including an assessment of the capacity, coverage and funding in palliative care, both now and post bill.
- Relationships with work on suicide prevention.
- Relationships with psychiatry.
- Relationships with psychological support.
- How organ donation will be facilitated for someone choosing assisted dying and how might this be affected by the healthcare setting (i.e. home) in which the service is delivered?
- How might the service be aligned with current arrangements for organ donation, which is typically only possible after intravenous medication rather than oral medication.
- Whether there would need to be a professional firewall between organ donation and the assisted dying service?
- Which existing systems will be used to ensure good communication channels between health services, coroners, police, undertakers and other key stakeholders to aid swift responses.
- Appropriate development and lead-in time.

### Clinical roles — Parliamentarians should consider:

- A robust and workable conscience mechanism.
- Clinical decision-making and sign-off processes.
- Evidence-based measures of prognosis.
- Role of the doctor in managing unexpected complications of resulting processes.
- Will the coordinating doctor or other healthcare professional be required to remain with the person until the moment of death?
- Will clinicians' involvement in decision making and/or delivery be time limited?
- Are there any clinical roles which must remain outside/inside of the process?
- Should there be a process for assessing clinicians' psychological wellbeing?
- Provision for psychological support for those professionals working in the service.

- Wider support for clinicians working in this area.
- Training capacity.
- Mental capacity assessment training.
- Current approaches to Deprivation of Liberty Safeguards (DoLS).
- Whether this should be a new, discrete specialty or a new area of professional responsibility?
- Should there be a register for different parts of the process?
- The division of responsibilities between relevant clinicians, other members of the multidisciplinary team, and the judiciary?

### Funding and finance — Parliamentarians should consider:

- Full establishment and running costs.
- Whether this will be a funded and delivered NHS service, NHS funded, or another model?
- Should the Bill explicitly state that the service will not involve fees for service for individual clinicians or organisations?
- Funding implications for other NHS and social care services (palliative care, organ donation, psychiatry, advice, counselling, social care etc.)
- Which body will collect data relating to assisted dying cases and how might this be used to inform future health service funding.
- Full funding for all aspects of any resulting service.

### Legal oversight, scrutiny, evaluation and Review — Parliamentarians should consider:

- Capacity in the legal system for supporting the process, including NHS lawyers and court services.
- Wellbeing support for patients and families involved in any legal processes.
- Which regulatory body/bodies will have responsibility for monitoring and dealing with any issues, queries and concerns?
- What processes should be in place to enable the scrutiny of individual cases? In England and Wales, there is the Medical Examiner system, but this does not extend to Scotland and Northern Ireland.

- What data should be published – numbers using the service, setting, those deemed eligible and ineligible, equalities data (all protected characteristics), and condition-specific monitoring?
- Will there be a built-in review embedded in the roll-out of the legislation?

The Academy is keen to work with parliamentarians during the committee stages in both Houses and would be happy to provide additional insights and advice, and to convene groups of clinicians to further explore key issues.

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