Terminally Ill Adults (End of Life) Bill – committee stage Briefing for line-by-line scrutiny

About

Marie Curie maintains a neutral position on assisted dying – we neither campaign for, nor against, a change in the law. Our core mission is to ensure that as many people as possible have access to high-quality care and support when they are dying – including palliative and end of life care. As the UK's leading end of life charity, we want to share our research and expertise to help inform parliamentarians as they consider the important topic of assisted dying.

Below are a number of key questions and areas – developed in consultation with Marie Curie's senior clinical staff- which we highlight and would encourage members of the bill committee to consider in further detail. This briefing is not intended to provide exhaustive commentary on the bill, or take positions on all of the issues raised, it is merely intended to share our reflections for the benefit of legislative scrutiny.

As highlighted in Marie Curie's written evidence (TIAB42) to the bill committee, we are also calling for amendments to the bill which recognise the patchy and perilous current state of palliative and end of life, and require government to put in place urgent plans to address this.

Clause 2: Terminal illness

> ***(1) For the purposes of this Act, a person is terminally ill if— (a) the person has an inevitably progressive illness, disease or medical condition which cannot be reversed by treatment, and (b) the person's death in consequence of that illness, disease or medical condition can reasonably be expected within 6 months.***

MPs should consider whether this definition of terminal illness is sufficiently clear to enable it to be used by relevant medical professionals for the purposes of determining eligibility to request an assisted death.

A similar definition is used to ensure accelerated access to social security support for everyone who needs it; it is based on clinical judgement, and is deliberately inclusive and flexible. This definition is designed to include people with a terminal illness diagnosis who will have many months – in some cases years – to live, and those for whom their prognosis is uncertain. It is important to be clear about the intent of this Bill, and whether MPs would wish it to include those people.

Prognostication of people with a terminal illness is inherently difficult and the bill currently includes no detail on how this should take place, and what level of skills/training/expertise should be required in order to make an assessment that somebody's death "can reasonably be expected within 6 months".

Different conditions can have very different trajectories at the end of life – in particular prognostication is particularly challenging for some non-malignant (non-cancer) conditions. This could potentially give rise to scenarios where it is difficult for doctors to ascertain reasonable expectation of death within six months, in effect creating two-tier eligibility. This may be particularly likely for groups with multiple co-morbidities. This issue could act as both a parity consideration (creating a barrier to access assisted dying) and a safeguarding consideration (widening eligibility beyond that envisaged by the Bill). There are also recognised gaps in the understanding of health care professionals about how terminal illness presents in certain groups which, as above, raises questions around both parity of access and safeguarding.

Clause 3: Capacity

> ***In this Act, references to a person having capacity are to be read in accordance with the Mental Capacity Act 2005.***

Fluctuating capacity can be a major concern for health and care professionals. It is important for MPs to recognise that in the course of a terminal illness capacity can fluctuate enormously and consider whether processes through which an assisted death is requested are sufficiently robust to respond to the needs of those with fluctuating capacity.

Clause 4: Initial discussions with registered medical practitioners

> ***(1) No registered medical practitioner is under any duty to raise the subject of the provision of assistance in accordance with this Act with a person.***
>
> ***(2) But nothing in subsection (1) prevents a registered medical practitioner exercising their professional judgement to decide if, and when, it is appropriate to discuss the matter with a person.***
>
> ***(3) Where a person indicates to a registered medical practitioner their wish to seek assistance to end their own life in accordance with this Act, the registered medical practitioner may (but is not required to) conduct a preliminary discussion about the requirements that need to be met for such assistance to be provided***

The bill does not require medical practitioners to raise assisted dying with a patient with a terminal diagnosis, but nor does it prevent a medical practitioner from doing so. However, MPs should consider the risk that in raising the issue, this could be considered as "pressure" to choose an assisted death and have possible negative impacts on the relationship between doctor and patient, and even risks of the medical practitioner's actions been seen as conflicting with the safeguarding requirements in the Bill.

As currently drafted, the Bill would also require medical practitioners either conducting initial discussions with patients regarding an assisted death, or providing assessment as to eligibility for an assisted death, to ***"explain to and discuss… any available palliative, hospice or other care, including symptom management and psychological support"***. However, this does not specify any requirement for what palliative care provision must be available to the patient, and nor does it recognise or address well-evidenced variations in service provision and access to services.

Clauses 5, 7, 8 and 9: Declaration and assessments

> ***(3) In this Act, "the coordinating doctor" means a registered medical practitioner— (a) who has such training, qualifications and experience as the Secretary of State may specify by regulations, (b) who has indicated to the person making the declaration that they are able and willing to carry out the functions under this Act of the coordinating doctor in relation to the person, (c) who is not a relative of the person making the declaration, and (d) who does not know or believe that they— (i) are a beneficiary under a will of the person, or (ii) may otherwise benefit financially or in any other material way from the death of the person***

There is limited clarity within the Bill as to what level of skills, training and expertise coordinating doctors should have – which specifies only that they have "***such training, qualifications and experience as the Secretary of State may specify by regulations***". MPs may want to explore this further, given the substantial requirements on those playing this role.

MPs should also consider whether a multidisciplinary team (MDT) should play a role in the declaration and assessment processes– palliative care is a speciality that often involves extensive involvement from a multidisciplinary team made up of doctors, nurses, therapists, psychologists, chaplaincy staff and social workers in considering the holistic needs of a patient. It should be considered whether an MDT assessment should be necessary, rather than relying so significantly on the judgement of a single "coordinating doctor".

The proposed processes also raise a number of practical questions, given the involvement of multiple clinicians required to be involved at various stages, the requirement that the "independent doctor" is not a partner or colleague in the same practice or clinical team as the coordinating doctor, and the substantial work involved in and expertise required of, both the coordinating doctor and the independent doctor. The impact on the capacity of existing services should be carefully considered. For example, would there be any risk of reducing the availability of palliative care services for patients who are not requesting an assisted death?

These elements of the bill also raise a number of further questions about parity of access between geographies, based on the availability of doctors and other clinicians willing to participate in assisted dying in a given place. This may disproportionately impact under-doctored communities, including those with high levels of socio-economic deprivation, rural and remote communities.

Clause 18: Provision of assistance

> ***(2) The coordinating doctor may, in accordance with this section, provide that person with an approved substance (see section 20) with which the person may end their own life. (3) The approved substance must be provided directly and in person by the coordinating doctor to that person.***
>
> …
>
> ***(6) 30 In respect of an approved substance which is provided to the person under subsection (2), the coordinating doctor may— (a) prepare that substance for self-administration by that person, (b) prepare a medical device which will enable that person to self-administer the substance, and (c) assist that person to ingest or otherwise self-administer the substance.***
>
> ***(7) But the decision to self-administer the approved substance and the final act 35 of doing so must be taken by the person to whom the substance has been provided.***

A number of terms here require careful definition in order to clarify the responsibilities and potential liabilities of the coordinating doctor in respect of the provision of assistance during an assisted death.

In particular, the Bill specifies that the coordinating doctor may "assist" the terminally ill person ***"to ingest or otherwise self-administer the substance".*** However, it does not define under what circumstances assisting in the self-administration of a substance would amount to administering the approved substance. For example, for a substance administered orally, would the coordinating doctor be able to help raise the cup to their lips? If so, to what degree?

Similarly (and given the Bill allows for a medical device to be used in the administration of the approved substance), could self-administration be via a non-oral route, such as a feeding tube, which is mechanically assisted? Might an approved substance be administered through other mechanical devices, such as a syringe pump, which nonetheless require a high level of involvement from a clinician to prepare and manage?

How assistance to self-administer is defined has implications for how accessible the option of assisted dying is for patients who have been determined to have mental capacity, but who does not have physical capacity to self-administer the approved substance without some form of assistance.

Clause 18: Responsibility of the coordinating doctor to remain with the dying person

> ***(9) The coordinating doctor must remain with the person until— (a) the person has self-administered the approved substance and— (i) the person has died, or (ii) it is determined by the coordinating doctor that the procedure has failed, or (b) the person has decided not to self-administer the approved substance.***

The Bill specifies that the coordinating doctor must remain with the dying person until they have died, it is determined the procedure has failed, or the dying person has decided not to self administer the approves substance.

However, the Bill does not clarify under what conditions the coordinating doctor is said to be "remaining" with the dying person. This is particularly notable given the specification that ***"the coordinating doctor need not be in the same room as the person to whom the assistance is provided."*** For example, could they be administering care to another patient, whilst also being said to "remain" with the dying person.

MPs should also consider whether they are content that no timescale is specified in the Bill within which the person must take the substance to cause their death, and the resource implications for that given that it is set out that an authorised health professional must remain with the person until they decide not to take it, or until they die.

MPs should also consider the responsibilities of the coordinating doctor if the terminally ill person decides to take the approved substance, but they do not die. This may or may not be due to failure to ingest or absorb the full prescribed dosage of the approved substance. Such a scenario could result in pain and distress for the terminally ill person, and uncertainty for the clinician present about the course of action they must take to minimise the patient's pain and distress.

This clause raises further queries about the location that an assisted death should take place. It should be explored further whether the process should take place at home or in another setting, and what this practically means for the coordinating doctor to "remain" with the patient. The implications should also be considered if all clinicians in a particular setting or geography were to opt-out of providing assistance.

Clause 23: No obligation to provide assistance etc

> ***(1) No registered medical practitioner or other health professional is under any 5 duty (whether arising from any contract, statute or otherwise) to participate in the provision of assistance in accordance with this Act.***

As currently drafted, the legislation places no obligation on medical and other professionals to participate in the provision of assistance in accordance with the Act, but it is not clear whether this will apply solely to individual professionals or to providers as a whole.

MPs should also consider the broader scope of employment protections with regard to views on assisted dying. Employees are additionally protected from discrimination on the basis of their religion and or protected philosophical beliefs under the Equality Act 2010. All employers will need to consider the potential for any of their employees (not just health care professionals) to bring cases to employment tribunal if they believe they have suffered detriment as a result of their beliefs in relation to assisted dying or their willingness to undertake work in relation to it. Employers will also need to consider the wider impact of the assisted dying debate on relationships between groups who share protected characteristics, including the impact of bias, discrimination and stereotyping.

Clause 20 and 28: The meaning of "approved substance" and the Prescribing, dispensing, transporting etc of approved substances

> ***(1) The Secretary of State must, by regulations, specify one or more drugs or other substances for the purposes of this Act.***

As currently drafted, the meaning of "approved substance" and the Prescribing, dispensing, transporting etc of approved substances would be delegated entirely to secondary legislation. The involvement and liabilities of prescribers should be carefully considered as part of consideration of the bill.

Clause 26: Dishonesty, coercion or pressure

> ***(2) A person who, by dishonesty, coercion or pressure, induces another person to self-administer an approved substance provided in accordance with this Act commits an offence.***

The Bill specifies that it is an offence to induce another person to self administer an approved substance by dishonesty, coercion or pressure. However, it does not define the circumstances under which dishonesty, coercion or pressure may be understood to have taken place.

For example, MPs might want to explore the circumstances under which raising the topic of assisted dying with a patient might be interpreted as "pressure" to choose an assisted death (particularly given the lack of clarity in the Bill as to how such initial conversations should be managed).

Clause 35: Review of this Act

> ***(1) The Secretary of State must, during the period of 12 months beginning at the end of the initial 5-year period— (a) undertake a review of the operation of this Act, (b) prepare a report on that review, and (c) as soon as reasonably practicable, publish and lay the report before Parliament***

The Bill would currently require the Secretary of State to review and report on the implementation of the Act 5 years after its assent. The Bill specifies that this must include ***"an assessment of the availability, quality and distribution of appropriate health services to persons with palliative care needs"***.

It is vital that such assessment is also made at the point of implementation of the act, to inform policy and spending decisions which enable improved access to high quality palliative and end of life care services.

We would also argue that this should be broadened to reflect a broader and more holistic consideration of palliative and end of life care needs, reflecting current clinical best practice, and therefore amended to refer to "health and care services to persons with palliative and end of life care needs".

Additional clauses required: improving the provision of palliative care

If the Terminally Ill Adults (End of Life) Bill is to proceed, we believe it is vital that it should include a clause requiring the government to produce and publish an urgent national strategy for improvement of palliative and end of life care.

Proposed new clause 1: Strategy for improvement of palliative and end of life care

To move the following Clause–

The Secretary of State for Health and Social Care must prepare and publish a strategy for improvement of palliative and end of life care, to include -

(1) An assessment of the current availability, quality and distribution of appropriate health and care services to persons with palliative and end of life care needs, including-
    (a) pain and symptom management;
    (b) psychological support for those persons and their families;
    (c) information about palliative care and how to access it;
(2) Quality standards for palliative and end of life care services which must be met in all localities;
(3) A national strategy and targets for palliative and end of life care, to support 24/7 delivery of local services, in line with the assessment of the current availability, quality and distribution of appropriate health and care services to persons with palliative and end of life care needs;
(4) A long term and sustainable funding strategy for palliative and end of life care;
(5) An approach to establishing NHS leadership for palliative and end of life care delivery, including responsibility for delivery of the strategy, implementation of the national delivery plan, and monitoring the availability, quality and distribution of appropriate health and care services to persons with palliative and end of life care needs.

Member's explanatory statement
This new clause would require the Secretary of State for Health and Social Care to produce a national strategy to improve access to, and the availability of, palliative and end of life care services.

Proposed New Clause 2: Assessment of the current availability, quality and distribution of palliative and end of life care services

To move the following Clause–

(1) The Secretary of State must undertake, prepare and publish an assessment, within 12 months from the day this Act is passed, of the state of health and care services to persons with palliative and end of life care needs.
(2) The assessment must include the quality and distribution of appropriate health and care services to persons with palliative and end of life care needs, including-
    (a) pain and symptom management;
    (b) psychological support for those persons and their families;
    (c) information about palliative care and how to access it;

Members explanatory statement
This new clause would require the Secretary of State for Health and Social Care to undertake and publish an assessment of the current availability, quality and distribution of palliative and end of life care services within 12 months from the day this Act is passed.

Amendments to reflect holistic consideration of palliative and end of life care needs

Amendment 1:
Clause 35, page 22, line 2, after "health", insert "and care"
Amendment 2:
Clause 35, page 22, line 2, after "palliative", insert "and end of life"

Member's explanatory statement
These amendments would broaden the scope of the assessment criteria for the Review of this Act, by referring to "health and care services to persons with palliative and end of life care needs" to provide a more holistic consideration of palliative and end of life care needs, reflecting current clinical best practice.

About Marie Curie

Marie Curie is the UK's leading end of life charity. We are here for anyone with an illness they're likely to die from, and those close to them. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system.

For more information or to arrange a meeting to discuss the contents of this briefing, please contact: parliament@mariecurie.org.uk