Terminally Ill Adults (End of Life) Bill – Report Stage Briefing for Parliamentarians

Summary

- 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. 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;
- One of the Terminally Ill Adults (End of Life) Bill's stated policy objectives is that the choice of an assisted death should be available to dying people as part of a holistic approach to end-of-life care, as an option alongside palliative care;
- However, it cannot be ignored that our palliative and end of life care system is presently in a perilous state, with significant inequalities in access to care, unmet need, and highly variable quality and distribution of care;
- Therefore if the Terminally Ill Adults (End of Life) Bill were to proceed, we believe there must be clear recognition within it that genuine choice at the end of life cannot exist unless dying people are able to choose to receive high quality palliative and end of life, and Parliamentarians should therefore ensure there are urgent plans to close the gaps in end of life care which exist today;
- **Marie Curie is therefore asking MPs to support amendment 21 to the bill.** This amendment would require the government to prepare and publish an assessment of the availability, quality and distribution of palliative and end of life care services as part of the first report on implementation of the Act (to be undertaken within 1 year of the Act being passed).
- We recognise that on its own this amendment will not guarantee improvements to palliative and end of life care services, but in requiring an immediate assessment of the state of health and care services available to persons with palliative and end of life care needs, we believe it would create a framework for accountability within this legislation and a firmer basis upon which future policy and spending decisions on palliative care can be made;

The state of palliative and end of life care today

Our palliative and end of life care system is presently in a perilous state. Research published as part of Marie Curie's Better End of Life research programme[1] highlights that whilst the number of people who need palliative and end-of-life care is increasing steeply, our health and care system is already struggling to meet that demand. The largest nationally

[1] Marie Curie; 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales'; Better End of Life 2024; Accessed at: www.mariecurie.org.uk/policy/better-end-life-report

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representative survey of people affected by dying, death and bereavement undertaken in a decade found that:

- **Too many people are dying in pain and without the support they need for their symptoms**- 1 in 3 people were severely or overwhelmingly affected by pain in their final week of life;
- **Gaps in 24/7 community care are preventing people from dying in comfort at home**- 1 in 2 people visited A&E at least once in their final three months of their life;
- **Patients and unpaid carers are suffering due to poor communication and coordination**- 1 in 2 people were unhappy with at least one aspect of care the person who died received;
- **Current workforce capacity is insufficient to meet demand for end of life care**- 1 in 5 people who died had no contact with a GP in the last three months of life;
- **Unpaid carers are taking on significant caregiving roles with little support**- 1 in 6 bereaved people met the criteria for 'disturbed' or complicated grief.

Around 90% of us will die with palliative care needs, yet around one in four people currently do not get the end of life care and support they need. And as our population ages and more people are living with, and dying from, multiple and complex conditions the need for palliative care will continue to grow.

A lack of sustainable funding for services and limited prioritisation of palliative and end of life care means that **there is currently a postcode lottery in access to services**, and concerningly, there are particular barriers to access for certain groups, such as people with non-cancer conditions, people living in poverty, those who live in rural areas, minoritised ethnic communities.

It is important to note that **there has not been a national strategy for palliative and end of life care since 2008**, and despite the legal duty introduced under the Health and Care Act 2022 on Integrated Care Boards (ICBs) in England to assess the palliative and end of life care services required in their area and commission them, the evidence is that ICBs are still failing to adequately fund or prioritise palliative care services.

Amendment 21

There has been much discussion about the relationship between this Bill and palliative and end of life care. We believe that requiring an assessment to be undertaken on the current availability of palliative and end of life care services **would provide the government with a benchmark against which its impact can later be measured**, alongside ensuring a better understanding of the care and support that is currently available to inform government policy and spending decisions.

Tabled by Munira Wilson MP, and co-signed by co-chair of the APPG on Hospice and End of Life Care Paulette Hamilton MP, **amendment 21** is supported by Marie Curie:

Clause 43, page 31, line 15, at end insert—

"(4) For the first reporting period referred to under subsection (2) (a) the report must set out an assessment of the state of health services to persons with palliative and end of life care needs and the implications of this Act on those services.

(5) The report (4) must, in particular, include an assessment of the availability, quality and distribution of appropriate health 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."

Member's explanatory statement

This amendment would require the Secretary of State for Health and Social Care to prepare and publish an assessment of the availability, quality and distribution of palliative and end of life care services as part of the first report on implementation of the Act (to be undertaken within 1 year of the Act being passed). This would mirror the assessment already required as part of the 5 year review of the act.

Committee stage debate and impact assessment

During Committee stage of the bill, amendments similar to the currently proposed amendment 21 were debated which would have required the government to undertake an assessment of current palliative care services. The Minister of State for Care's response highlights more than ever why such an assessment is desperately needed – he said: "Palliative and end-of-life care services are broad, holistic services, provided by a range of professionals and providers—generalist and specialist—across the NHS, social care and voluntary sector organisations. Therefore, measuring the provision is difficult, as relevant consultations and tasks are not always coded as palliative or end-of-life care. Commissioning and contracting processes do not consistently support data collection… It is also practically difficult to identify the Bill as the catalyst of the implications on those services over the specific period, as they are affected by multiple factors"[2].

The Government's own impact assessment on the BBill acknowledges that there are high levels of demand for end-of-life and palliative care across England and Wales, including unmet need and variation in quality of provision, but there is currently limited national data collection to map the availability, quality and distribution of palliative care. It notes that there are currently no official statistics in England and Wales on the number of terminally ill adults, nor the cost of their palliative and end-of-life care, and that as part of the required monitoring and evaluation should the Bill pass, new data would need to be collected on current palliative and end-of-life care experiences. The assessment also highlights other potential impacts of the Bill on palliative and end of life care, including on demand for services, requirements for training and the workforce. **In this context, introducing the requirement for a comprehensive assessment of the current availability, quality and distribution of palliative care on the face of the Bill is desperately needed.**

Limitations

We recognise that including this clause within the Bill will not guarantee any improvements to palliative and end of life care, but in requiring government to publish an assessment of current care provision, we believe it can provide a stronger framework for accountability (of both government and local commissioners) and a firmer basis upon which future policy and spending decisions on palliative care can be made.

Marie Curie is also continuing to call on the UK Government to commit to developing a national strategy for improvement of palliative and end of life care (PEoLC), with targets

[2] Terminally Ill Adults (End of Life) Bill Committee (Twenty-ninth sitting) Debated on Tuesday 25 March 2025. Columns 1472-1478

for improving the availability, quality and distribution of integrated health and care services for everyone with palliative care needs in local populations, as part of the 10 Year Health Plan for England due to be published in June 2025.

Although legislation on assisted dying in England and Wales is a matter for the UK Parliament, if the Bill becomes law it will impact devolved public services in Wales, where the provision of end of life care is the responsibility of the Welsh Government. If amendment 21 were to be accepted and the Bill progresses, action would therefore be required to ensure any assessment of palliative care takes account of devolution and the appropriate responsibilities of the two governments. Welsh Ministers have set out their ambitions for PEoLC in the Quality Statement, however, further work is required is make these ambitions a reality. Marie Curie Cymru continues to work with policymakers in Wales to ensure that the necessary changes are made to ensure that everyone can access high quality PEoLC in the right place, at the right time, and will continue to monitor the progress of this Bill to consider its implications for devolved policymaking.

Areas for broader scrutiny

There are several other areas within the Bill which would have a significant relationship with, or impact upon, the delivery of palliative and end of life care. Detailed measures in these areas are largely to be secured by regulation, but we would welcome further scrutiny of these areas, alongside a commitment that the Minister will consult with end-of-life care providers as relevant regulations are developed:

Procedure for prognosis: Prognostication of people with a terminal illness is inherently difficult and the Bill currently includes no detail on how this should be consistently undertaken.

Place of death: the Bill does not currently set out a clear direction for where an assisted death might take place.

The availability of palliative and end of life care: As currently drafted, the Bill would require medical practitioners either conducting initial discussions with patients regarding an assisted death or providing an 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 neither recognises nor addresses well-evidenced variations in service provision and access to services.

Provision of assistance: 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.

Approved substance: 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 legislative scrutiny of the bill.

Marie Curie is the UK's leading end of life charity. We're 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. Contact our public affairs team at: parliament@mariecurie.org.uk