Terminally Ill Adults (End of Life) Bill – Lords Committee Stage Briefing for Peers

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**. A lack of sustainable funding for services and limited prioritisation of palliative and end of life care means we currently have a postcode lottery in access to services, as well as particular barriers to access for certain groups.
- **We believe 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 care.** Parliamentarians should therefore ensure there are urgent plans to close the gaps in end of life care which exist today.
- We warmly welcome the recent commitment from Stephen Kinnock MP, Minister of State for Care, that a new national palliative and end-of-life care strategy and implementation plan (for England) will be published "in the very near future".
- However, Marie Curie would still support an amendment to the declaration process within the bill, which would guarantee that terminally ill adults if they so request would have a right to have their palliative and end of life care needs assessed by an appropriate professional, and be provided palliative care in line with those assessed needs.

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

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

- **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.

There is currently a lack of sufficient and sustainable funding for palliative and end of life care. **On average in 2023/24, the NHS only provided funding for 39% of the cost of Marie Curie's hospices and 48% of the cost of Marie Curie's nursing services.** The remainder of the costs for delivering vital end of life care are met by Marie Curie's fundraised income. Whilst we are very grateful for the generosity of Marie Curie's supporters, this is not a sustainable way to fund an essential part of our health and care system.

This 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**. 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, and ethnic minority 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, our evidence shows that ICBs are still failing to adequately fund or prioritise palliative care services.[2]

The Government's own impact assessment of the Bill acknowledged that there are high levels of demand for palliative and end-of-life care across England and Wales, including unmet need and variation in quality of provision, but there is currently limited national oversight 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 Bill's relationship to palliative and end of life care in England and Wales

Marie Curie maintains a neutral position on assisted dying – we neither campaign for, nor against, a change in the law. But if the Terminally Ill Adults (End of Life) Bill is to progress, there must be clear recognition that there are currently high levels of unmet need for

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[2] Marie Curie, '"The night times are frightening": gaps in 24/7 community care for people at the end of life' Policy briefing, May 2025. Accessed at: https://www.mariecurie.org.uk/document/experiences-at-the-end-of-life-in-england-and-wales

palliative and end of life care across England and Wales. Given that one of the 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 (alongside the option of palliative care), it is vital that parliamentarians deeply consider what the relationship would be between a potential voluntary assisted dying service and our palliative and end of life care system.

We were pleased that an amendment was agreed in the Commons, requiring 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). Whilst this change will not guarantee any improvements to palliative and end of life care, we believe that in requiring government to publish an assessment of current care provision, 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 had also sought amendments to this bill which would require the UK government to produce a national strategy for the improvement of palliative and end-of-life care, with targets for improving the availability, quality and distribution of integrated health and care services for everyone with palliative care needs in local populations. These suggested amendments were unfortunately considered out of the bill's scope, but we were nonetheless pleased to see that appearing before the Bill's Lords Select Committee, Stephen Kinnock MP, Minister of State for Care has committed that a "new palliative and end-of-life care strategy and implementation plan" would be presented by government "in the very near future".

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. 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.

Proposed amendment to the Bill

Marie Curie supports a proposed amendment which would guarantee an offer of palliative care assessment and treatment for somebody who is seeking to make a first declaration that they wished to be provided with assistance to end their own life. This would amend Clause 8 (Initial request for assistance: first declaration) to ensure that an eligible terminally ill adult, **<u>if they so request</u>**, would have a right to have their palliative and end of life care needs assessed by an appropriate professional, and be provided palliative care needs in line with those assessed needs. This is a guarantee which we would like to see introduced for all people who are terminally ill, regardless of whether or not somebody may wish to consider an assisted death. However, we believe such a universal guarantee would be considered beyond the scope of this bill, and there is a current opportunity in this Bill to ensure that this guarantee is at least introduced to ensure those exploring an assisted death do not feel compelled to pursue this on account of inadequate access to the palliative care that they need.

Marie Curie supports the following amendment (261), tabled in the names of Baroness Ritchie of Downpatrick and Lord Farmer:

Clause 8 (Initial request for assistance: first declaration), page 5, line 13, at end insert—

"(5A) Where a terminally ill adult makes a first declaration, they must, if they so request—

(a) have their palliative and end of life care needs assessed by an appropriate health or social care professional, and
(b) be provided with palliative and end of life care in line with their assessed needs to the extent necessary to enable them to decide whether such care would affect their wish to be provided with assistance to end their life.

(5B) The Secretary of State must, by regulations, make further provision in relation to the provision of palliative and end of life care in England for persons who have made a first declaration to the extent necessary to enable such persons to establish whether such care would affect their wish to be provided with assistance to end their life.

(5C) The Welsh Ministers must, by regulations, make further provision in relation to the provision of palliative and end of life care in Wales for persons who have made a first declaration to the extent necessary to enable such persons to establish whether such care would affect their wish to be provided with assistance to end their life."

Marie Curie also supports the following related amendment (264), tabled by Lord Hunt of Kings Heath:

After subsection (5C) insert—

"(5D) The Secretary of State must, by regulations, make further provision in relation to the provision of specialist palliative and end of life care to persons who have made a first declaration to ensure that an assessment can be given of their needs and whether such care might affect their wish to be provided with assistance to end their life."

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:

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.

Impact on specialist palliative and end of life care services: Given that many of the practical and logistical details of how a voluntary assisted dying service may operate are not yet defined and will be detailed by regulation, it remains unclear what the practical implications may be for existing palliative and care services.

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" and to make an offer of referral. However, this neither recognises nor addresses well-evidenced variations in service provision and challenges of 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. 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.

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.

Implications for devolved policymaking in Wales: Legislating for assisted dying poses some complex questions in respect of devolution. While justice is a reserved matter, health is devolved. The Bill as currently drafted straddles both of these areas.

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.

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