Terminally Ill Adults (End of Life) Bill – Second Reading

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.
- **It is important to consider the current perilous state of palliative and end of life care.** 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.
- Recent research shows that **almost one in three people** in the UK die without the palliative care they need each year. That's nearly one person dying with unmet need **every three minutes**.
- **Unmet need means symptoms and concerns go unaddressed**, that people struggle to access the support they needed from primary and community caregivers, it means that people die in pain and discomfort without having their needs met.
- "*All I know is that my mum was in pain at the end and that should never have happened*." – Claire, describing her mothers end of life experience.
- In the UK we have an ageing population, with **more people dying with comorbidities, meaning the care they require will be more complex and intensive**. This presents a challenge to a system that is already failing to meet the care and support needs of almost one in three people. As a result Marie Curie estimate that in the next 25 years, unmet need for palliative care will rise by 23% – around 40,000 more people in 2050 compared to 2025.
- This is the result of persistent lack of prioritisation and chronic underfunding of palliative and community care services, made worse by failure to invest in workforce.
- Regardless of whether the law changes, **it would be intolerable for anyone to feel they had to choose an assisted death because of poor access to, or inadequate provision of, palliative and end of life care.** Parliamentarians must therefore ensure there are urgent plans to close the gaps in end-of-life care which exist today.
- **Marie Curie supported an amendment to the Bill in the previous parliamentary session**, relating to a review of the availability, quality and distribution of palliative and end of life care services one year following from the passage of the Bill, which was agreed to in the Commons.

- **We welcome the government's commitment to producing a Modern Service Framework (MSF)** for Palliative Care and End of Life Care in England which aims to address inequity of access to good quality palliative care. However, we believe that this must be accompanied by transformation funding to catalyse the shift to delivering new models of care.
- It is vital that parliamentarians consider what the implications are of the development of a potential voluntary assisted dying service and the existing palliative and end of life care system.

The state of palliative and end of life care today

Our palliative and end of life care system is in a perilous state. Research published as part of Marie Curie's Better End of Life research programme 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:

- **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 almost one in three 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 2024/25, the NHS only provided funding for 34% of the cost of Marie Curie's hospices and 47% 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. While we welcome the Government's decision to develop a Modern Service Framework for Palliative Care and End of Life Care in England, we note that it will not be accompanied by a fully funded delivery plan. Previous attempts to improve

palliative care provision, such as the legal duty introduced under the Health and Care Act 2022 on Integrated Care Boards (ICBs) in England to commission palliative and end of life care services that meet local population need, have failed to ensure ICBs adequately fund and prioritise palliative care services.

We can see the impact of inadequate palliative care provision on our wider NHS and in the experiences of terminally ill people. Lack of access to palliative care in the community means that dying people and their carers often have no alternative but to attend A&E or call out an ambulance when they need help. More people now die at home (28%) or in a care home (20%), but **42% of deaths in England in 2024 occurred in hospital**. Hospital emergency service use in the final months of life remains high, **with more than 650,000 out-of-hours visits to UK emergency departments** by people at the end of life. This is especially true amongst people in deprived areas.

The Government's own impact assessment of the Bill from the last parliamentary Session 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.

Progress on addressing the crisis in palliative and end of life care

Some recent progress has been made to begin addressing these issues. The 10 Year Health Plan for England sets out an ambition to shift care from hospital to community, centred on the development of neighbourhood health service: a crucial aim for patients approaching the end of life who currently aren't able to access the care they need 24/7 and closer to home. The Neighbourhood Health Framework sets out an aim to increase the number of people identified as approaching end of life by 10%, and reduce non-elective admissions and hospital bed days for this cohort by 10% over the next 3 years. And the Department for Health and Social Care is currently developing the first new national plan for palliative care and end of life care since 2008, in the form of a Modern Service Framework, which will set out the government's ambition for system change.

But in order to drive rapid improvements in people's experiences of end of life care across our country, a major delivery effort will be required. That's why, to support implementation of the Framework and enable the scale of change required, we are calling on the Government to establish a palliative care and end of life care transformation fund. Alongside wider action on workforce, strategic commissioning, and accountability across all health and care settings, this would represent a substantial but proportionate investment to begin delivering the improvements in palliative care that are so desperately needed, while supporting the Government's wider ambitions for more joined-up, community-based care.

Areas for further 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 Wales: Legislating for assisted dying poses some complex questions in respect of devolution. 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, while justice is a reserved matter. It is imperative that accountability for palliative and end of life care in Wales remains with the Welsh Government and Senedd. Any elements of the Bill that relate directly to the assessment, delivery and availability of palliative and end of life care must be cognisant of devolved responsibilities.

As in England, the palliative and end of life care system in Wales is under immense pressure, with around one in three adults with unmet palliative care needs. Over the past four years much work has been undertaken to put in place a clear strategic framework for palliative and end of life care in Wales. Central to this is the *Quality Statement for Palliative and End of Life Care*, which has been refreshed and is due to be published in Autumn 2026, and the

National Service Specification for Wales: Palliative and End of Life Care Services. Focus must now be on delivery against these high-level ambitions and quality standards.

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