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 – 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;
- Our palliative and of life care system is presently in a perilous state. Research published earlier this year 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 demand;
- A lack of sustainable funding for services and limited prioritisation of palliative and end of life care means we currently have a postcode lottery for accessing services and inequalities in access to these services for some particular groups;
- Therefore if the Terminally Ill Adults (End of Life) Bill were to proceed, 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 care: Parliamentarians must recognise the present perilous state of our palliative and end of life care system and ensure there are urgent plans in place to address it;
- Marie Curie is therefore calling for an amendment to the bill should it proceed, which would place a duty upon government to develop an urgent strategy for the improvement of palliative and end of life care;
- Alongside producing a strategy for improvement of palliative and end of life care, the government must use upcoming milestones - including the development of the 10 Year Health Plan and the Spending Review - to deliver the significant policy change and investment required in order to improve end of life care.

Key terms

Terminal illness: We define a terminal illness is an illness or condition which cannot be cured and is likely to lead to someone's death. It's sometimes called a life-limiting illness.

Palliative care: Offers physical, emotional and practical support to people with a terminal illness. It can be offered at any point after a terminal diagnosis. Having palliative care doesn't necessarily mean that somebody is likely to die soon – some people have palliative care for years.

End of life care: Offers treatment and support for people who are near the end of their life.

PEoLC: Palliative and end of life care (PEoLC), referring to a holistic model of care and support for people with a terminal illness which prioritises people's wellbeing.

Unmet needs, rising fast

As our population ages more people will be living with, and dying from, multiple and complex conditions. Between 2023 and 2048 the number of people with palliative care needs in the UK is projected to increase by more than 147,000 (a 25% increase). **Marie Curie's best estimates suggest that around 1 in 4 people currently do not get the end of life care and support they need.**

Around 90% of us will die with palliative care needs. Every single one of us deserves to have our preferences on the care and support we receive listened to with respect. But the needs, interests and preferences of most people at the end of life are deeply neglected both in public discourse and public policy. Partly as a result of this, **there is a significant gap in end-of-life care in the UK – one which too often is socially biased against people living in poverty, people from ethnically minoritised groups, and a number of other groups.**

For a small proportion of people, the choice of whether to have an assisted death could play an important part in meeting people's end of life wishes. However, it is only a small proportion. In Oregon in the United States around 0.6% of dying people choose an assisted death, in Canada around 4%, in Switzerland 1.5%. It would be reasonable to expect that, even if it were legal in the UK, the vast majority of dying people would not choose an assisted death. **But the idea that anybody might choose an assisted death because our health and care system cannot offer them the care they need at the end of life should be intolerable to all of us.**

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 earlier this year 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:

- **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.

A lack of sustainable funding or prioritisation of palliative and end of life care

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

---

[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

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. As a recent inquiry by the APPG on Hospice and End of Life Care[2] has highlighted, statutory funding for hospice services is insufficient and varies enormously between areas. This means that **the services hospices provide for dying people and their families and the value they bring to our wider health and care system is already at risk.**

In addition to the long term underfunding of palliative and end of life care, further immediate cost pressures are putting current levels of service provision at risk. Firstly, the 5.5% NHS Pay Award for 2024/5 has placed strain on non-NHS providers of NHS services, such as Marie Curie, who have aligned key terms and conditions for clinical and clinical support roles to the NHS Agenda for Change pay scales. Such providers are not properly factored into funding models despite the heavy reliance upon charitable providers to deliver end of life care on behalf of the NHS. Secondly, the increases to employer national insurance contributions announced at the Autumn Budget will apply to end of life care charities, which in 2025/6 alone will result in around £3million in additional costs to Marie Curie.

The Health & Care Act 2022 introduced a new legal responsibility for Integrated Care Boards (ICBs) in England to commission palliative care services that meet the needs of their local populations. But research conducted on behalf of Marie Curie highlights that **this duty has yet to result in greater strategic prioritisation and funding of palliative and end of life care services.** A survey of ICBs conducted by KPMG[3] in June 2023 found that 50% of responding ICBs have not made or do not plan to make significant capital investment in PEoLC and over 40% of responding ICBs told us that current investment in PEoLC needs is not sufficient to meet the needs of their needs of their local populations, or that they did not know if it was sufficient.

Inequalities in access to palliative and end of life care

The current model of funding for hospices and palliative and end of life care is contributing to a postcode lottery and significant inequalities in access to care. Reliance on charitable funding means there is not universal access to services in the way that the NHS achieves in other areas of healthcare. Below are some of the groups which we know already experience significant inequalities in accessing palliative and end of life care, but **we would urge parliamentarians to consider the potential relationship between patients choosing an assisted death and wider inequities in access to health services should the Terminally Ill Adults (End of Life) Bill proceed.**

People with non-malignant terminal conditions, i.e. conditions other than cancer: Existing healthcare treatment pathways for cancer are often well-placed to recognise the condition as potentially incurable, enabling the management of associated PEoLC needs. By contrast, people with non-malignant conditions are less likely to be able to access PEoLC, despite experiencing equivalent symptomatic burden and having comparable care needs to people with cancer.

---

[2] All-Party Parliamentary Group Hospice and End of Life Care; 'Government funding for hospices'; 2024; Accessed here

[3] Marie Curie; 'Palliative and end of life care in Integrated Care Systems: Exploring how Integrated Care Systems are responding to the Health and Care Act'; 2023; Accessed here

People living in poverty and deprivation: Marie Curie research has found that 111,000 people die in poverty every year in the UK[4]. PEoLC quality indicators often include whether people are supported to be cared for in their home rather than in hospital. In the UK, living in poverty is associated with increased risk of death in hospital rather than in the community, and more emergency hospital admissions in the final months of life.

Those who live in rural areas: In England, 25.4% of the rural population are aged 65 and over compared with the urban population where 17.1 per cent are 65 and over[5]. The challenges that living rurally can present are further exacerbated when someone requires PEoLC support. Analysis of the 189 specialist adult inpatient hospices in England and Wales found that rural and more deprived areas were comparatively under-served compared to urban centres and more affluent areas[6].

Minoritised ethnic communities: People from minoritised ethnic communities access PEoLC less and later than some other population groups, and clinicians may be ill-equipped to support them. Delayed and unmet palliative and end of life care need amongst these communities can be due to "lower access to services, lack of cultural sensitivity among healthcare providers, language barriers, previous negative experiences, and conflicting values between family/religion and the notion of palliative care."[7]

Other groups which experience significant inequities in access to PEoLC: As well as geographic and ethnic disparities in the care people receive, research by Marie Curie indicates that other groups face particular barriers in access to palliative care, including people who are living alone, or with dementia – as well as people with learning disabilities, those who are homeless, people in prison, and LGBTQ+ people.[8]

What changes are required to ensure adequate palliative and end of life care is available?

Without urgent action, gaps in access to palliative and end of life care will only grow. There is currently no realistic national or local plan to address the scale of this challenge. Below are the urgent recommendations for improving palliative and end of life care which Marie Curie and partners[9] set out as part of our 2024 manifesto:

Deliver a new funding solution for palliative and end of life care to end the postcode lottery in access:

- Recognising palliative and end of life care as a core component of our health and care system;
- Ensuring parity of esteem and fair pay for those working to deliver support for dying people in the NHS and end of life care charities;
- Ensuring providers are paid fairly and equitably for services;
- Delivering a long term investment in palliative and end of life care, to address inequities in access and ensure that local commissioners are strategically prioritising and properly funding PEoLC

---

[4] Marie Curie; 'Exploring poverty and fuel poverty at the end of life in the UK'; 2024; Accessed here

[5] Department for Environment, Food & Rural Affairs. Rural population and migration statistics. 2021

[6] Gatrell AC, Wood DJ. Variation in geographic access to specialist inpatient hospices in England and Wales. Health & place 2012;18(4):832-840

[7] Chidiac C, Feuer D, Flatley M, et al. The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation. Palliative Medicine 2020;34(9):1241-1248

[8] Marie Curie: A Place for Everyone report: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2020/a-place-for-everyone-report.pdf

[9] Hospice UK, Marie Curie, National Bereavement Alliance, Sue Ryder and Together for Short lives; 'A Manifesto for palliative and end of life care'; 2024; Accessed here '

Introduce a national delivery plan for palliative and end of life care in every nation to support delivery of local services:

- Enabling commissioning of services that meet the needs of the whole population;
- Planning and funding a health and care workforce that can respond to increased future need;
- Ensuring 24/7 access to palliative and end of life care including through a single point of access in every local area offering advice, guidance and support;
- Improving access to medicines through more pharmacies stocking palliative medicines and more professionals trained to prescribe them in local communities.

Guarantee that palliative and end of life care services meet each individual's needs, including those of people dying at home:

- Personalised care and support planning for every individual reaching the end of their life, including bereavement and mental health support for carers and families;
- Sharing of digital care plans across health and care services to enable joined-up support in the community for every individual and their family and carers;
- Involving people with direct experience of dying, death and bereavement in co-designing local palliative and end of life care services.

Act to ensure that nobody dies in poverty and tackle inequalities in palliative and end of life care:

- Ensuring that terminally ill people of working age are not pushed into poverty simply for dying too young – through an entitlement to a state pension equivalent level of income;
- Protecting everyone with a terminal illness from high energy costs through targeted support, a social tariff on energy prices, and the government covering the cost of running essential medical devices at home;
- Delivering a cross-government strategy addressing the health inequalities experienced by disadvantaged groups throughout their lives, including at the end of life.

Improve support for families and carers of people with a terminal illness

- Increasing support for carers of people at the end of life through better identification, needs assessment, financial and bereavement support;
- Implementing a cross-government bereavement plan, covering all areas of public policy which affect bereaved people, including bereavement support;
- Extending of statutory bereavement leave and pay entitlement of two weeks to all people with a close relationship to a person who has died.

Areas within the bill which require detailed scrutiny

There are a number of areas within the bill which would have a significant relationship with, or impact upon, the delivery of palliative and end of life care. Parliamentarians should consider further detailed 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 take place. There are concerns that some people who have an assisted death may have lived longer than six-months. The six-month criteria could also create inequalities as it can be more challenging to prognosticate non-cancer conditions.

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 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.

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.

Participation of professionals and services: 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.

Review of availability of palliative and end of life care services: Within the current drafting of the 'Review of this Act' clause, the Bill would require the Secretary of State to review and report on the implementation of the Act 5 years after its assent. Specifically, this must include "an assessment of the availability, quality and distribution of appropriate health services to persons with palliative care needs". However, we would argue it is vital that any such assessment is also made at the point of implementation of the act, so that that its impact on palliative and end of life care services can be fully understood and addressed. 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".

Marie Curie's proposed amendment on improvement of PEoLC

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 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. The reality is that today many people struggle to access the care and support they need at the end of life. Therefore if the Terminally Ill Adults (End of Life) Bill were to proceed, we believe it is vital that it should include a clause aimed at securing urgent improvements to palliative and end of life care.

We believe it is vital that Parliament recognises the perilous state of our palliative and end of life care system, and puts plans to address that crisis on the face of this bill. Marie Curie will continue to work with parliamentarians on all sides of the assisted dying debate to ensure that robust plans are put in place to ensure everybody is able to access high quality palliative care.

Proposed clause re. Improvement of palliative and end of life care

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—
    i. pain and symptom management;
    ii. psychological support for those persons and their families;
    iii. 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.

Limitations of this clause

We recognise that including this clause within the bill will not guarantee improved access to palliative and end of life care, but in requiring government to put in place a strategy for improvement, we believe it can provide a stronger framework for accountability (of both government and local commissioners) in England. Alongside producing a strategy for improvement of palliative and end of life care, the government must use upcoming milestones - including the development of the 10 Year Health Plan and the Spending Review - to deliver the significant policy change and investment required in order to improve end of life care.

In Wales, any legislative measures to improve the provision and delivery of PEoLC is a matter for the Senedd and 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.

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