Marie Curie response to Autumn Budget 2024 Briefing for Parliamentarians

1st November 2024

Summary

- Marie Curie welcomes the significant funding made available for the NHS at the Autumn Budget, but we are disappointed by the omission of any specific measures to support palliative and end of life care;
- The government must ensure that adequate funding reaches palliative and end of life care services, through both changes to commissioning and an investment in innovative models of care which will enable charities like Marie Curie to help build an NHS fit for the future;
- 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. With around a third of NHS costs accrued in the last year of life, the design and delivery of end of life care has huge implications for public spending;
- If the government is to realise its ambition to shift more healthcare out of hospitals and into the community, then it will need to invest in innovative new models of end of life care that reduce wider pressures on the health and care system;
- Without urgent action, more people will die without the care and support they need. We already estimate that 1 in 4 people are dying without the care and support they need at the end of their lives.
- We desperately need the government to develop a plan to fix end of life care, and a fairer funding solution that ensures equitable access to palliative care and reduces providers' reliance on charitable donations;
- Rises in employer National Insurance contributions are going to put considerable additional cost pressures on not-for-profit organisations like Marie Curie, which will lead to services being put under further pressure.
- We are calling on the Government to use the upcoming 10 Year Health Plan and the Spending Review to develop a strategy for the future of palliative care and to support it with sustainable funding.

The current problems in palliative and end of life care

There is currently significant unmet need for palliative and end of life care. This is due to both a postcode lottery for accessing services and inequalities in the end of life experiences for some marginalised communities. **Marie Curie estimates that 1 in 4 people currently don't get the end of life care and support they need. That's 150,000 people every year.**

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Recent research published by Marie Curie[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:

- **Too many people are dying in pain and without the support they need for their symptoms:** During the last week of life, one in three dying people were severely or overwhelmingly affected by pain, and 38% felt depressed most or all of the time.
- **Gaps in 24/7 community care are preventing people from dying in comfort at home**: Almost half of the people surveyed (49%) said their loved one visited A&E at least once in the final three months of life.
- **Patients and unpaid carers are suffering due to poor communication and coordination of care**: Half of respondents were unhappy with at least one aspect of the care received, and of those, one in eight made a formal complaint.
- **Current workforce capacity is insufficient to meet demand for end of life care**: Respondents said that staff in all settings did not have enough time to care for dying people, and one in five dying people had no contact with their GP in the last week of life.
- **Unpaid carers are taking on significant caregiving roles with little support which is having lasting psychological repercussions into bereavement:** 16% of bereaved people met the criteria for 'disturbed grief', but 79% of those people received no support from bereavement services

The Health & Care Act 2022 introduced a new legal responsibility for Integrated Care Boards to commission palliative care services that meet the needs of their local populations, but this has yet to result in greater prioritisation and funding of these services. Only 73% of Integrated Care Systems have a strategy which covers palliative and end of life care, the majority feel that local services do not fully or significantly meet local population needs, and half have not made or do not plan to make significant capital investment in PEoLC[2]. Targeted funding and clearer direction from central Government is needed in order to ensure that ICBs are properly funding and prioritising palliative care.

Additional pressure on charities like Marie Curie

National Insurance Contributions

We are disappointed that the Government is not providing support for charities on the increased employer National Insurance contributions. We are already dependent on donations from the public and this additional cost pressure may have a detrimental impact on the amount of care we are able to provide. We will now need to ask for more funding from our NHS commissioners or rely further on kind donations from the public to continue to provide our services.

Government have a history of not properly considering non-NHS providers of NHS services when planning funding to cover cost rises. We need to see non-NHS providers of NHS services fully funded especially given these national insurance increases.

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[1] Better End of Life Report 2024

[2] Palliative and end of life care in Integrated Care Systems, 'Survey Report: Exploring how Integrated Care Systems are responding to the Health and Care Act 2022'

NHS Pay Award
The announcement of a 5.5% NHS Pay Award for 2024/5 has already generated additional cost pressures for non-NHS providers of NHS services, such as Marie Curie, who have aligned terms and conditions for clinical and clinical support roles to the NHS Agenda for Change pay scales.

Last year we recouped only a small proportion of the costs of the 5% consolidated pay award for 2023-24 from health commissioners across England. And whilst we were extremely grateful for support the previous Government provided to cover the cost of nonconsolidated payments made – for most of the year we were left in doubt as to whether we would be able to recoup any additional support for these payments at all.

The Government must ensure that the NHS pay award is fully funded across the whole of the health sector and not just provider trusts. Given the focus on 'one workforce' non-NHS organisations delivering services on behalf of the NHS that have aligned clinical and clinical support roles to the core NHS Agenda for Change terms and conditions need to be factored into any funding model. This is particularly important for palliative care services where a high proportion of services are delivered by non-NHS providers on behalf of the NHS.

How the Government can address problems in palliative and end of life care

We welcome the Government's ambition of shifting "more healthcare out of hospitals and into the community, to ensure patients and their families receive personalised care in the most appropriate setting". However without significant investment this will not be achievable in palliative and end of life care. The Government must use the upcoming 10 Year Health Plan and the Spending Review to develop a strategy for the future of palliative care and to support it with sustainable funding. By investing in innovative models of end of life care we can improve patients' experience at the end of life and reduce wider pressures on the health and care system.

Best Practice Model: The Integrated Mersey Palliative Care Team

The **Integrated Mersey Palliative Care Team (IMPaCT)** was established in 2020 to ensure seamless provision of end of life care for adults in the Liverpool area. Before the IMPaCT model was introduced, local palliative and end of life care services were fragmented and difficult for patients and carers to navigate. This was resulting in more hospital admissions in the last days of life, fewer people dying at home and a smaller proportion of people on the GP palliative and end of life supportive care register than the national averages.

IMPaCT started by creating two specialised palliative and end of life care hubs. These hubs provide a proactive, streamlined, coordinated service which has achieved: **44% reduction** in unplanned hospital admissions in the last 90 days of life; **12% reduction** in proportion of deaths in hospital; and **38% increase** in proportion of people on supportive care register.

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Poverty at the end of life

People with a terminal illness should be able to spend the last months and years of life focusing on what really matters – making memories with their families and loved ones, and living as well as they can for as long as they are able.

However, Marie Curie's research shows that currently more than 90,000 people die in poverty each year[3]. And being diagnosed with a terminal illness and reaching the end of life increases a person's risk of falling below the poverty line. We welcome the investment in the Household Support Fund and Discretionary Housing Payments at the Budget, alongside the introduction of new Fair Repayment Rate within Universal Credit, but further changes are needed to our welfare system to ensure everyone is financially secure at the end of their lives.

Suggested questions

- Too many people with a terminal illness are currently dying without the care and support they and their unpaid carers need. What plans does the Government have to ensure that funding for palliative and end of life care is placed on a more sustainable footing?
- The increase to employers contributions to National Insurance will add further cost pressures for charities like Marie Curie providing vital end of life care on behalf of the NHS, alongside the existing additional cost of matching the 5.5% NHS pay award for clinical and clinical support staff. What support does the government intend to provide to charitable providers of NHS services to help meet these additional costs?
- 84% of Marie Curie's caring staff have cared for patients who are struggling with the cost of living, and each year 90,000 of people die in poverty. What support does this budget provide for people living with a terminal illness who are struggling to make ends meet?

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

[3] https://www.mariecurie.org.uk/blog/90000-people-die-poverty/346076

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