# Fixing Palliative and End of Life Care
# Marie Curie Policy Briefing

## Summary

- Palliative and end of life care is currently in crisis. Approximately 90% of the people who die each year need palliative care, but almost 1 in 3 dying people are currently not getting the care and support they need.
- Far too many people are reaching crisis point at the end of their lives and need to call out ambulances, visit A&E or be admitted to hospital in an emergency because they cannot access support in community settings. Around 56% of healthcare expenditure on people in the final year of life is spent on emergency hospital care, and 14% of all emergency hospital admissions in England involve people in the last year of life.
- The UK government is currently developing a Palliative Care and End of Life Care Modern Service Framework. This represents a once-in-a-generation opportunity to fix end of life care and ensure that all dying people get the care and support they need.
- To achieve this, the Modern Service Framework must address the lack of support available outside of normal working hours; it must embed palliative care in the government's envisioned neighbourhood health service; and it must create a palliative care workforce that is fit for the future.
- But the Modern Service Framework will also need to be accompanied by appropriate resourcing and robust accountability mechanisms to ensure that health systems are meeting the framework's ambitions.
- The UK government's new Neighbourhood Health Framework sets out an ambitious intention to deliver a 10% reduction in non-elective admissions and bed days of one day or over for people in the end of the life cohort, which would deliver a potential annual saving of between £775million and £790million each year. But without upfront investment to catalyse the shift from hospital to community for patients at the end of life, it is not realistic to expect that current patterns of care and public expenditure on this cohort can be significantly reshaped.
- The Modern Service Framework should therefore be accompanied by a three-year palliative and end of life care transformation fund, making at least £200million per year available to invest in services with proven effectiveness in reducing the need for acute care for patients at the end of life, and to kick-start the government's intended shift from hospital to community care for this group.

## What are current experiences of care at the end of life?

Whether or not people of all ages can die with dignity – able to access the care and support they need, financially secure and able to meet their material needs, and in the place of their own choosing – is a significant marker of a civilised society. But a range of recent evidence suggests that for far too many people today, their experiences of the end of life are marked not by dignity, but by avoidable pain, poverty, and significant uncertainty around where to turn for the care and support they need.

**A landmark 2026 study on defining and estimating unmet palliative care needs in the UK** shows that nearly one in three people in England die with unmet need for palliative care[1]. That means dying with both significant levels of unaddressed symptoms and concerns and inadequate access to sufficient care from GP services. That represents around 170,000 people in England each year – or nearly one every three minutes. And we know that there are profound inequities in access to palliative and end of life care, with people from different groups and with different diagnoses having widely differing experiences.

Research published as part of the **Better End of Life research programme** [2] has demonstrated 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 undertaken in over a decade (across England and Wales) of people affected by dying, death and bereavement found that one in three dying people were severely or overwhelmingly affected by pain in the last week of life. Gaps in 24/7 community care are preventing people from dying in comfort at home, patients and unpaid carers are suffering due to poor communication and coordination, current workforce capacity is insufficient to meet demand for end of life care, and unpaid carers are taking on significant caregiving roles with little support.

Research on **Public attitudes to death, dying and bereavement in the UK[3]** highlighted that most people want to receive care at the end of their life and die in the community rather than in hospital, but 24/7 palliative and end of life support in community settings is often inadequate. This research also found that there is a worrying lack of discussion about people's preferences for the end of their life or confidence that their preferences will be respected: 86% of people haven't discussed end of life wishes with anyone; 93% of people haven't discussed end of life wishes with healthcare providers; and 38% of people think expressing end of life wishes wouldn't make a difference to the care they receive.

The **Health and 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 not yet resulted in a greater strategic prioritisation or funding of palliative and end of life care services[4].

## Unmet needs, rising fast

As our population ages more people will be living with, and dying from, multiple and complex conditions. Over the next 25 years, the number of people with palliative care needs in the UK is projected to increase by more than 147,000 (a 25% increase). With current levels of unmet need for palliative care, it is estimated 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.

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[1] Marie Curie, 'Measuring unmet need for palliative care' (February 2026); Accessed at www.mariecurie.org.uk/document/unmet-need-in-uk-report-2026

[2] 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

[3] Marie Curie, 'Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey' (October 2024). Available at: www.mariecurie.org.uk/public-attitudes-todeath-and-dying-report-2023

[4] 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; available here

Yet 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 and respected. 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 are significant gaps in end of life care in all parts of the UK today – gaps which are both geographical and which reflect inequities in access to services for people living in poverty, people from ethnically minoritised groups, and a number of other groups.

With a significant proportion of NHS costs accrued in the last year of life, the design and delivery of end of life care has huge implications for healthcare capacity and reform. 14% of all emergency hospital admissions, and 30% of all days spent in hospital following an emergency admission, involve people in their last year of life[5]. Hospital is the most common place of death in England, with almost 43% of deaths occurring there[6].

Emergency admissions to hospital and emergency department attendance increases in the final months of life[7] and frequent hospital admissions are generally indicative of poor care planning and poor quality of end of life care[8]. As our population ages and a greater number of people die each year, this will place our health and care system under ever greater pressure, but there is currently no realistic plan in place to transform healthcare for those approaching the end of life, or address the significant gaps in palliative care that exist today.

## Palliative Care and End of Life Care Modern Service Framework

Marie Curie has welcomed the Department for Health and Social Care's commitment to developing a Palliative Care and End of Life Care Modern Service Framework for England, with a planned publication date of Autumn 2026 and implementation from 2027. We have long campaigned for a national strategy for Palliative and End of Life Care, and this will be the first such national plan since 2008.

This framework represents a once-in-a-generation opportunity to fix end of life care and ensure that dying people get the care and support they need. To achieve this, the new Modern Service Framework must address the lack of support available outside of normal working hours; it must embed palliative care in the government's envisioned neighbourhood health service; and it must create a palliative care workforce that is fit for the future. Below are Marie Curie's detailed recommendations for how these 3 key objectives must be realised:

### 1. *Addressing the lack of support available outside of normal working hours*

Terminal illness does not respect the clock. The health of a person living at home with an advanced illness can deteriorate suddenly at any time – day or night, during the week or at the weekend. These are anxious moments for the person with a terminal illness and for family or friends who are caring for them. Pain and other symptoms may suddenly worsen, and fears about dying without dignity or the company of loved ones may surface.

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[5] Department for Health and Social Care, Palliative and end of life care factsheet: Patterns of care, England 2024

[6] Office for Health Improvement & Disparities Palliative and end of life care profiles January 2025 update: statistical commentary https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-january-2025-update/palliative-and-end-of-life-care-profiles-january-2025-update-statistical-commentary

[7] Office for Health Improvement and Disparities, Palliative and end of life care factsheet: patterns of care, England 2022. Available at: fingertips.phe.org.uk/documents/peolc_ patterns_of_care_factsheet_2022.html

[8] Nuffield Trust; 'End of life care: We look at trends in the quality of end of life care'; accessed 20.01.25 at: nuffieldtrust.org.uk/resource/end-of-life-care

Patients and their carers in this situation need to be able to urgently access palliative and end of life care (PEoLC), including medicines, equipment and other forms of personalised care and support. However, if this deterioration occurs outside of 'normal' working hours (Monday to Friday, 9am-5pm), accessing care in or near to their own home may be neither quick nor easy – especially if they have not already been registered or referred for palliative care, or if they live in a rural or deprived area.

24/7 access to care and support for people with terminal illnesses in the UK has been consistently recommended as a minimum requirement for nearly two decades. NICE Guidelines [NG142] & [NG61] say that people approaching the end of their life, their carers and other people important to them should have access to: a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care; an out-of-hours end of life care advice line; an out-of-hours pharmacy service that has access to medicines for symptom management in people approaching the end of their life.

Despite this longstanding guidance, research conducted by Marie Curie in 2025 found that only 7 of the 42 ICBs in England said they have a dedicated 24/7 single point of access to PEoLC advice, guidance and onward referral, when needed, to other services. In many cases, even where services exist access is not universal, with help in some places only available to professionals rather than patients and carers themselves, or advice is available only to patients already known to palliative care services[9].

In order to address these significant gaps in 24/7 support, the Palliative Care and End of Life Care Modern Service Framework should incorporate measures to:

- **Create a universal gateway to 24/7 PEoLC advice, guidance and support by dialling 111 and selecting the PEoLC option**. Every part of the country should have a 24/7 single point of contact PEoLC telephone advice line, staffed by professionals with specialist palliative care expertise who can provide advice, guidance and support to access local services, available to all people with a terminal illness, their carers and health and care professionals, and sustainably funded by ICBs. People with a terminal illness and their close carers should be able to access the PEoLC phone line via 111 to ensure equitable access for everyone, instead of it only being accessible to people already known to specialist palliative care services. This model has already been successfully tried and tested in Cambridge and Peterborough, where it significantly improved access to palliative care for people from the most deprived parts of the area.

- **Improve access to medicines in the community for people at the end of life by removing regulatory, prescribing and digital barriers.** More community pharmacies should be commissioned to stock palliative medicines during the out-of-hours period, more professionals should be trained to prescribe and administer them in local communities, and digital technology should be used to make all this happen quickly and easily for people with a terminal illness.

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[9] Marie Curie; "The night times are frightening": gaps in 24/7 community care for people at the end of life; May 2025; Accessed at: www.mariecurie.org.uk/document/gaps-in-247-community-care-report

- **Every ICS in England should have a 2-hour urgent community response service operating 24/7 for people with palliative and end of life care needs.** Urgent Community Response services – rolled out across all areas since 2022 – are seeing consistently high levels of referrals due to patients having end of life care needs. But these services are also not routinely available on a 24/7 basis. In order to reduce avoidable use of ambulances, A&E visits and emergency hospital admissions, all areas should have a 24/7 2-hour urgent community response service available to patients with end of life care needs.

### 2. *Embedding palliative care in neighbourhood health*

The 10 Year Health Plan for England sets out an ambition to shift care from hospital to communities. In no part of the health system is this a more pressing challenge than in end of life care.

Hospital remains the most common place of death in England, with more than two in five people dying there – and 41% of that group dying alone. As a result, of the £11.7 billion spent each year on healthcare support for people in the final year of life across the UK, an incredible £8.6 billion is spent in hospitals. Yet there is strong evidence that with the right support in place in community settings, more people can be helped to stay out of hospital and die in their own homes instead of calling an ambulance, visiting A&E and having unplanned hospital admissions. A death in hospital is rarely the best place for the patient (or the NHS staff team) and is far more expensive than supporting a death at home or in a care home.

The UK Government's recently published Neighbourhood Health Framework identified patients receiving end of life care as a high priority cohort for integrated neighbourhood teams to initially focus on, and also set out that better identification of people coming to the end of life and improved access to services so people can die in a place of their choosing would be key objectives for the neighbourhood health programme between now and 2029. However, further measures will be needed within the Modern Service Framework to ensure that these ambitious goals can be realised:

- **Ensure palliative care is at the centre of plans for Neighbourhood Health Centres and virtual wards**, by ensuring palliative care specialists are part of multi-disciplinary teams in neighbourhoods and virtual wards, and that both models draw on innovative emerging new approaches to integrated PEoLC in community settings.

- **Ensure early identification of palliative care needs in in all health and care settings.** In light of the recent removal of the quality indicator for GPs to establish and maintain a register of all patients in need of palliative care within the GP Contract for 2025/26, alternative measures are urgently required to improve early identification of people with palliative care needs and ensure that each is supported to access appropriate community services. Early identification of palliative care needs in hospitals is also important for improving quality of life for people with limited time left and ensuring they avoid unnecessary treatments and have the right support for their pain and other symptoms. Identifying palliative care needs early in both GP and hospital settings could help address unequal access to these services as all communities access healthcare in these settings.

- **Scale up proven models of care which can deliver the shift from hospital to community for patients at the end of life.** For instance, embedding palliative care specialists in hospital emergency departments, to enable proactive identification, assessment and treatment of patients at the end of life, and where appropriate enable their discharge from hospital to a preferred place of care.

- **Guarantee quality advance care plans and active use of these through universal shared care records**. This requires improved training and funding for all health and care professionals in advance communication skills and advance care planning and ensuring that plans are regularly reviewed, updated and can be shared digitally for use by all professionals involved in a person's care.

### 3. *Ensuring that the palliative care workforce is fit for the future*

Palliative and end of life care will not improve on its own. It needs both generalist and specialist workforces with the right skills to improve care in the right ways. Every health and care professional is likely to care for people at the end of life at some point in their career. Palliative and end of life care is not currently a compulsory part of either initial training or continuing professional development for most health and care professionals, leaving many feeling ill-equipped to support people at the end of life in planning, providing and coordinating care.

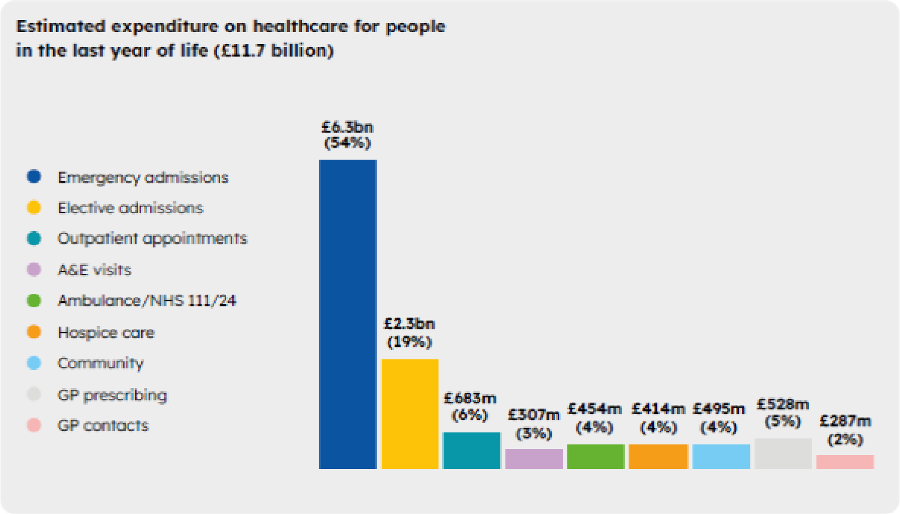
- **Plan and resource a workforce that can respond to increased future need for PEoLC,** especially in community settings. Workforce planning must focus on investment in the GP, district and community nursing and specialist palliative care workforce that is needed to achieve the shift from hospitals to community. Plans must ensure parity of esteem between the NHS and charitable hospice workforce in pay and conditions, alongside full alignment of skills training and professional development to enable 'one workforce'.

- **Make PEoLC a compulsory part of training for all health and care professionals, including those in emergency medical services.** Every health and care professional is likely to be involved in caring for people at the end of life at some point in their career. PEoLC is not a compulsory part of either initial training or continuing professional development for most professionals, leaving many feeling ill-equipped to support people at the end of life in planning, providing and coordinating care. Training would enable people receiving PEoLC to be better supported at home, avoiding unnecessary A&E visits or hospital admissions.

## Enabling delivery of the Modern Service Framework through a transformation fund

To ensure that the Modern Service Framework is effective and drives long-term improvements in access, quality and sustainability of palliative and end of life care across England, it must be properly resourced. To enable effective delivery of the framework, as well as to help achieve the shift from hospital to community envisaged in the 10 Year Health Plan for patients at the end of life and accelerate achievement of integrated neighbourhood working for this population cohort, **the UK government should establish a three-year palliative and end of life care transformation fund, making at least £200million per year available over this period.**

Analysis undertaken by The Nuffield Trust and Health Economics Unit on **Public expenditure in the last year of life**[10] highlights significant public expenditure (£22 billion in 2022) on people in their final year of life across the UK, equating to £33,960 per person. Over half of this total expenditure (almost £12 billion) was on healthcare, but the analysis makes clear that current health spending is disproportionately distributed towards hospital care rather than well-anticipated, coordinated and holistic care in the community. Of public funds spent on healthcare for people in their last year of life, 81% was spent in hospital, and 56% was spent on emergency hospital care. Only 11% of healthcare expenditure for people in their last year was spent on primary and community care.



**Source:** Nuffield Trust, Health Economics Unit and Marie Curie, 'Public expenditure in the last year of life', 2025

This research demonstrates that we spend five times as much on supporting people in the final year of life as hospital inpatients, as we do through supporting them with primary care, community health care and hospice care[11] combined. Unsurprisingly given the low levels of investment in community care for people at the end of life, emergency admissions to hospital and Emergency Department use increases in the final months of life[12], with frequent hospital admissions being indicative of poor care planning and poor quality end of life care[13].

Ambitious targets have been set in the Department of Health and Social Care's new Neighbourhood Health Framework to reduce non-elective admissions and bed days of one day or over for people in the end of the life cohort by 10%. With 9.8 million bed days annually spent in hospital by patients in the last year of life following an emergency admission[14], and each bed day costing between £791 (non-elective long stay) and £806 (non-elective short stay)[15], realising this target has the potential to save between £775million and £790million each year for our healthcare system. But without upfront investment to catalyse the shift from hospital to community for patients at the end of life, it is not realistic to expect that current patterns of care and public expenditure on this cohort can be significantly reshaped.

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[10] The Nuffield Trust and Health Economics Unit, 'Public Expenditure in the last year of life' (February 2025), available at https://www.nuffieldtrust.org.uk/research/public-expenditure-in-the-last-year-of-life

[11] excluding NHS hospice services.

[12] Office for Health Improvement and Disparities; Palliative and end of life care factsheet: Patterns of care, England 2022 https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-factsheet-patterns-of-care-england-2022

[13] Nuffield Trust; 'End of life care: We look at trends in the quality of end of life care'; accessed 20.01.25

[14] Table 4: Emergency admissions and time spent in hospital following emergency admission by age, England for the 12 months August 2023 to July 2024; Palliative and end of life care factsheet: Patterns of care, England 2024 https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html#emergency-hospital-admissions

[15] https://questions-statements.parliament.uk/written-questions/detail/2025-12-15/100046

A three-year palliative and end of life care transformation fund would enable investment in cost-effective, innovative and integrated models of care that meet population need and prevent further escalation of pressures on acute services arising from poorly co-ordinated palliative and end of life care. There are existing models of care which are delivering these improved outcomes for patients and better value for money[16], but these models need investment to be scaled and replicated system-wide. In the longer term the costs of delivery of services with proven effectiveness at reducing reliance on hospital care should be paid for by a transfer of resources from the acute sector. A palliative and end of life care transformation fund will be a highly effective and capital-efficient vehicle for catalysing this reshaping of current patterns of public expenditure on people at the end of life.

## How much funding would be required?

The Neighbourhood Health Framework sets out an intention to deliver a 10% reduction in non-elective admissions and bed days of one day or over for people in the end of the life cohort. This would deliver a potential annual saving of between £775million and £790million each year. A time-limited investment of £200million per annum, for three years, would represent just over a quarter of the potential savings which could be realised if care of this cohort was shifted from hospital to community settings.

## Delivering sustainability through a social investment approach

Social investment is the use of repayable finance to help an organisation achieve a social purpose. The investment is only repaid if mutually agreed outcomes are achieved.

A reduction in non-elective admissions and bed days at the end of life would deliver savings to the acute sector as a result of demand reduction. Using a social investment model, the transformation fund could be invested upfront to establish services intended to deliver these outcomes, but on successful delivery, outcome payments would be made to the service provider from the acute sector. These outcome payments would then enable the ongoing sustainability of the service. An example of how this might work in practice is as follows:

Payment is made from the transformation fund to establish a community service intended to deliver reductions in end of life hospital care

The community service provider contracts with acute sector for payment on the basis of delivering reductions in acute service demand

Community service provider delivers intended outcomes

Acute sector releases outcome payments as contracted, which are reinvested in the community service - enabling its longer term sustainability beyond the lifetime of the transformation fund.

By contracting for outcomes, a social investment model could be used to ensure sustainable impact from a palliative and end of life care transformation fund beyond its three year lifetime. This approach would also have the benefit that whilst it would gradually shift the costs of delivering community services with proven effectiveness in reducing the need for hospital care to the acute sector, it would only do so on the basis of acute sector demand reductions having already been realised.

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[16] Making the case for investment in palliative and end of life care: A guide for Integrated Care Boards https://www.mariecurie.org.uk/globalassets/media/documents/for-professionals/mc-icb-investment-guide-toolkit.pdf

***To resource the Palliative Care and End of Life Care Modern Service Framework, the UK government must:***

- **Create a Transformation Fund for Palliative and End of Life Care to enable investment in innovative and integrated models of PEoLC which enable a shift from hospital to community based care.** This Fund should provide £200 million p/a funding over a three-year time frame from the Department of Health and Social Care to Integrated Care Boards in return for a viable plan from each ICB for local improvements to access, quality and sustainability of PEoLC. This would incentivise ICBs to adopt and scale new models of care with proven and positive impacts on patient care and cost-effectiveness. There is a precedent for such a fund in the Macmillan-funded Social Finance End of Life Care fund which has operated for more than a decade and delivered significant improvements in patient care, reductions in the number of hospital bed days occupied by people at the end of life, and contributed to vital improvements in access for underserved communities.

- **Consider delivering this fund at least in part through a social investment approach**, with outcomes contracted to the acute sector. This would: (1) ensure a clear outcome focus is maintained; (2) embed a mechanism for longer term sustainability of transformative services which are successful through outcome payments made from the acute sector; and (3) by not requiring upfront investment from the acute sector, but instead only requiring payments on the basis of outcomes delivered.

- **Address poor commissioning practice.** The Department for Health and Social Care must ensure that ICBs are commissioning strategically, and that contracts for charitable providers of end of life care cover a greater proportion of the operational costs of delivering these services, to reduce reliance on charitable fundraising and improve financial sustainability. This should include provision for ensuring that charitable providers of PEoLC services are compensated for changes to national policy which directly affect them such as changes to National Insurance contributions for employers, Agenda for Change terms and conditions for NHS staff and the minimum wage. It should also ensure that contracts are commissioned over a medium-term time frame to improve financial sustainability.

## Accountability for delivery

The Palliative Care and End of Life Care Modern Service Framework must include robust targets and accountability mechanisms to ensure that health systems are meeting the framework's ambitions. It must deliver clarity for commissioners and delivery bodies by setting expected care standards. It must also make clear actions that will be taken to hold partners to account if they do not deliver these standards.

***To address variation in quality and gaps in care, as well as to ensure stronger accountability over delivery of palliative and end of life care, the Department for Health and Social Care must:***

- **Improve quality standards for PEoLC services,** by introducing minimum standards which must be met in all localities. These should build on the Ambitions Framework for PEoLC and provide a basis for regular auditing of the accessibility, quality and sustainability of end of life care services.

- **Improve data collection on PEoLC,** as limited data on activity, quality and spending in community PEoLC and hospice services hinders achieving greater equity in provision and service improvement and innovation across the UK. Improved data collection and publication would assist providers, commissioners and policy makers to make more informed and evidence-based decisions about future support for people at the end of life.

## 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