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Marie
Curie

Public expenditure in the last year of life

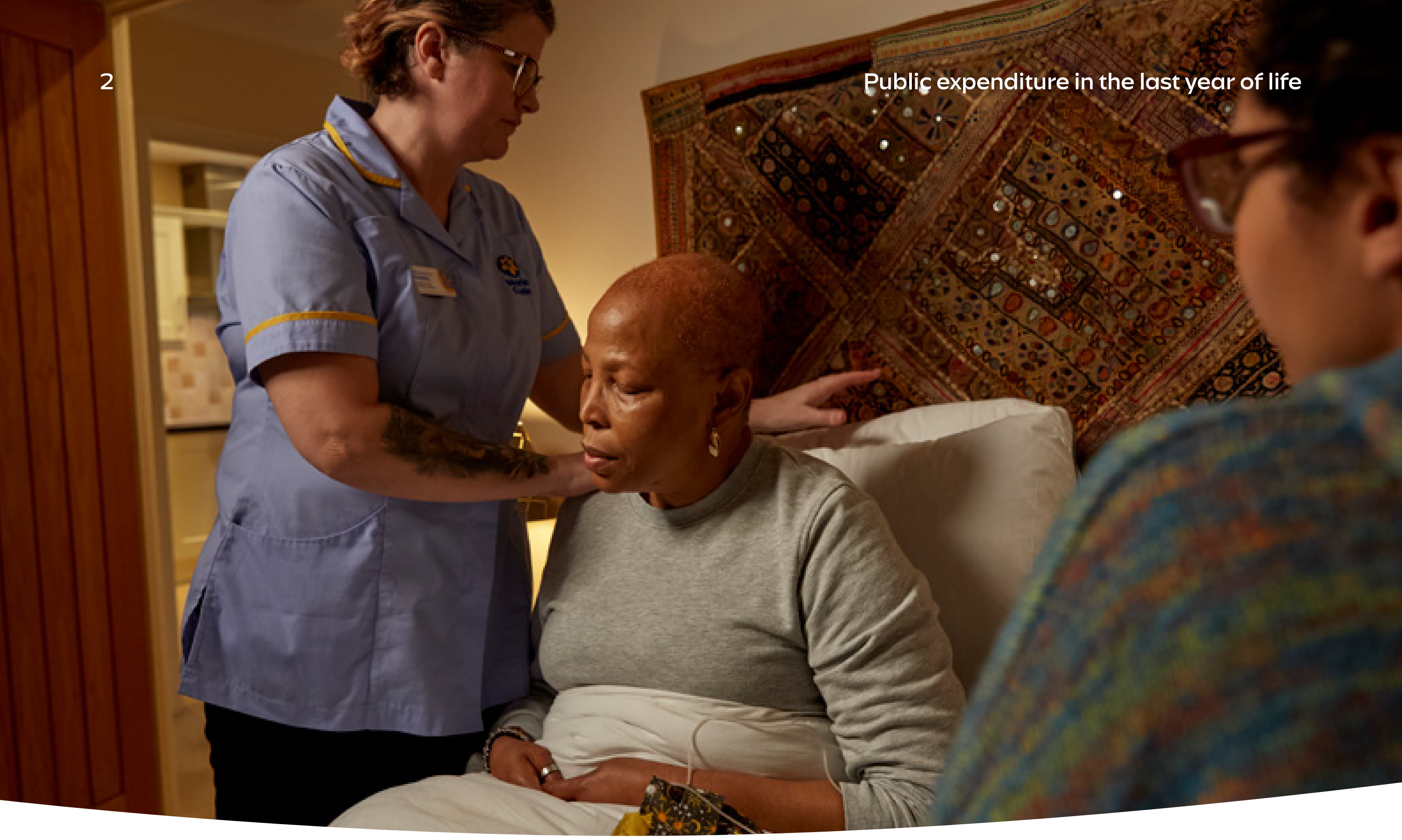
Policy briefing, February 2025

About

- 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;
- Whether or not people of all ages can die with dignity - able to access the care and support they need, financially secure and with material needs met, and in the place of their own choosing - is a key 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 uncertainty around where to turn for the care and support they need;
- More people now die at home, but emergency admissions to hospital and emergency department use increases in the final months of life. 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 public spending;
- This briefing summarises the findings of our latest research into public expenditure in the last year of life. It puts these findings in the context of what we know about access to quality end of life care and sets out recommendations for policy change

Summary of findings

- New research undertaken by The Nuffield Trust and Health Economics Unit on behalf of Marie Curie 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, 22% (almost £5 billion) was on social care, and 25% (£5.5 billion) was on social security;
- Despite these high levels of overall expenditure on people at the end of life, this 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;
- In fact, 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 and hospice care (excluding NHS hospice services);

- There is therefore an urgent need to reimagine the policy response for people in the final year of life across the UK and reshape public expenditure on this group;
- Palliative and end of life care must be a priority for health reform efforts across all four UK nations and policymakers should target a long term shift in expenditure on people in the last year of life from hospital to community;

Context

What are current experiences of 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 published by Marie Curie and others 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.

Recent research published as part of the **Better End of Life research programme**[1] 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.

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[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: **mariecurie.org.uk/policy/better-end-life-report**

The **Dying in Poverty 2024**[2] report found growing levels of poverty at the end of life, with 111,000 people each year now dying in poverty and 128,000 dying in fuel poverty. It demonstrated that working age people are at a much greater risk of dying in poverty: 28% of these people who died in 2023 died in poverty, compared to 16% of pension-age people. And poverty at the end of life affects some groups (like women and minoritised ethnic groups) significantly more than others, alongside huge geographical variances in the proportion of people dying in poverty.

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; 38% of people think expressing end of life wishes wouldn't make a difference to the care they receive.

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). Around one in four people currently do not get the end of life care and support they need.

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 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 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 public spending. More people now die at home than before the COVID-19 pandemic, but in general, emergency admissions to hospital and Emergency Department use increases in the final months of life[4] and frequent hospital admissions are indicative of poor care planning and poor quality of end of life care[5]. 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 the funding context for end of life care is extremely uncertain. Both the NHS and charitable hospices are facing extreme financial pressures, and long term investment in the primary and community care workforce has been insufficient to meet the rising demand[6].

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2. Marie Curie, 'Dying in Poverty 2024: Exploring poverty and fuel poverty at the end of life in the UK', available at: **mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/2024/reports/m1214-dying-in-poverty-report_digital_compressed.pdf**
3. Marie Curie, 'Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey' (October 2024). Available at: **mariecurie.org.uk/document/public-attitudes-to-death-and-dying-bereavement-uk-report-2024**
4. 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**
5. 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**
6. Baird B et al., Making care closer to home a reality. The Kings Fund (2024) Available at: **kingsfund.org.uk/insight-andanalysis/reports/making-care-closer-homereality**

What type of support do people need in the last year of life?

Marie Curie advocates for a holistic approach to looking after people at the end of life, ensuring that all of a person's physical, emotional and practical needs are met. This means that good care and support will be specific to each individual, and may need to be provided by a range of sources and services. Good support for people in the final year of life cannot just be provided by hospices or palliative care specialists; Change will need to provided by generalists in other health settings, through the vital work of unpaid and family carers, and a whole range of public services must be prepared to meet the needs of people approaching the end of life.

Opportunities for change

Significant policy milestones are approaching across the UK which present the opportunity to improve policy for the benefit of people in the final year of life: The UK government will deliver the Spending Review 2025 and a new NHS England 10 Year Health Plan; the Welsh Government is developing a new service specification for palliative and end of life care and reviewing commissioning approaches to ensure that the aspirations of the Quality Statement for Palliative and End of Life Care are met; In Northern Ireland, a new three-year strategic plan for reform of the Health and Social Care System is in development; and in Scotland, the Government is about to publish its new Palliative Care Strategy and its new National Clinical Strategy, with the implementation plans for both still in development.

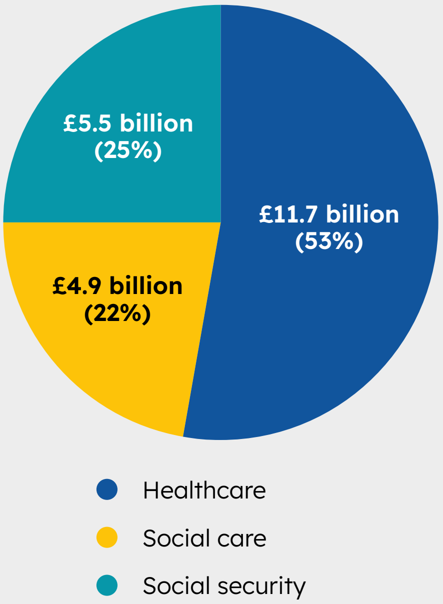
These are all vital opportunities to ensure that everyone has access to the care and support they need at the end of their life, in the right place and at the right time. In this briefing we share findings from new research on public expenditure at the end of life and make a number of policy recommendations which have the potential to both significantly improve people's experiences of the end of life, as well as reducing wider pressures on our health and care systems.

Public expenditure in the final year of life: Research findings

Methodology

This research was undertaken by the Nuffield Trust and Health Economics Unit on behalf of Marie Curie. Findings relate to public expenditure for people aged 18 and over in the last year of life, whether or not they were known to be at the end of life, and includes healthcare, social care,

Overall public expenditure on people aged 18 and over in the last year of life



and social security expenditure. Some of this expenditure - such as the State Pension - would be incurred irrespective of whether someone is in their last year of life, but these are all important contributors to quality of life. The analysis used data from all four UK nations where available, extrapolating from relevant alternative data where necessary. It draws on a range of data sources, though data specific to the last year of life was limited and variable by sector and nation. This briefing focuses on overall estimates for the UK, although nation specific estimates are available for each of the UK four nations in appendices to the research report.

Overall analysis of expenditure

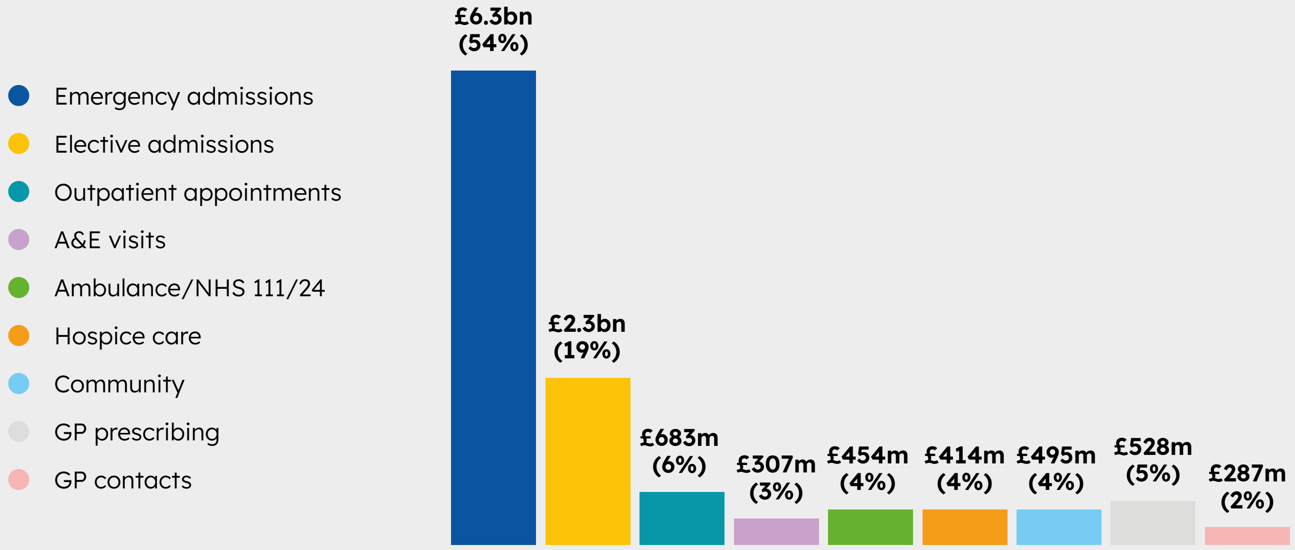
This new research estimates that in 2022 there was at least £22 billion in public expenditure for people in the last year of life in the UK. This amounts to £33,960 of public expenditure per person.

Over half of this expenditure was on healthcare (almost £12 billion), 22% on social care (almost £5 billion) and 25% on social security (£5.5 billion).

Health spending

The research estimates that UK governments spent £11.7 billion providing health care to people in their last year of life in 2022.

Four fifths of health expenditure was spent on hospital care (81%, £9.6 billion), with emergency and elective inpatient admissions alone accounting for 73% (Figure 1). A&E attendances and emergency admissions, account for 3% (£307 million) and 54% (£6.3 billion) respectively, so taken together, over half all health spending is on urgent hospital care. Unplanned out-of-hospital care, including



Estimated expenditure on healthcare for people in the last year of life (£11.7 billion)

ambulance services and NHS 111/24 in Scotland, contributed around 4% (£454 million) to spend in the last year of life.

In stark contrast, only 11% of health care expenditure for people in their last year was spent on community care (£495 million) and primary care through a GP (£815 million). Statutory funding of independent hospices accounted for less than 4% (£414 million)[7].

Social care spending

The research estimates UK authorities and trusts spent almost £5 billion in 2022 providing social care services to people in their last year of life.

Over three quarters (78%) of social care expenditure was spent by local authorities (or health and social care trusts in Northern Ireland). This included residential and nursing care (£3.1 billion, 63% of all social care expenditure), home care, and other services such as provision of equipment and home adaptations.

NHS Continuing Healthcare packages accounted for 22% (£1 billion) of social care expenditure.

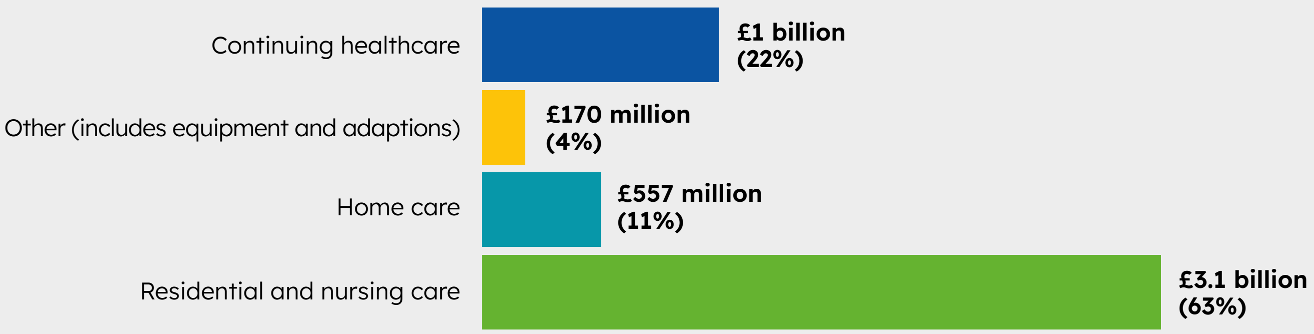
Estimates didn't include costs incurred by individuals and families. For example, a third of residential care in England is estimated to be self funded (Office for National Statistics 2023).

Social security spending

Findings indicate UK authorities spent almost £6 billion in 2022 on social security for people in their last year of life.

The State Pension accounted for 89% (£4.9 billion) of overall public spending on social security and benefits for people in the last year of life, as most deaths occur among people over the State Pension age and as most people receive this, regardless

Estimated total social care expenditure on people aged 18 and over, in their last year of life (£4.9 billion)



[7] 44% of independent hospice costs are funded by the public purse. Total expenditure on independent hospice services (including the 56% of service costs funded by charitable contributions) would still only account for 8% of health care expenditure. NHS hospice services are included in estimates for NHS hospital, community and other healthcare services

of income or being at the end of life. Only 11% of expenditure was on benefits linked to ill health (Personal Independence Payment (PIP) and Attendance Allowance, £430 million, 8%) and means tested benefits (including Universal Credit and Pension Credit, £187 million, 3%).

Although representing the smallest amount of public expenditure on social security, means tested benefits are very important from an equity perspective, as these are received by people with the lowest levels of income.

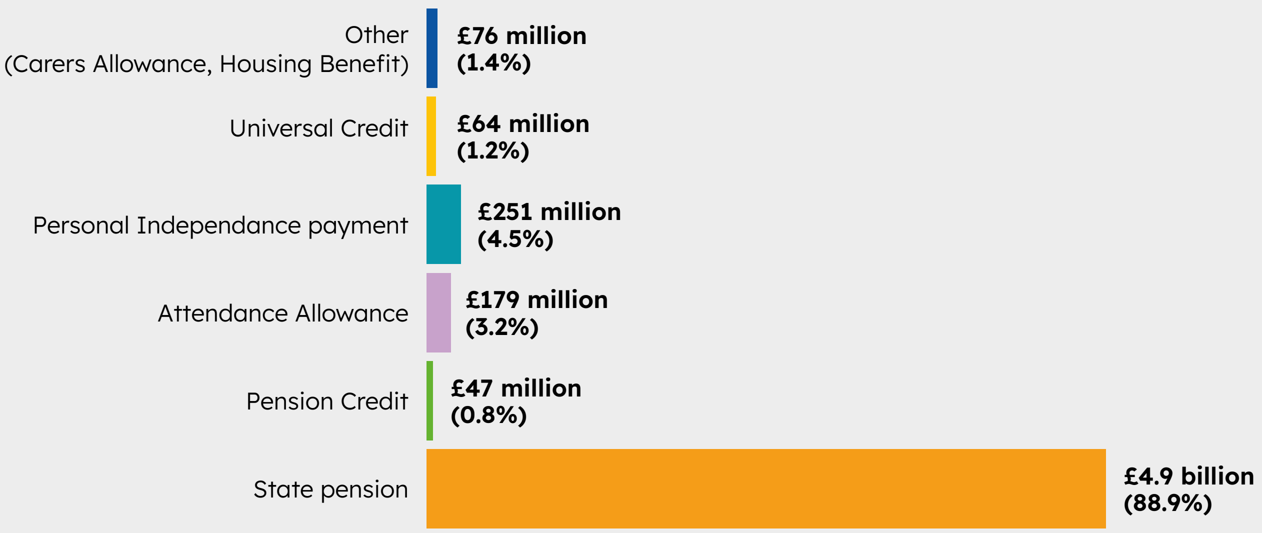
Implications for policy

Despite high levels of overall expenditure on people in the final year of life, this analysis makes clear that current spending is disproportionately distributed towards hospital care rather than well-anticipated, coordinated and holistic care in the community.

Health and social care are areas of devolved policy making in Wales, Scotland and Northern Ireland. But these findings demonstrate that concerted action is required across England and the Devolved Nations to reimagine the policy response for people in the final year of life and reshape public expenditure on this group. Such a change has the potential both to deliver better care and support for those at the end of life, while also reducing wider pressures on our health and care systems.

The UK Government also holds a majority of the powers required to address wider financial needs and support for people in the final year of life, so we make recommendations here which apply to the UK government but which would benefit people across the UK.

Estimated expenditure on social security for people aged 18 and over in the last year of life



Recommendations for policy change

1. Making palliative and end of life care a priority for health reform efforts across all four UK nations (PEoLC)

PEoLC must be featured prominently within the UK Government/NHS England's 10 Year Health Plan

- Develop a national strategy for England for improvement of palliative and end of life care (PEoLC) with targets for improving the availability, quality and distribution of integrated health and care services for everyone with palliative care needs in local populations. This strategy should aim to achieve 24/7 delivery of co-ordinated and quality PEoLC services for everyone through a national service specification that supports Integrated Care Boards (ICBs) to deliver in full on their legal duty to commission palliative care services in the Health & Care Act.
- 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.
- Strengthen the Quality Outcome Framework indicator for placing people on the palliative care register by setting ongoing management targets with points incentives commensurate with those for other major health conditions. This should improve early identification of people with palliative care needs and ensure each is supported to access appropriate community services.
- 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.

For the Welsh Government

- Ensure that the forthcoming service specification for palliative and end of life care sets out clear and measurable actions that will improve the availability, quality and accessibility of palliative and end of life care in all parts of Wales and ensure the aspirations of the Quality Statement are realised.
- Establish a sustainable funding solution to support the whole palliative and end of life care system, which ensures that the diverse needs of terminally ill people are met and the right care is delivered in the right place and at the right time.

For Scottish Government

- Scottish Government should recognise and implement a Right to Palliative Care in its palliative care strategy, to be upheld by the development and implementation of Minimum Service Standards.
- The Strategy Delivery Plans should include measurable indicators to show how palliative care improvement is contributing to wider NHS Scotland Reform, including prevention of avoidable hospital admission and a health and social care workforce with the skills to identify and support people who need palliative care in hospital and in the community.
- Transparent and sustainable resourcing of palliative care is needed within the NHS, in social care and among independent specialist providers.

For the Northern Ireland Executive:

- Establish a long term sustainable regional funding model for the independent hospice sector. This must meet current pressures, as well as future projected population need with the strategic policy direction to support that.
- A new palliative and end life care strategy for Northern Ireland is required to deliver up to date strategic direction and support to ensure hospice services and other palliative care providers can provide the care people need. This needs to include a fully funded action plan which takes account of workforce planning and with timelines and accountability for delivery.
- Introduce a dedicated palliative care strategic policy lead role that sits in the Department of Health to give necessary oversight and ensure issues for palliative care are considered in all relevant policy planning and decision making.

Improving data collection on public expenditure in the final year of life

- 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;
- Equally, relevant health and social security datasets aren't routinely linked to mortality registers, inhibiting understanding of health services use and benefits receipt by people in the final year of life;
- 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;
- **Across the UK nations, improving data collection on public expenditure in the final year of life must be a priority, encompassing:**
  - More standardised data collation for services and benefits relevant for people in the final year of life;
  - Support in data analysis;
  - Investment in data infrastructure including data harmonisation across the four nations;
  - Skills to support data collection and sharing;
  - Guidance on how data should be better used to inform service specifications.

2. Targeting a long term shift in expenditure at the end of life from hospital to community

- There must be a clear long term ambition for all UK governments to shift health expenditure on people at the end of life from hospital to community settings, supported by appropriate targets.
- For example, a long term target to reduce hospital expenditure by 20% (£1.9billion) and a corresponding increase in expenditure on community based (community/GP/hospice) health services over a 10 year period would represent a doubling of current expenditure on community services, and should be supported by an accompanying long term target to reduce hospital bed day use by patients in the final year of life.

3. Investing in innovative and integrated models which can deliver the shift to community based care

- In order to enable a long term shift in expenditure, a short term investment is required in innovative and integrated models of palliative and end of life care. These models have the potential to enable the shift from hospital to community PEoLC provision, reduce the significant inequities in access, and support service innovation to improve quality and cost effectiveness. Existing models of best practice delivered in some areas will need to be scaled and replicated.
- A three year transformation fund for NHS England should be delivered as part of Spending Review 2025 and distributed via local commissioning bodies to enable primary care and non-NHS providers to play their part in an integrated 'whole system' approach to meeting population need for palliative care.

Best practice model: Reactive Emergency Assessment and Community Team (REACT) Service

Marie Curie's REACT is an innovative, integrated service model for improved palliative and end of life care in the Bradford area.

The service was launched in June 2022 with social impact bond funding, as a collaboration between Bradford Teaching Hospitals Foundation Trust (BTHFT), Social Finance, and Marie Curie, and also supported by Macmillan Cancer Support, Better Society Capital and Commissioning Better Outcomes. It has been developed in recognition of the local challenges from unwarranted clinical variation, deprivation, health inequalities and system pressures. REACT has two, interlinking arms:

- Emergency Department (ED) REACT: a consultant led in-reach model in which patients with palliative care needs presenting to the ED are proactively identified, assessed, treated, and offered an alternative to hospital admission through a supported transition into Community REACT.
- Community REACT: a multidisciplinary urgent community response service and virtual ward for patients in crises in their last year of life, delivering holistic care and support for up to 72 hours before facilitating transfer of care to appropriate community services.

Between June 2022 and May 2024, REACT received 984 referrals, of which 35% were not previously known to palliative services. 70% of people supported by REACT had non-cancer diagnoses and 38% were from the most deprived areas.

For people in their last year of life referred to ED REACT, mean bed days reduced from 38 to 20 for those admitted to hospital, and to 15 for those admitted to Community REACT. Interim evaluation indicates the model's financial sustainability, with a 2:1 return on investment. Patient and staff experiences have been overwhelmingly positive.

4. Securing and building an end of life care workforce for the future

- 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 general practice, district and community nursing, specialist palliative care, and the social care workforce that is needed to achieve the shift from hospitals to community. Plans across UK nations must ensure parity of esteem between the NHS and charitable hospice workforce in pay and conditions and 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.
- Addressing funding and commissioning challenges which undermine coordinated delivery. A new funding framework for PEoLC must recognise ‘one workforce’ and enable non-NHS providers to meet the obligations of Agenda for Change as well as higher national insurance costs.

5. Addressing wider financial needs and support for people living with terminal illness

- The UK government should lead development of a joint action plan to end poverty and fuel poverty at the end of life across the UK, working alongside devolved and local governments. This should be taken forward alongside the wider policy changes set out in Marie Curie’s Dying in Poverty report, and include measures to improve the identification, recording and sharing of information about people living with terminal conditions, both in the last 12 months of life and with longer prognoses.
- The UK government should guarantee a State Pension level of income for working age people with a terminal illness. To provide financial security at the end of life, working age people living with a terminal condition with less than a year to live should be guaranteed to receive at least a State Pension level income.
- The UK government should introduce a social tariff for energy that people with a terminal diagnosis can access, to address fuel poverty amongst people at the end of life. That tariff should provide at least a 50% reduction on bills, and be available to people living with a terminal illness to help them meet the extra costs of terminal illness at a time when their income is likely to have fallen.
- All UK governments should increase support for carers of people at the end of life through better identification, needs assessment, financial and bereavement support.

For more information please contact

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