Shaping support for people at the end of life: A guide for local government

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.

However, we know we can't deliver change alone. As a local elected representative, you have a vital role to play in ensuring that people living with a terminal illness in your local area receive the best possible care and support.

What is palliative and end of life care (PEoLC)?

Palliative care offers physical, emotional and practical support to people living with a terminal illness. It can be offered at any point after a terminal diagnosis. Palliative care, sometimes called 'supportive care', aims to make sure people feel supported and comfortable while living with terminal illness. This will usually focus on:

- managing symptoms
- offering emotional, spiritual and psychological support
- offering practical support, including planning for the future or helping provide equipment
- giving people a good quality of life.

End of life care refers to palliative care which is provided in the final year of somebody's life. It aims to help people live as comfortably as possible in the time they have left, which can include physical symptom management, emotional support and talking about their final wishes.

How is PEoLC funded and delivered?

Palliative care and end of life care can be delivered by hospices and end of life care specialists, but it's also delivered as part of general health and care services like in GP surgeries, hospitals and through district nursing. To meet a growing need for palliative care as our population ages and more people are living with complex conditions, we need a whole-system approach to palliative care. This is to ensure that people approaching the end of life receive the right care, at the right time, in the right place.

But there's currently a lack of sufficient and sustainable funding for palliative and end of life care. The NHS and charitable hospices face significant funding challenges. In **2023/24**, the NHS only provided funding for 39% of the cost of Marie Curie's hospices and 48% of the cost of Marie Curie's nursing services, on average. The remainder of the costs are met by Marie Curie's fundraised income, which is not a sustainable way to fund such an essential part of our health and care system.

We also need to consider how we can ensure that public expenditure on people approaching the end of life is delivering the best possible care. In a **recent analysis** of public expenditure in the final year of life, we found that in 2022, £22 billion was spent on caring for and supporting people in their final year of life across the UK, equating to £33,960 per terminally ill 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 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, 56% was spent on emergency hospital care, but only 11% on primary and community care.

The role of local government

Councils have a critical role to play in helping people to die well. Many of the core services that local authorities provide, such as social care, are important components of a high-quality approach to end of life care. Furthermore, as place-based leaders, councils can help to play a convening role locally and work in partnership with other agencies and the wider voluntary sector.

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 this legal duty hasn't resulted in better funding for PEoLC services or greater strategic prioritisation. Local authorities are well positioned to use the influence their democratic legitimacy on the Integrated Care Partnership (ICP) brings to ensure that palliative and end of life care receives the attention it deserves within local health systems.

The state of palliative and end of life care today

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. The poor state of palliative and end of life care across England was brought to light through Marie Curie's **Better End of Life Report**, which demonstrated that while 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.

- **Gaps in 24/7 community care are preventing people from dying in comfort at home.** One in two people visited A&E at least once in the final three months of their life, while two in three areas either did not have a designated phone line available or were only partially covered by a support phone line.
- **Patients and unpaid carers are suffering due to poor communication and coordination.** One in two people were unhappy with at least one aspect of care the person who died received and only one in three people who died discussed their wishes with healthcare professionals.
- **Too many people are dying in pain and without the support they need for their symptoms.** One in three people were severely or overwhelmingly affected by pain in their final week of life.
- **Current workforce capacity is insufficient to meet demand for end of life care.** One in five people who died had no contact with a GP in the last three months of life.

Unequal access to palliative and end of life care

There is persistent inequity between different groups in terms of access to, and experiences of, palliative and end of life care, and bereavement support. This is not only distressing for people and their loved ones but also has a wider impact on the whole local health and care system. Improving local support for dying and bereaved people could reduce strain on GP and hospital services in crisis and help alleviate pressure on stretched social care services.

We know that some marginalised groups are disproportionately more likely to experience barriers to accessing the right care and support for them at the end of life, including:

- people with conditions other than cancer
- the oldest old, i.e. people aged 85 years or over
- minoritised ethnic communities
- people living in remote, rural and deprived
- people with learning disabilities
- imprisoned people
- LGBTQ+ communities.

ICBs should have strategies in place to address inequities in access to services.

The impact of terminal illness on financial security

Poverty is having a huge impact on people with a terminal illness. Our 2024 **report** found that across the UK there are 111,000 people that die each year in poverty. Working-age people are at much greater risk of dying in poverty: 28% of working-age people who died with a terminal illness in 2023 died in poverty, compared to 16% of pension-age people with a terminal illness.

Energy costs increase dramatically for someone living with a terminal illness: at least 128,000 people died in fuel poverty in 2022, struggling to heat their homes or run vital medical equipment.

There are stark differences among local authorities and regions, with people in some local authorities being almost three times as likely to die in poverty as in others. Among working-age people, poverty rates in the North East in the last year of life were 34% – a full 50% higher than the areas with the lowest rates of end of life poverty.

For pension-age people, Yorkshire and the Humber had the highest poverty rates at the end of life at 22.8%, nearly three quarters higher than the lowest region. A higher proportion of people die in poverty in the North East and North West, accounting for half of the top twenty areas for deaths in poverty across England. Across every region, people at the end of life are more likely to be in poverty than those who aren't.

The NICE (National Institute for Health and Care Excellence) NG6 guidelines serve as a vital framework for addressing health risks linked to cold homes and fuel poverty. **A report by National Energy Action and Marie Curie** reviews five out of the 12 NG6 recommendations, showcasing initiatives like winter planning in Richmond and Wandsworth Councils, and support services from NHS Herefordshire Integrated Care Board. Despite these efforts, significant gaps remain in achieving universal implementation of NICE's recommendations.

Carer's assessments and needs

Unpaid carers (who are often family members, but sometimes friends or other people providing care and support without payment) play an essential role in delivering high quality palliative and end of life care. Providing care at home allows for better access and delivery of PEoLC, reducing hospital (re)admission and alleviating pressure on the healthcare system.

However, the demands of caregiving are unsustainable for many. It can affect their mental health, employment, and financial security. This is exacerbated for carers providing care for someone in their final days, due to the unique challenges of this time.

The introduction of the 2014 Care Act created a legal duty for local authorities to provide statutory carers' assessments and support carers. Identifying carers is a prerequisite to carers' assessments. Yet only 13% of carers across the UK are on local authority registers, meaning 87% of carers are slipping through the cracks.

The Carer Support Needs Assessment Tool Intervention (CSNAT-I) is a five-stage, person-centred process of assessing and supporting the needs of informal family carers using a comprehensive tool. Carers are encouraged to consider their own needs, separate from the needs of the patient. In a **survey** of UK hospices, 37% of hospices used formal assessment, 47% used informal assessment approaches, and 16% did not assess carers at all.

Questions to ask your ICB

- How does the ICB plan to meet **growing need for palliative and end of life care** as our population ages and more people live with complex conditions?
- What plans are in place locally to enable **early identification** of palliative care needs?
- Does your ICB have service provisions in place that offer everyone the opportunity to set out their **wishes for the end of their life**?
- How does the ICB work with local providers to ensure that PEoLC services are **sustainably funded**?
- How does palliative and end of life care feature in the ICB's **Integrated Care Strategy and Joint Forward Plan**?
- How is your ICB resourcing **electronic care coordination** systems to ensure sustained use and regular auditing?
- How does the ICB use data to understand **local population need and address inequalities and inequities** in access to PEoLC?
- Does your Health and Wellbeing Board have strategies in place to minimise winter deaths in line with **NG6 guidelines** to prioritise those with a terminal illness?
- Does your ICB have a **24/7 single point of access advice line** for palliative and end of life care?
- What arrangements are in place locally to provide **out-of-hours access to palliative and end of life care medicines**?
- Does your ICB promote **formal assessment approaches such as CSNAT** in all end of life care settings to support identification of carer needs and to signpost carers to the right resources and support?

Further resources and reading

- **Time to Care in England: Better End of Life Report**
- **Marie Curie: Dying in Poverty Report**
- **Public attitudes to Death and Dying**
- **Public expenditure at the end of life research**
- **NICE NG6 Guidelines**

Whatever the question, we're here to help

If one of your constituents is living with a terminal illness or reaching the end of life, our trained team, including information and support officers, Marie Curie Nurses, bereavement support specialists, energy support officers and trained volunteers, can give practical information and emotional support.

Covering all terminal illnesses, we can help with information on everything needed, from symptom management and day-to-day care, to financial information and bereavement support.

Call our free Support Line
0800 090 2309* or chat to us
online at **mariecurie.org.uk/support**

If you have any questions or would like to arrange a meeting with us, please contact

local@mariecurie.org.uk

Marie Curie is the UK's leading end of life charity. Whoever you are, whatever your illness, we're with you to the end.

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