Marie Curie

Fixing end of life care in West Sussex



Why we urgently need to fix end of life care

Each year in West Sussex, 9,847 people reach the end of their lives. 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 the reality for too many people today falls far short of what we all hope for and should expect.

End of life care in the UK is broken. Every year, almost one in three people at the end of life don't receive the care they need. Dying people suffer avoidable pain and trauma because access to end of life care is inconsistent and unequal. 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. And the cost of living crisis continues to have a huge impact on people with a terminal illness, with poverty affecting more than 100,000 people each year at the end of their lives – including 1,263 people in West Sussex.

This is a critical moment for action to improve palliative and end of life care. As a result of our ageing population, with many facing multiple and complex conditions at the end of life, the number of people needing end of life care in the UK will rise by almost 25% between 2025 and 2050.

New models for delivering vital end of life care in the community are needed to reduce pressure on the NHS and social care and, where it's their preference, to support more people to be cared for at home at the end of their lives.

This report outlines the challenges in West Sussex and presents a clear roadmap to ensure everyone can access the dignity, support and comfort they deserve at the end of life.

Your key stats for West Sussex

There were **9,847** deaths in **West Sussex** in 2024

Due to the ageing population, the number of deaths is projected to rise to **12,736** by 2047

Each year, an estimated **3,116** people in **West Sussex** do not receive the palliative and end of life care they need. If these levels of unmet need were to stay constant, this could rise to **3,792** by 2050.

37.5%
of deaths occur in hospital (England average = 42.8%)

5,533 people (0.6%) are on the palliative care support register (England average = 0.6%)

End of life care in the UK is broken

For many, the end of life is marked by crisis, avoidable hospital admissions and a struggle to access the care needed to die in their place of choice. Too many people struggle to access the right services in complex, fragmented healthcare systems at a time when they are at their most vulnerable.

There is currently significant unmet need for palliative and end of life care. Estimates suggest in England almost one in three people who need palliative care are not receiving it. Applying national estimates to West Sussex, this would equate to around 3,116 people in West Sussex going without the care they need each year.

Profound and persistent inequity exists in access to, and experiences of, care and support for people affected by death and dying. Disproportionately represented among those without access to the palliative and end of life care they need are groups and communities experiencing wider societal disadvantage. These include people living in rural or deprived areas; minoritised ethnic communities; people with learning disabilities; imprisoned people; people experiencing homelessness; and LGBTQ+ communities. Failure to address the social determinants of health through preventative approaches results in minoritised, marginalised groups being much more likely to experience a bad death.

In particular, there is a real lack of out of hours care in many parts of the country. 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. Pain and other symptoms may suddenly worsen. Patients and their carers in this situation need to be able to urgently access support, but we know in too many cases they feel they have nowhere to turn.

Many people often have no choice but to call 999, endure distressing ambulance journeys and spend their precious final hours in hospital, which is traumatising for them and their families, and expensive for the NHS. In England, 61% of those who die each year currently use an ambulance in their last three months, and over half visit A&E. Alarmingly, across England 6.6% of deaths are preceded by at least three emergency admissions in the last three months of life.

“With Dad we had no care at home. We had to keep going to A&E. It was awful. If it was a weekend there were never enough staff. It was just so chaotic. At home we were left to it. My sister and I would drive huge distances late at night, completely exhausted, trying to find a chemist that had drugs for his pain.”

Kate Dobbs, who cared for her father when he was dying.

A lack of co-ordination can also create challenges for carers in knowing who to contact for help or understanding what is available. Unpaid carers (who are often family members but can also be friends or other people providing care and support without payment) play a critical role in providing support and care to individuals at the end of life, often juggling multiple responsibilities and facing significant emotional and practical challenges. Evidence consistently shows that the presence of a carer leads to better outcomes for patients at the end of life and alleviates pressure on the healthcare system. Better community care that is easier to navigate, including ensuring good provision of out of hours support, would help to reduce the burden on unpaid end of life carers.

Despite most people expressing a preference to die at home, hospital is the most common place of death. This is because in many areas care isn’t available to enable them to fulfil their wish, with too many nurses, GPs and community pharmacists not receiving appropriate training about the needs of people at the end of life. Many people with a terminal illness also experience significant delays in having the assessment and funding put in place for the Fast-Track Continuing Healthcare they need in order to be discharged from hospital or remain in their own homes. This results in many people having to spend their final days and weeks in hospital. In West Sussex, 37.5% of deaths occur in hospital, compared to 42.8% across England.

Nine in ten of us will require palliative care at the end of our lives. Yet, palliative and end of life care isn't a core NHS service. Government and the NHS funds only around one third of end of life care in the UK, the rest falling to charities who are themselves struggling with rising demand and costs. Although Integrated Care Boards have a duty to commission palliative care services which meet the needs of their local population, too many are failing to prioritise end of life care in their plans and strategies.

Unless we fix this now, more people will go without the right care because:

- **Demand is rising fast.** The UK population is growing and more of us are living longer, often in ill health. By 2048, an additional 150,000 people across the UK every year will need end of life care.

- **Pressure on budgets is increasing too.** As well as grappling with growing demand, NHS and care provider budgets are under pressure from the continued cost of living crisis, including higher operating and staff costs.

- **Current funding models are failing to keep people out of hospital.** Public expenditure on healthcare for people in the final year of life is heavily skewed towards hospital care rather than community-based care. Reducing spend on expensive hospital care will enable us to support more people at home and in the community.

Marie Curie is leading this transformation

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. It launched in 2022 as a collaboration between Bradford Teaching Hospitals Foundation Trust, Social Finance, and Marie Curie to tackle challenges like health inequalities and system pressures. REACT has two, interlinking arms:

- Emergency Department REACT which identifies, assesses and treats patients with palliative care needs presenting to A&E and offers an alternative to hospital admission through a supported transition into Community REACT.
- Community REACT – an urgent community response service for patients in crises in their last year of life, delivering holistic care and support for up to 72 hours before connecting people to longer-term community services.

Between June 2022 and May 2024, REACT received 984 referrals, of which 35% were not previously known to palliative services. 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.



Supporting GP practices in Derbyshire

Marie Curie nurses have partnered with GP practices across Derby and Derbyshire to improve end of life care. Funded by Marie Curie, the project embeds Marie Curie nurses in 23 GP practices (with more to join), where they collaborate with local teams to identify patients in need, support families, and ensure that end-of-life care is a routine part of clinical discussions. A Marie Curie Advanced Specialist Nurse is also stationed at Chesterfield Royal Hospital's Emergency Department to help identify patients approaching the end of life and facilitate their discharge to preferred places of care, reducing unnecessary hospital admissions. This approach is designed to equip local healthcare teams with the skills and knowledge to provide timely, compassionate, and effective palliative care.

The initiative responds to findings from the Derby and Derbyshire Integrated Care Board, which highlighted gaps in identifying patients at the end of life and higher-than-desired hospital admissions in the last months of life. The project aims to ensure that more people can die with dignity in their chosen setting, often at home. Early feedback from local GPs and care leaders underscores the positive impact on patient experience, staff morale, and the sustainability of high-quality palliative care in the community.



Hospice care at home

In many parts of the country, Marie Curie Nurses, Healthcare Assistants and other healthcare professionals provide care and support in the comfort of people's own home, day or night. These services provide support with symptom management, help people and their carers to plan the care they need and provide vital emotional support.

In some areas, Marie Curie also provides Urgent Hospice Care at Home, bringing fast, responsive care so people don't have to wait for the next scheduled visit and can avoid the anxiety of rushing to hospital.

Hospice Care at Home services help people with any illness they're likely to die from, and the people close to them.

"Neil was at home and he was pain free when he passed, and that's all he wanted from the start. You just can't ask for more. Marie Curie was unlike anyone else on his journey.

"I'd been doing everything for him and knew exactly how things needed to be done – and Marie Curie just got it immediately. The sense of care they had for Neil; I can't even put it into words. The only way I could describe it was like being helped by angels."

Georgina, whose husband Neil was cared for at home by Marie Curie Nurses.



Financial insecurity at the end of life

In addition to difficulties with accessing care at the right time in the right place, amid the ongoing cost of living crisis many people are also spending their final months in financial hardship. More than 100,000 people die in poverty across the UK each year, including 1,263 in West Sussex.

Many people will have experienced poverty throughout their lives and continue to experience it as they reach the end of life – for many others, however, the often devastating financial impact of terminal illness is what drives them into poverty. A combination of falling income and additional costs (the cost of travel to appointments, medications, and especially higher energy bills) – can drive even families who were previously financially stable into poverty.

Poverty at the end of life affects all groups in society, but some more than others. People from minoritised ethnic groups are far more likely to die in poverty than white people, including almost half of Black working-age people, and nearly 40% of Black pensioners. And working-age households have a much higher rate of poverty than pensioners. Working-age people are put at increased risk of poverty at the end of life in large part due to the continuing gap between the working-age and pension-age benefit systems.

Nobody should die in poverty. Improving financial support for those living with terminal illness – through ensuring those who become terminally ill in working age can access the same level of support as pensioners – would begin to address the additional costs that see many people with terminal illness face a higher risk of poverty.

Your key stats for West Sussex

1,263 people die in poverty each year in **West Sussex** (13.8%, compared to 17.6% across the UK)

21.8%
of people of working age and 12.8% of people of pensionable age die in poverty in West Sussex

"I've been renting private. It's gone up three times since I've been here, the rent. I've only got little heaters because I can't afford to run the electric ones on the wall. I've been living in one room for months and months now to try and keep warm."

Peter, 72, Marie Curie Storyteller

How to fix end of life care

To deliver the kinds of care people want and to prepare for a significant increase in demand, as a country we must fundamentally rethink our approach to how we care for and support people at the end of life. We must start fixing end of life care now, so that everyone can spend their final days without pain and die with dignity in the place of their choice.

We are calling for:

- **Stronger leadership and oversight of palliative and end of life care at all levels.** A stronger national policy framework is needed to end the postcode lottery and improve access to quality care. But better local oversight and accountability is also required to ensure health systems are prioritising these vital services.

- **A shift in resources from acute to communities.** There is clear evidence that good quality end of life care in the community helps to reduce inappropriate A&E attendances, prevent hospital admissions and facilitate timely discharge. Palliative care must embedded within the new Neighbourhood Health Service and be an integrated function within multi-disciplinary teams that provide proactive, person-centred care.

- **Improvements in how care is coordinated.** Integrating services will help terminally ill people and their carers to navigate often complex healthcare systems, reducing frustration and distress. We should prioritise early identification of palliative care needs in in all health and care settings, enable more consistent advanced care planning, and ensure care records can be shared between settings.

- **Access to care 24/7 and better access to medicines.** Terminally ill people, their carers and health and care professionals in every part of England should have a single point of access for advice and guidance at any time of day or night, including at the weekend. This would mean that everyone with a terminal illness – not just those already known to the NHS – and their carers should be able to call 111 and select an 'end of life care' option to speak to a palliative care specialist who can provide advice, guidance and support to access local services.

- **Policymakers to prioritise people with a terminal illness for financial support.** The government should ensure the working-age benefits system provides protection against poverty, comparable to that provided to pension-age households. And local authorities in England should prioritise people living with terminal illness for discretionary financial help, such as council tax support and the new crisis and resilience fund.

Marie Curie in your area

In 2024/25, across the South East

- we supported approximately 655 people through our nursing services

In 2024/25, across the South East

- 1,021 people accessed our Information and Support Line.

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.

Through our policy, public affairs and campaigning activity, we work alongside elected decision-makers to improve public policy and provide a better life for people living with a terminal illness and their families.

Get in touch to discuss how we can work together: **parliament@mariecurie.org.uk** or **local@mariecurie.org.uk**

If you or someone you know is living with a terminal illness or bereavement, they can call our free Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/support**

*Your calls may be recorded for training and monitoring purposes