Death Deserves Better:

The case for transforming palliative and end-of-life care

Because no one should face death or grief alone

Foreword

For 75 years, Sue Ryder has supported people through terminal illness, cared for people at the end of their life, and helped others cope with grief. This experience – built by our staff, volunteers, supporters and the people and families who have trusted us – shapes the analysis and proposals in this paper.

Hospices provide outstanding, compassionate care and rightly hold a special place in the communities they serve. The contribution of every member of staff – from nurses to support staff to senior leadership – and the incredible passion and compassion they show as they tirelessly campaign and care are beyond question. Sue Ryder is proud to be part of that tradition.

But not everyone gets this care, and our experience also brings responsibility to be honest about what must change. People are living longer with more complex conditions, demand is rising, inequalities persist, and too many people still miss out on the care they need. The model that served previous generations cannot, on its own, meet today's needs or those of the future.

This paper makes the case for evolution, not rejection: protecting the compassion and expertise at the heart of hospice care while creating a more universal, integrated and proactive system that builds on the positive examples we see across the hospice movement and commissioning landscape. This means reaching people earlier, supporting more care at home and in communities, strengthening specialist provision in hospitals, ensuring inpatient hospice care is available where it is most needed, improving everyone's understanding of a good death and ultimately, improving patient outcomes and experiences.

The choices ahead will not always be easy, but standing still would fail society. By working together – with the NHS, government, hospices, communities and supporters – we can ensure that we can reduce harm in society, reframe death and dying, and enable many more people to receive the care, dignity and choice they deserve.

James Sanderson
Chief Executive, Sue Ryder

Contents

The context 4

The problem 5

The solution 9

The implications 20

Appendix. What is good palliative and end-of-life care? 23

The story of Sue Ryder 24

The context

The modern hospice model as most people know it was developed in the 1960s and 70s, in an era when cancer was significantly more fatal, when those with complex conditions rarely survived long enough to need sustained palliative support, and when most people who needed end-of-life care needed it in one place, for a relatively short time.

Extraordinary medical advances and other social factors over the last 60 years mean that world has changed.

People are now living up to 15 years longer than they were then, but with greater complexity, and sometimes with multiple long-term conditions. These factors can interact in ways the healthcare system, and hospice sector, was not designed to manage. Life events that might have resulted in death 30 or 40 years ago are now treatable within the NHS. Complex conditions that once required inpatient hospice care can now often be managed by primary care or specialist community support, enabling people to remain at home in familiar surroundings, with those they love.

The Government has recognised this shift. The 10-Year Health Plan commits to moving care out of hospitals and into communities, with a more dedicated focus on prevention and earlier intervention. Palliative care is integral to that ambition. Supporting people earlier in their illness alleviates suffering, reduces crisis admissions, avoids harm, and contributes directly to relieving pressure on ambulance services, hospitals, and primary care.

Our mission – **to make sure that everyone needing palliative care, approaching the end of their life or living with grief can access the support they need** – is as urgent today as it has ever been. What must change is how we pursue it. We cannot address today's problems through the delivery of a hospice care model that is 60 years old. Without intervention, the crises in palliative and end-of-life care (PEoLC) will worsen – this is predictable, but it's also clear how we can stop it from happening.

Hospices are quite rightly loved by those whose lives they have touched and by those communities who have supported them tirelessly over many years. The vital role they have played is not in question. Despite the wonderful care hospices have delivered over the years, unless we continue to evolve, we will not be doing our best for those who rely on us.

Too many people do not get the death they deserve. Together we can change this: Death Deserves Better.

"For my loved one to remain at home with professional support to ensure comfort, dignity and full pain relief."

Tracy's wish

The problem

Death, alongside birth, is one of the few life events that unites all of us. Such a natural event should be met with access to appropriate care and intervention. Despite the almost universal need, almost one in three people are missing out on the care they need in the UK today,[1] and demographic changes mean this is set to get worse.

Our national discomfort with talking about death has allowed a crisis of care to grow unnoticed and unaddressed. This also means too many who are left behind after a death miss out on grief support, which can lead to further problems for people and society.

If we are honest as a country, we have a serious problem with PEoLC. The public tell us they want to be cared for and die at home and the system wants us to shift care into the community, but spending is heavily weighted towards caring for people in hospital settings. Many NHS standards are focused on acute settings too. Of public funds spent on healthcare for people in their last year of life, 81% is spent on hospital care, and 56% spent on emergency hospital care.[2]

The sector works tirelessly, and the quality of care delivered – at Sue Ryder, across the hospice sector, and by the many dedicated NHS professionals working in this field – is among the best in the world. But we are not reaching everyone who needs us, and the sector's ability to do this is limited by current commissioning arrangements and resources not focused in the right way. The gap in care is widening, and action is necessary to change this.

The scale of unmet need

Over 650,000 people die annually in the UK,[3] and 90% will need some form of care towards the end of their life.[4] This may involve palliative care, which focuses on managing symptoms of a life-limiting condition, or end-of-life care, which provides physical and emotional support during the final weeks or days of life. Research shows that almost one in three people do not receive the PEoLC they need.[5] It is hard to imagine the public response if those statistics applied to any other area of health. Yet this is the quiet reality of dying in this country, and we do not talk about it enough.

The consequences are clear. The majority of people want to die at home,[6] and yet over 40% die in hospital, compared to 28% at home, 21% in care homes, and just 5% in hospices.[7] Currently, there is lots of variation in end-of-life care delivered in hospitals, and this can mean corridor care. Almost 3,000 people a day receive corridor care in the NHS[8] and over half of nurses have reported having to provide end-of-life care in corridors or non-clinical areas.[9]

1 https://www.mariecurie.org.uk/document/unmet-need-in-uk-report-2026
2 https://www.nuffieldtrust.org.uk/sites/default/files/2025-02/Public_expenditure_in_the_last%20year_of_life_finalreport.pdf
3 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathregistrationsummarystatisticsenglandandwales/2025
https://www.nrscotland.gov.uk/publications/adoptions-births-deaths-marriages-and-civil-partnerships-in-scotland-2025-registrar-generals-annual-statistical-tables-of-vital-events/
https://www.nisra.gov.uk/publications/weekly-death-registrations-northern-ireland-2025
4 https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2023/how-many-people-need-palliative-care.pdf
5 https://www.mariecurie.org.uk/document/unmet-need-in-uk-report-2026
6 https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401b_padd_briefing_final.pdf
7 https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html#place-of-death
8 https://commonslibrary.parliament.uk/research-briefings/cbp-10938/
9 https://www.mariecurie.org.uk/media/press-releases/marie-curie-and-nursing-standard-survey-reveals-pressures-on-time-and-care-planning-are-affecting-end-of-life-care

> "I had to care for a deteriorating palliative lady in the corridor in A&E due to no bed availability in the hospital. It was distressing for myself, the patient and the patient's family, who were very angry with the situation. It wasn't something that could be helped at the time, but the patient was deteriorating significantly throughout my shift, and I was terrified she was going to pass away in an A&E corridor." – **Quote from a nurse in the 2026 Royal College of Nursing report 'On the frontline of the UK's corridor care crisis'.**[10]

Demand for PEoLC has been projected to rise by 55% in the 10 years to 2031[11] so these problems are set to worsen without urgent action.

At Sue Ryder, we know that delays in care and a lack of joined-up services mean that people in desperate need of the high-quality care we provide die before they reach us. Many are not referred to us even though they could benefit from our care. This shouldn't happen.

Too many people also struggle with the consequences of bereavement – the lingering and sometimes devastating effects of grief have a huge impact. For example, bereavement in the workplace costs the UK economy nearly £23 billion a year and makes an impact on public finances of around £8 billion a year.[12] Early intervention with the right information could help to reduce the number of people whose trauma, and sometimes guilt, leads them to require additional clinical support, something which puts further strain on primary care and mental health services.

Inequality runs through the system

The gaps in access are not random. They fall hardest on those with the greatest need.[13] People from a narrow group within society are most likely to access hospice services. This is further compounded by a model where communities fundraise for local access to these services and long-term traditional community support such as district nursing and access to GPs has become more variable and stretched.

Sue Ryder research with the University of Birmingham found that inequalities such as low socio-economic status, low health literacy, and social exclusion increase a person's likelihood of experiencing inequity in PEoLC.[14] People who live alone are 52% more likely to die in hospital than those who live with others.[15] These determinates are in addition to the known inequalities that exist for populations such as people who are LGBTQ+, people experiencing homelessness, and people with learning disabilities. Our reach as a sector into communities like these is unjustifiably low. Ethnic minorities, patients without cancer, the oldest old and those living in rural or deprived areas are less likely to access hospice care.[16] This is not inevitable. It's a choice that emerges when commissioning doesn't address the gaps in a system that has been charitably funded and is building focused.

Demand for PEoLC is growing, and so without structural change, the gap between those who need care and those who receive it will widen further, faster. As a sector, we can and must do more to meet people where they are. This means supporting a more diverse population in their homes, being present where people present in crisis, and expanding our footprints to address the inequity of different geographies with the support of strategic commissioning.

10 https://www.rcn.org.uk/Professional-Development/publications/rcn-frontline-of-the-uk-corridor-care-crisis-uk-pub-011-944
11 https://media.sueryder.org/documents/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England_1.pdf
12 https://media.sueryder.org/documents/Sue_Ryder_Grief_in_the_workplace_report_0.pdf
13 https://committees.parliament.uk/publications/50461/documents/273119/default/
14 https://www.sueryder.org/blog/inequity-report/
15 https://www.strategyunitwm.nhs.uk/news/playing-our-part-conversations-about-death
16 https://spcare.bmj.com/content/12/2/142

The easiest choice, for any charity and for the sector as a whole, is to continue doing what has always been done. Current models of care have served those who can access them well, and we are rightly proud of them. But they were built for a different time. They cannot meet the scale of today's crisis, or the UK's needs in the years ahead. While there will always be inherent inequalities within systems, a new model of care can fast track change to drastically reduce the inequalities embedded within the current system – allowing people to access care where they want it and where they need it. Coupled with improved population analysis to inform strategic commissioning and support from government to build primary care services back to required levels, significant reduction in inequality at the end of life is possible.

The financial model is under acute and growing strain

The cost to deliver hospice care continues to increase as does the need, yet in reality services are contracting not expanding. The total hospice sector spend in 2023–24 reached £1.55 billion, the highest on record, driven by inflation and rising wage costs.[17] In August 2026, Hospice UK reported that hospices across England ended the last financial year with a collective deficit of more than £70 million – more than double the previous year.[18] Almost 60% of hospices have either made changes or considered reductions to balance their budgets.[19] Specialist community hospice visits have fallen by 150,000 in a single year – exactly where services should be growing.[20]

Meanwhile, fundraising returns across the independent adult hospice sector are falling: the sector generated between £2.07 and £2.15 for every £1 spent on fundraising between 2014 and 2019. By 2023–24, that had fallen to £1.96.[21] The NHS provides, on average, 40% of the funding the adult hospice sector requires to run its services.[22] No other clinical specialism operates on this basis. If the NHS contracts hip and knee replacements to the private sector, it expects to pay the full cost of the clinical care. The same principle should apply here. Not only is the full cost of clinical care not covered, but the range of services, pathways and resulting funding sources hamper the ability to provide joined-up care for patients across the system.

The hospice sector has been in financial difficulty for decades. Heavy reliance on fundraising and retail to deliver core hospice services prevents investment in the reform required to reach the thousands of people who cannot currently access PEoLC. While government money is required to close the gap between those who need care and those who receive it, it is also true that more money directed at the current model cannot achieve this aim. For many reasons, average hospice occupancy sits at 77%,[23] yet thousands miss out on the care the sector can provide. **The question is not only whether there is enough funding – it is also whether the current care models and scope of services being funded are still the right ones.**

17 https://www.nao.org.uk/wp-content/uploads/2025/10/the-financial-sustainability-of-englands-adult-hospice-sector.pdf
18 https://www.hospiceuk.org/latest-from-hospice-uk/hospice-deficits-have-more-doubled-year
19 https://www.hospiceuk.org/latest-from-hospice-uk/hospice-deficits-have-more-doubled-year
20 https://www.hospiceuk.org/latest-from-hospice-uk/hospice-deficits-have-more-doubled-year
21 https://www.nao.org.uk/wp-content/uploads/2025/10/the-financial-sustainability-of-englands-adult-hospice-sector.pdf
22 https://www.nao.org.uk/wp-content/uploads/2025/10/the-financial-sustainability-of-englands-adult-hospice-sector.pdf
23 https://hospiceuk-files-prod.s3.eu-west-2.amazonaws.com/s3fs-public/2025-11/Hospice%20Sector%20Data%202024-25%20-%20Big%20Conversation%20October%202025%20(1).pdf

Why the moment to act is now

For 75 years, Sue Ryder has been at the forefront of PEoLC, and we recognise that change is needed for ourselves and the wider system.

The challenges have been building for years, and there have been more than enough reports demonstrating the devastating impact of poor PEoLC. What is different today is the opportunity to respond to them. Since coming to power in 2024, the Government has placed health and social care reform at the centre of its agenda, with the explicit goal of shifting care out of hospitals and into communities. Within this, the Government has increasingly recognised that improving PEoLC is not peripheral to its ambitions – it is integral to them. More PEoLC at home eases pressure on primary care and reduces emergency ambulance call outs and hospital admissions, as well as freeing up acute beds.[24, 25] Without these shifts, the NHS will not achieve the goals it has set out for future sustainability.

The Government's publication of a Modern Service Framework (MSF) for palliative, end-of-life and bereavement care – due in 2026, and one of only six MSFs announced across the NHS – will set national standards and goals, creating a new platform for accountability and investment. The MSF will support the NHS to increase identification of those approaching the end of life by 10% and reduce non-elective admissions and hospital bed days by 10% for those at the end of life. The debate around assisted dying has further raised the national profile of PEoLC: in his first month in office, the Prime Minister recognised that there needed to be a 'fixing of the funding of palliative care and social care' before any assisted dying framework could be considered. This is a great moment that the sector must step up to meet.

If the Government is serious about fixing the funding issues facing the sector, then collectively, we must look at the long-term sustainability of any 'fix'. Reform of PEoLC must be seen as an opportunity to align funding, services and needs, ensuring community and neighbourhood care works across the spectrum of people and places. **The political and policy conditions for bold reform are better now than they have been in a generation.** We need providers, the Government, and the NHS to step up to the challenge. And importantly, we need our supporters – those who've made it possible to deliver outstanding care for so many years – to help us reach more people within their communities. Without the support people selflessly give to the hospice sector, it won't be possible to make the changes needed to stop so many missing out and improve people's outcomes.

This opportunity cannot be wasted – death deserves better, and now is the moment to prove it.

"That no one has to lie in a hospital ward waiting for palliative care and passes away still waiting – I hope everyone can have a quiet calm place where they can be with family or friends or even on their own when they pass away."

Susan's wish

24 https://www.nuffieldtrust.org.uk/sites/default/files/2017-01/marie-curie-end-of-life-full-web-final.pdf
25 https://www.mariecurie.org.uk/document/unmet-need-in-uk-report-2026

The solution

We need a fundamentally different ecosystem for PEoLC: one that is universal, integrated, and proactive. A system that supports people at every stage of their illness, from the point of diagnosis, to live as well as possible right up until the end of their lives. One that does not provide better care for some based on where they live, the complexity of their illness, or who they are. The need is universal, so the model should be too.

The NHS has defined what good should look like and this stands as a template for what should be in place.

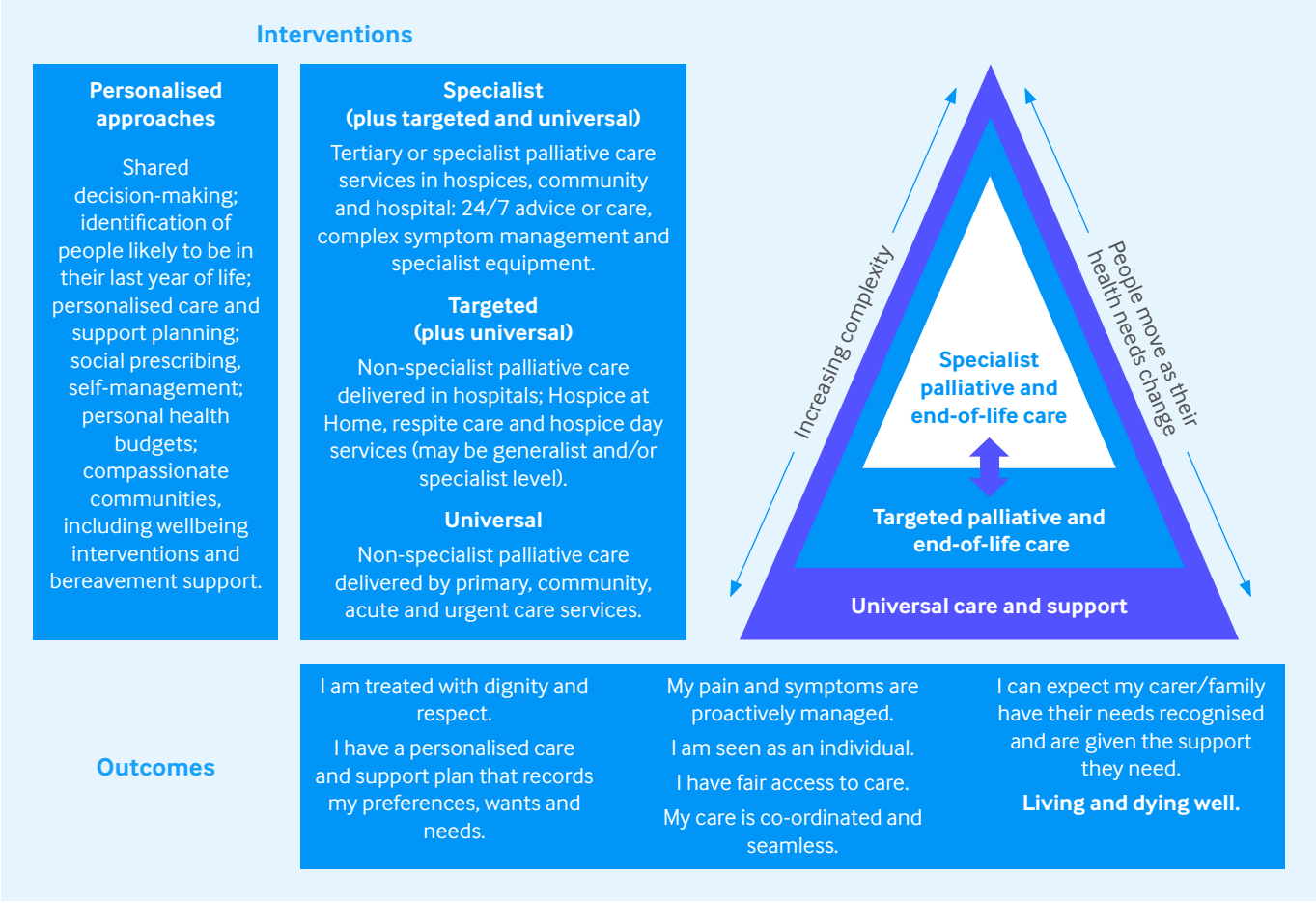


Figure 1. Universal palliative and end-of-life care

Reproduced from NHS England (Jan 2023) Specialist palliative and end-of-life care services adult service specification.[26]

However, delivering a fundamentally different model requires foundational improvements to incentivise growth, scale, consolidation and innovation, allowing hospices to contribute even greater system benefits. These improvements are reflected in Hospice UK's calls for government[27] and include:

- ensuring full cost recovery of the services you would otherwise expect the NHS to have to provide
- securing multi-year contracts with appropriate inflationary increases (in line with Agenda for Change) that support services to plan for and deliver care to those currently missing out

26 https://www.england.nhs.uk/wp-content/uploads/2023/01/B1674-specialist-palliative-and-end-of-life-care-services-adult-service-specification.pdf
27 https://www.hospiceuk.org/our-campaigns/fair-funding-for-hospices

- providing national accountability for equitable provision of PEoLC so that strategic commissioning of these services is measured appropriately and prioritised at a local level, despite budgets being smaller than other areas of healthcare delivery
- addressing issues within wider primary care provision to support an effective shift towards the community, enabling early identification and improving continuity of care across providers.

Through addressing these underpinning factors, it becomes possible to deliver a new ecosystem for PEoLC; one that starts with the people who need care, not with the infrastructure we have always had. It should build on the best of what currently exists, but not be blinkered by it, and it should not be afraid to make difficult decisions and stop things, as well as start new things. The services the sector provides must meet the needs and wants of those receiving care and be built around dignity, comfort and connection. Personalised approaches by definition mean a greater ability to tailor how and where we care for people, not finding ways for them to fit in with what currently exists.

We need to be direct about the implication of this: as community PEoLC improves, more people should be able to receive support at home. Better hospital patient flow, coordination of specialist palliative care and use of capacity is likely to reduce demand for inpatient hospice beds.

This should be understood as a system that is working – not as a failure. Bed closures don't have to be the measure of a sector in decline; they can be the measure of one that has learned to reach more people in the places they want to be or where is best suited to their needs. The debate must shift away from buildings and beds towards people, outcomes, and reach.

Sue Ryder believes the system needs five keys shifts to achieve this.



Figure 2. Sue Ryder's five shifts

Shift one: home and neighbourhood as the primary place of care

Case study: Sue Ryder North East and Yorkshire region, lived experience

"My husband, Bob, was diagnosed with lung cancer in 2024. He had surgery again and did really well. Then, last October, we found out that the cancer had returned and was stage 4, and there weren't many treatment options available. The hospital then referred us to Sue Ryder.

"Very quickly, we were assigned a nurse, Nicola, who came to visit us at home. At that stage, Bob was still quite well, so the support was more in the background, there when we needed it. It wasn't until the last two months that we had more visits and support.

"Bob was absolutely a homebird and was happy as long as he could be at home with me. He always looked forward to evenings and having a bit of a routine. The care from Nicola enabled Bob to remain at home with dignity and not feel pressured to go into hospital or a hospice. The Sue Ryder team made us aware of their support available and quickly ensured it was in place, helping him have his last wishes." – Tracey, Leeds

The only place where the capacity to deliver PEoLC can significantly increase without drastic and unrealistic increases in funding is in people's own homes and communities. This is also where the majority of people state they want to be, it's where there's the greatest potential to tackle inequity, and it's where the Government's 10-Year Health Plan is pointing the whole health system.

Yet current patterns of expenditure remain heavily weighted towards managing crises in hospital – the evidence of which can be seen in areas like district nursing roles, which have declined by 43% since 2009 despite facing significant increases in demand over the same period.[28] Of all healthcare expenditure on people in their final year of life, 56% is spent on emergency hospital care, while only 11% is spent on primary and community care.[29]

Evidence shows that hospital use can be reduced. Research from Macmillan Cancer Support shows that having 10 community contacts in the last 90 days of life can reduce the risk of dying in hospital by 18%.[30] Considering wider aspects than PEoLC, similar outcomes can also be seen from a shift to upstream prevention of deterioration. As an example, £5.8 billion is spent annually on frailty-related healthcare activity,[31] and 20% of all people with frailty admitted to hospital as an emergency stay more than 21 days.[32] Evidence shows this is avoidable – and that proactive care in the home for people with frailty can help to reduce the need for multiple and urgent interactions with the health system.[33]

28 https://www.nuffieldtrust.org.uk/resource/the-lamentable-decline-of-district-nurses-in-the-nhs-in-england
29 https://www.mariecurie.org.uk/document/public-expenditure-in-the-last-year-of-life-report
30 https://www.researchgate.net/publication/376110345_A_Picture_of_End-of-Life_Care_in_England
31 https://pubmed.ncbi.nlm.nih.gov/31297511/
32 https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/Geriatric-Medicine-Sept21h.pdf
33 https://www.bgs.org.uk/sites/default/files/content/attachment/2024-10-29/Be%20proactive%20-%20Evidence%20supporting%20proactive%20care%20for%20older%20people%20with%20frailty.pdf

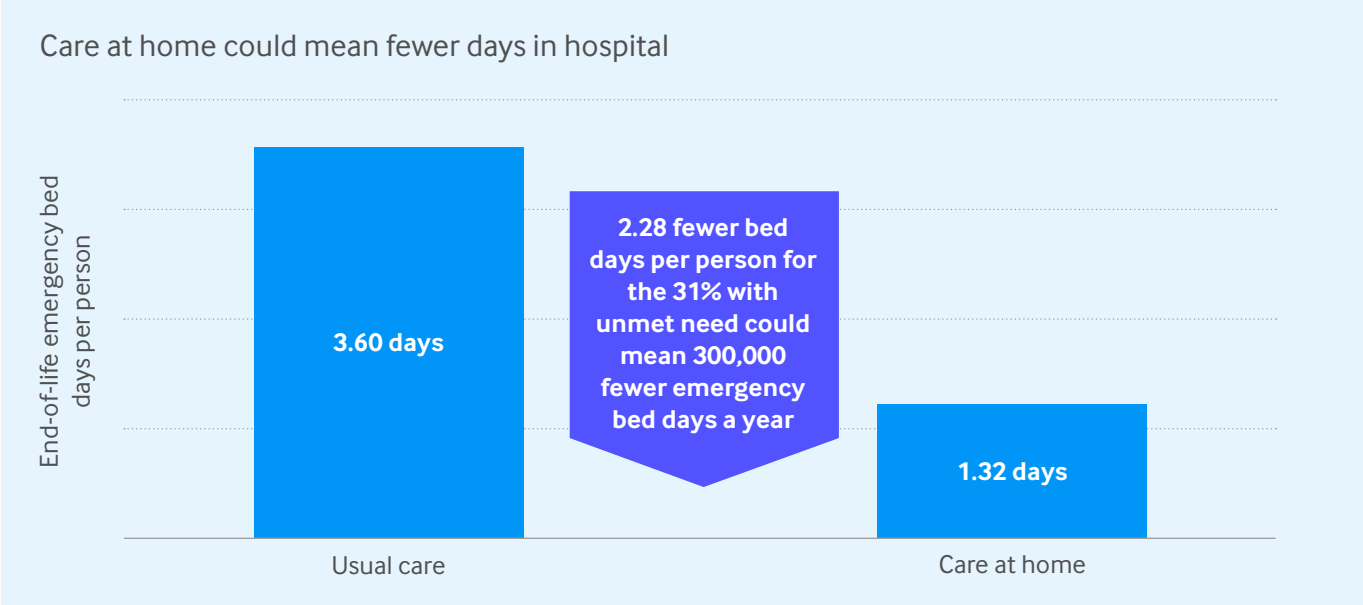


Figure 3. Reduction in bed days with increased care at home

Sue Ryder estimates that better access to care at home could mean around 300,000 fewer emergency hospital bed days and around 44,000 fewer deaths in hospital each year. That would be a reduction of nearly 20% in hospital deaths.[34]

The model uses the share of people with unmet palliative care needs as a guide to how many need nursing at home but aren't getting it. It assumes they would see the same benefits as in earlier research looking at the impact of at-home nursing on hospital admission.[35, 36]

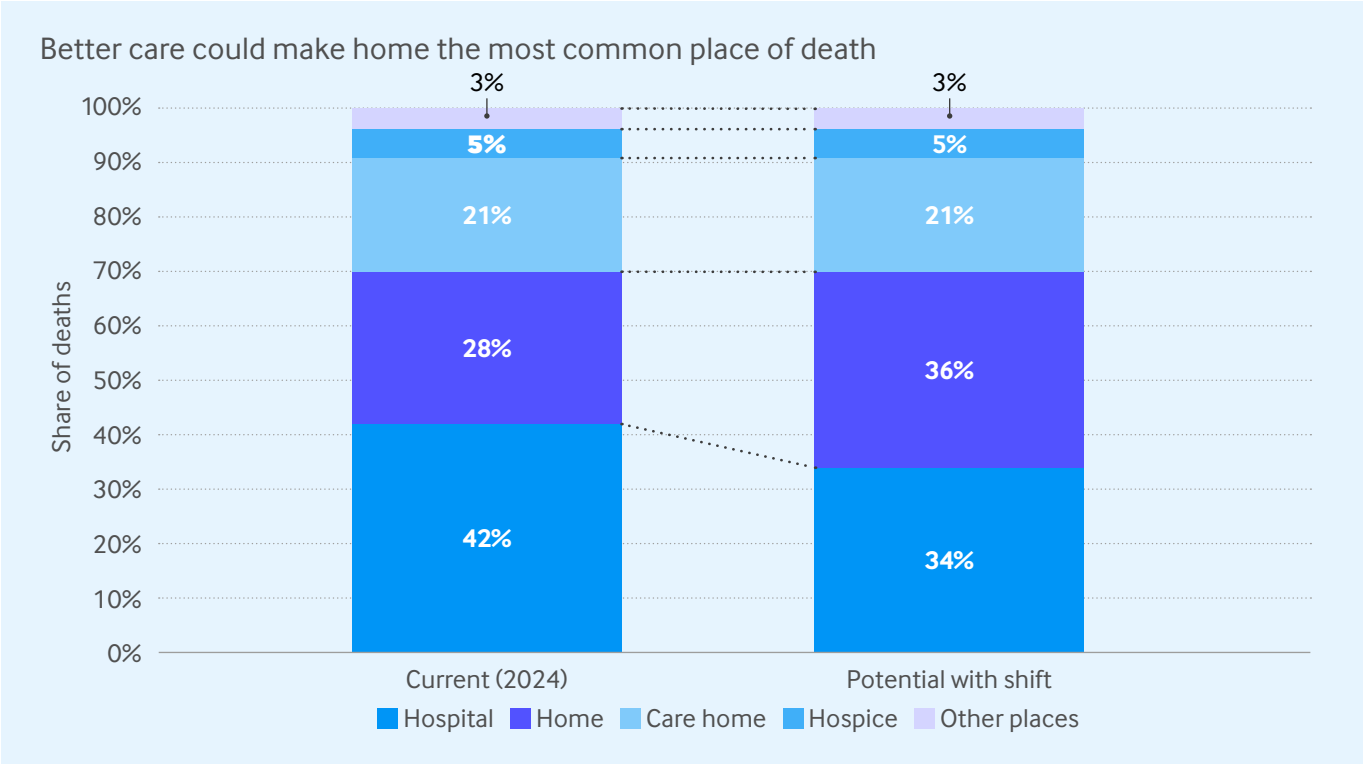


Figure 4. Shift in where people die with increased care at home

34 https://media.sueryder.org/documents/Projected_Care_Model_Shift_2026.pdf
35 https://www.mariecurie.org.uk/document/unmet-need-in-uk-report-2026
36 https://www.nuffieldtrust.org.uk/sites/default/files/2017-01/marie-curie-end-of-life-full-web-final.pdf

If all the modelled shift from hospital were to people's own homes, home would become the most common place of death in England. The share of people dying at home would rise from **28% to 36%**, while the share of people dying in hospital would fall from **42% to 34%**.[37, 38] In practice, it's likely this shift would be spread across people's own homes or other usual place of residence within the community, such as care homes, as people shift to the most appropriate setting for their needs at that time. The intervention this modelling is based upon takes place in a person's own home and therefore a direct shift to care home cannot be estimated.[39, 40]

This modelling shows investment in community PEoLC should be a core part of NHS demand and capacity planning. Providing the care people need at home could improve their experience towards the end of life and release substantial capacity within the acute sector, allowing swifter access to essential support for patients for whom admission cannot be avoided. The support required from primary care to deliver this, not least through an ability to improve continuity of care, cannot be overlooked as a core component.

Community PEoLC is not a compromise – it is the direction the evidence, the people we serve, the policy environment and the funding models are all signalling. Among wider recommendations that include mandated 24/7 specialist palliative care, better support for future care planning and improving understanding around palliative care, the Commission on PEoLC recommends the improvement of rapid response to advice and access to community services.[41]

This means virtual wards and remote monitoring; telephone advice and single-point-of-access hubs; community nurse specialists working within Primary Care Networks (PCNs); increased Hospice at Home services; 24/7 access to advice, assessment, and symptom management and proactive outreach to communities that currently receive too little. Palliative care must become a core component and flagship of neighbourhood health – not a specialist add-on only accessed in crisis, but an upstream, preventative presence that helps people plan well and improves experiences in the final years and months of life. Improving care in the community does not just mean that more people can be cared for at home, but also that people with more complex needs are able to receive the right care in the home rather than in hospital. This approach will reduce the probability and possibility of people going into hospitals.

37 https://media.sueryder.org/documents/Projected_Care_Model_Shift_2026.pdf
38 https://fingertips.phe.org.uk/profile/end-of-life
39 https://www.nuffieldtrust.org.uk/sites/default/files/2017-01/marie-curie-end-of-life-fullweb-final.pdf
40 https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2024.html
41 https://palliativecarecommission.uk/

The solution

A core consideration of an improved community PEoLC approach is better integration with all community partner infrastructure, including social care and social services. Palliative care providers cannot do this alone. An increased focus on how all partners work together within a neighbourhood team will mean that people can receive the right support earlier in their health trajectories and remain at home if possible, or be cared for in alternative community settings such as a care home.

This shift is not only more in line with patient preference but is more cost effective: research from 2026 found home-based specialist palliative care was associated with reduced costs of £7,908 per person who died.[42]

These models are already proven. Community-based palliative care reduces emergency admissions, alleviates GP workload, and reduces ambulance callouts. In our palliative care hub in Bedfordshire, developed in partnership with Keech Hospice, we have demonstrated what this looks like at scale. Our Community Alongside model, about to launch in Southend-on-Sea as part of the Coastal Navigators' Network, will build further evidence. By focusing on services that prevent the need for downstream crisis responses, we can actively relieve pressure on acute hospital care.

Case study: Bedfordshire palliative coordination service

In Bedfordshire, palliative hospital care costs over £11 million annually, accounting for over 2,100 admissions and over 26,000 bed days – with many patients in hospital unnecessarily, and for too long.

Sue Ryder had received feedback that support services were difficult to navigate, with GPs unsure how or who to refer to across specialist palliative care providers.

In early 2026 we launched a 24/7 coordination service, connecting patients, families and healthcare professionals with support, with GPs retaining primary clinical oversight.

Through one referral route, the service brings together NHS community services, Sue Ryder and Keech Hospice resources, helping people receive coordinated, proactive care at home.

Within nine months of launch we have seen a reduction in hospital admissions, with more people being managed stably in the community and receiving care in their preferred place. Conversations around Advance Care Planning have also risen from 5% to 61% of patients.

Case study: Sue Ryder Bedfordshire pallative coordination service, lived experience

"My mother-in-law Jodi fell ill in April this year. She came back home from the hospital and needed care during May and June. It was all very smooth. From University College Hospital, London, we were able to get her discharged to our house in Bedfordshire.

"Fortunately, the carers from Sue Ryder were able to start immediately. It was an amazing experience to be honest. Jodi had never really been that ill before so it was really good that the support all fell into place so well.

42 https://journals.sagepub.com/doi/10.1177/02692163261423755

"When she got to the final stages and needed more care they were just marvellous. They did a really great job. It was helpful to talk with them too, and they would tell me what symptoms or signs to look out for as things progressed. The palliative care nurses that work alongside the Sue Ryder team were also fantastic with her medication and would pop in all the time. We also had doctors pop in.

"The other thing I would say is that it was clear everyone spoke to each other. It was really fantastic. I think there were four or five different agencies including Sue Ryder, the palliative care nurses and the district nurses and all those teams collaborated really seamlessly from my perspective and were obviously in touch with one another, which made everything a lot easier to manage."
– Angela, Bedfordshire

Case study: Improving access to hospice care in deprived communities through a remote breathlessness service

Patients in the Gloucester Inner City Primary Care Network (PCN) were not accessing Sue Ryder's successful Gloucestershire breathlessness service, despite high local need. The PCN serves 35,657 patients and falls in the second-lowest deprivation decile nationally. The city has some of the country's highest smoking rates, and the area has one of the highest rates of Chronic Obstructive Pulmonary Disease (COPD).

Sue Ryder worked with a local GP to deliver a GP-based, physiotherapy-led palliative breathlessness clinic for this patient cohort.

The GP practice provides space, administration, patient screening and recruitment. Sue Ryder contributes specialist palliative respiratory expertise and access to wider hospice services.

Staff report that patients attending the clinic use less rescue medication and fewer inhalers, and book fewer GP appointments.

There have also been recorded improvements in symptom self-management on the modified Chronic Respiratory Questionnaire score.

Non-attendance has been extremely low, despite the PCN team's initial concerns about typically high non-attendance in this patient group.

By running the clinics within a GP practice, patients can access treatment in a familiar environment using systems and staff familiar to them. This has been extremely successful in improving equity of access for this patient cohort.

Case study: Staffordshire Hospices Collaborative Virtual Ward

In 2026, Stoke-on-Trent and Staffordshire ICB awarded a two-year contract of £4.5 million to the area's four hospices to deliver an 80-bed specialist palliative care virtual ward, supported by a 24/7 advice line and rapid response teams from early 2027.

The service aims to prevent at least 500 hospital admissions and save 5,000 acute bed days in its first year, as well as enabling more than 90% of patients to receive care and die in their preferred place, among other performance indicators.

It is based on a proven hospice-led virtual ward at Compton Care, Wolverhampton's hospice, which supported 880 patients in 2025–26, saved over 8,000 acute bed days, and enabled 98% of patients to avoid further hospital admission while achieving their preferred place of care or death.

This is a strong example of how hospices are working as strategic partners with the NHS and fellow hospice providers, using specialist expertise to deliver better outcomes for patients while reducing pressure on hospitals.

Shift two: specialist palliative care embedded in every hospital

Over 40% of people currently die in hospital and a joined-up effort from the system is required for this to change. It's well recognised that there is an overreliance on emergency hospital care: from September 2022 to August 2023, an emergency admission occurred in the month prior to death for 80% of people who died in hospital.[43] Patients in their last years and months should not make avoidable trips to A&E; this is distressing for many patients and can sadly cause serious harm. Recent figures show that A&E overcrowding is linked to over 550 deaths per week and has a significant negative impact on the entire hospital.[44]

For some, hospital will be the most appropriate setting and must be a place where people can receive compassionate, tailored and clinically excellent PEoLC. As patients' needs become more complex, some require input from multiple specialisms or acute interventions that can mean longer hospital stays. Community-based provision may not be possible; conditions may deteriorate rapidly, and people with the most complex needs may require support from multiple functions across an acute care environment. Others may fall through community safety nets even within a fully reformed system – particularly those who lack trust in primary care or whose families can no longer care for them at home and find themselves facing an emergency.

We hear encouraging examples of hospital specialist palliative care teams enabling the right care in this setting, including by becoming more confident in using complex drug plans to meet symptom needs, drawing on plans more usually seen in hospice inpatient units. These teams need additional resources to develop and run dedicated wards or provide consistent input where more complex symptom management can become commonplace. For this to be achieved, improvements need to be made. Currently, while specialist palliative care is available in many hospitals, it's not consistent and it's not 24/7. A 2025 audit found that 64% of hospitals offer face-to-face (nurse and/or doctor) care 8 hours per day, 7 days a week.[45]

Delivering this standard of care requires well-coordinated specialist services and a knowledgeable, confident hospital workforce. Specialist clinical services should support patients, families and ward staff 24 hours a day, 7 days a week, alongside robust education and training programmes that equip staff across each trust to deliver excellent PEoLC. Working closely with ward teams, specialists can provide in-reach support across hospital sites, helping people to be discharged home or to their usual place of residence, where possible, whilst also supporting those to have a good death in hospital for those who need to remain there.

43 https://www.nuffieldtrust.org.uk/news-item/how-are-hospital-services-used-at-the-end-of-life-0
44 https://rcem.ac.uk/press-release/hundreds-of-deaths-each-week-associated-with-ae-overcrowding-new-research-suggests/
45 https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2025/NACEL%202025%20State%20of%20the%20Nations%20Report%20-%20FINAL.pdf

These teams already work tirelessly across hospital wards but often struggle to secure sufficient visibility and priority for PEoLC among competing demands. Hospital leaders must make this care a clear organisational priority, championing collaboration, continuous improvement and innovation. The right expertise, services and clear pathways must be available where and when people are dying, helping patients receive appropriate care while making better use of hospital beds.

Sue Ryder supports the introduction of a new model to support this, providing services across this spectrum within hospital grounds, combining NHS infrastructure and reach with PEoLC clinical expertise. People, professionals and expertise are at the heart of good PEoLC, and there is a clear gap in the setting where most people currently die.

Case study: Marie Curie Responsive Emergency Assessment and Community Team (REACT)

Marie Curie REACT works closely with the emergency department of the Bradford Royal Infirmary to identify people at the end of life earlier. It provides specialist palliative care assessments to decrease hospital admissions.

REACT aims to enable patients to receive high-quality end-of-life care in their usual place of residence, whilst avoiding unnecessary hospital admissions.

Since the service launched in November 2022, it has achieved significant improvements, reducing average hospital bed days from 38 to 17, saving over 20,000 bed days, and improving equitable access to care in Bradford and the surrounding area.[46]

Shift three: hospice beds – right-capacity, well-located, sustainably funded

Hospice inpatient units (IPUs) will continue to play a role for people with complexity at the end of life – this is not in question. **But they must be the right capacity, well-located, and sustainably funded – determined by population need, not institutional history.** Local commissioners can see where hospices are central to the community shift – very rural communities and those where acute services are hard to reach, or where acute services exist but remain stretched, and outsourcing specialist inpatient care makes the most sense. The success of an IPU should be determined by its ability to operate at high capacity and to reach a diverse and representative range of people, integrating more closely with local systems to ensure the appropriate flow of patients.

Where inpatient capacity is needed and a hospice is the right provider, the clinical care should be fully funded by the NHS. Where community services can meet more needs at lower cost and greater reach, resources should shift accordingly. These are local decisions, made in genuine partnership with ICBs, NHS commissioners, and other providers to ensure the right level and location of services across all PEoLC needs.

The underlying principle is clear: people and outcomes, not buildings, measure a system's success. The Public Accounts Committee report on the financial sustainability of adult hospices recognised that NHS England has been too slow to enforce a commissioning approach for the provision of palliative care that focuses on the quality of outcomes for patients.[47] This does not mean expecting the NHS to fund everything the hospice sector currently provides. As charities, we can develop services beyond an accepted NHS clinical model and create environments distinctive to our sector. Funding this wider charitable offer cannot be solely the responsibility of the state.

46 https://www.mariecurie.org.uk/media/press-releases/marie-curie-team-celebrates-national-win-at-inaugural-nhs-excellence-awards
47 https://committees.parliament.uk/work/9279/financial-sustainability-of-adult-hospices-in-england/

We have, for too long, mixed up two separate things – the cost of meeting the clinical needs of someone who is dying or in need of palliative care, and the cost of delivering a charitable service, one that is so loved by many, and has been determined by an independent provider.

As a sector, we know the value that this mixed model approach can provide for patients. We see daily that just providing for the clinical needs of a person and their family is not enough. The time we can spend with patients and the grief support we can give to families and loved ones are good examples of this. For many, it's the ethos and the people working in the palliative care sector which normalises and enables a positive death experience. We should not lose this from our approach. Both are important and must be uncoupled to ensure the right level of support is directed to hospice services from the NHS and our supporters.

Sue Ryder has already begun to make decisions to deliver this shift. At Sue Ryder Thorpe Hall Hospice in Peterborough, we reduced inpatient beds from 20 to 15 to reflect the demand in the local area – ensuring our resources are where they are most needed and most used. These are not easy choices. They will be contested. But they are the right ones.

Shift four: a society confident enough to talk about death

As a society, we are bad at talking about death and dying, and this silence has a harmful impact on people at the end of life and their families.

A 2025 Health and Social Care Committee Expert Panel evaluation highlighted that PEoLC patients, service users and their families are too rarely given the opportunity to plan effectively for the future.[48] Nine out of ten people in the UK have not written an Advance Care Plan.[49] Yet people who make plans for the end of their lives are almost twice as likely to die in the place of their choosing,[50] and Advance Care Planning (ACP) can be effective at reducing hospitalisations.[51, 52] Families who have had honest conversations about wishes face less trauma when making decisions on behalf of loved ones. If we change the conversation, we can change the outcomes.

All patients should have the opportunity to engage in collaborative discussions with healthcare professionals to explore values, treatment preferences, and goals of care – which should include preferred place of death. There needs to be open, honest, and ongoing conversations with patients about prognosis, preferences, and care options. Alongside ACP, patients and carers must be equipped with information about their condition, symptom management strategies, and available local services and benefits. This supports self-management and helps individuals to navigate the healthcare system, ensuring they receive all the care and support they need.

The conversation should not stop after a death. Too many people also struggle with the effects of grief, which can be profound and strike at anytime. It can manifest in many ways – issues such as depression, anxiety, financial instability, and loneliness are often not recorded or recognised as grief related, but have it at their root. As a society, we need a public health approach to grief – it makes sense that we make it everyone's business and provide pathways that focus on a spectrum of support, from service providers and community-based approaches to formal therapy support for those who need it. The upcoming MSF must ensure that ICBs include high-quality bereavement support within service provision.

48 https://committees.parliament.uk/publications/50461/documents/273119/default/
49 Attitudes to palliative care research conducted by Censuswide and commissioned by Sue Ryder, March 2024
50 https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/9238-10061/missed-opportunities-advance-care-planning-report
51 https://bmjopen.bmj.com/content/13/2/e064914
52 https://journals.sagepub.com/doi/10.1177/0269216314526272

The taboo around death is cultural, not inevitable. Public campaigns, accessible digital tools, community conversations, and health professionals equipped and confident to raise the subject can all shift the norm. Sue Ryder provides support across the spectrum of care, including reducing avoidable trauma through our PEoLC support, providing information and advice on death and grief, an online bereavement community for peer-to-peer support, single session therapy and multiple counselling sessions for those in need. We are committed to working with the Government and the NHS to improve ACP across the system, to enable people to record and share their wishes with those involved in their care. Last year, over 220,000 grieving people came to Sue Ryder for something they could not find elsewhere: someone who understood. We will continue to break down the taboos surrounding death and dying and build a society more willing to talk about and plan for the end of life.

Shift five: skills and training across the entire system

The skills needed to recognise when someone needs palliative support, to have honest conversations about death and dying, and to make appropriate referrals must be far more widely distributed across the health and social care system. Despite death being a universal human experience, despite most people wanting to die at home, and despite the societal shift needed in our ability to talk about death and grief, the training around PEoLC for the healthcare professionals people encounter every day lags far behind more specialised areas.

A 2025 Health and Social Care Committee Expert Panel evaluation found the health and social care workforce ill-equipped to meet the needs of people at the end of life because of insufficient provision of education and training.[53] Similarly, the Commission on PEoLC found that clinicians identified the lack of adequate training as a major barrier to delivering high-quality PEoLC. It recommends education and training in palliative care for all health and social care staff.

GPs, community nurses, care home workers, paramedics, pharmacists and allied health professionals, such as physiotherapists and occupational therapists, all support dying people every day, often with little specialist palliative care training. They deserve the skills and confidence to do it well. Improving and increasing training for healthcare professionals will enable earlier identification, better symptom management, more appropriate use of specialist services, and fewer crisis admissions. It will also help normalise conversations about dying – supporting a move away from the over-medicalisation of death that we so often see.

The NHS should work with organisations like Sue Ryder to draw on years of expertise in training, education and development of practical tools. This is not a peripheral activity. It is central to the systemic change we are describing, because it can't succeed without a workforce that is equipped to deliver it.

53 https://committees.parliament.uk/publications/50461/documents/273119/default/

The implications

The shifts described are not incremental improvements to the existing model. They represent a fundamental change in how PEoLC is conceived, funded, and delivered. That has implications for the NHS, for the hospice sector, for Sue Ryder, for patients and for the public.

For the sector

The hospice sector has been warning of a crisis for over 20 years. And yet a fundamental change to the model has not been attempted. As a sector, we must work together to become the pioneers of something new. This will require us to be open to doing things differently and stepping away from what has always been done.

Change is possible – and there are already inspiring examples of it happening around the country: running virtual wards, hospice staff working inside hospitals, starting initiatives that reach much further into communities. But these innovations go against the grain of how hospices have come to be understood: by the public, by donors, and by large parts of the NHS. The sector needs to lead the reframing. That means prioritising population reach and improving patient outcomes over institutional preservation, and working in genuine partnership to provide the right capacity and locations for hospice services. As a sector, we need to feel confident that we can adopt ideas and innovations that help us grow.

Change can be difficult. But our mission – what we ask our brilliant staff, supporters and volunteers to help us deliver – stays the same. To watch a crisis worsen when we have the tools and moment to address it would be a dereliction of our duty. To stand still is a choice, and it is not one we will make.

For patients

For patients, fewer people will miss out and inequities in care will be reduced.

These shifts would mean support is available based on need, not diagnosis, postcode, or ability to navigate the system. Care should reflect what matters to each person, be provided earlier in people's trajectories and be available in the most appropriate setting for each individual, with reliable home and community support that respects their wishes and clinical needs – not an expectation that families manage alone.

Hospital and inpatient hospice care should remain available but not as the first or last port of call when another setting is more appropriate, with admission never treated as failure but an opportunity to get it right for the patient in front of us. Every setting should offer dignity, comfort, clear communication, and physical and emotional support. Families and carers should receive practical help and bereavement support. Success should be measured by people's experience and whether their needs are met, not simply where they die.

Importantly, the excellence in care that is expected from hospice services remains, with less focus on the location, and more on the patient.

For Sue Ryder

Sue Ryder cannot achieve its mission through the model it has inherited from the pioneers of our past. We know we need to radically change our delivery to ensure we can play our part in fixing the wider system. The current model is only reaching approximately two thirds of the people who need PEoLC. Our goal is to help change that, so nobody misses out – not by replicating the existing model at greater cost, but by working differently and in deeper partnership.

In 2024–25 we cared for 9,400 people. By 2030, our goal is to double the number of people we support from the 2024 base and deliver 95% of our services within the community. By 2035, it is to reach at least three times as many as we did in 2024–25 – without a threefold increase in cost.

We recognise that while we aim to triple the number of people whose lives we touch, we will not be able to triple the resources available to do it. That is why the 'how' matters as much as the 'what'. Working differently, in genuine partnership with the NHS and other providers, and investing in community and preventative models rather than costly inpatient infrastructure, will help us to bridge that gap. As a provider of services in multiple areas of the country, Sue Ryder is uniquely placed to deliver the shifts we have described. But we still need our communities and supporters more than ever. Some of what we do today will need to change – our organisation will change. What will not change is the expertise at the heart of our care: the skills and commitment our staff and volunteers bring every day. It's why people trust us, and it's what our future is built on. We will seek wide support for this plan – and we will be transparent about the choices we are making and why.

What we are asking for

Transforming PEoLC cannot be done by any single organisation. It requires action across the system. We are making four sets of asks.

We are asking the NHS and the Government to:

- Commission differently and increase accountability. Set targets for PEoLC to drive strategic commissioning, using the Modern Service Framework to deliver consistency, adequate resourcing and inequity reduction.
- Set a baseline for the integration of PEoLC as a core component of neighbourhood health infrastructure – within PCNs, ICBs, and the developing neighbourhood health teams – not as a specialist afterthought, but as a foundational element.
- Sustainably fund the clinical cost of specialist palliative care delivered by hospice and community providers on the same basis as other contracted NHS services – full cost recovery, consistently applied.
- Bridge the gap in funding required to support sector transformation and to extend services to the one in three who currently miss out.
- View PEoLC as a core component of the prevention and system planning NHS agendas. Support earlier identification and referral to palliative care, so that people are not reaching services only in the final hours or days of life – and so the proportion dying before they reach specialist care reduces significantly, and ultimately patient experience and outcomes improve.
- Invest in workforce training, embedding palliative care skills as a core part of clinical education across primary, community and acute settings – reducing the over-medicalisation of death wherever possible.

We ask our colleagues across the hospice and palliative care sector to:

- Prioritise reaching more people, and start new conversations with other local providers and the NHS to review and reform provision – stretching our collective resources to match local population need.
- Be open about fairness in funding – we can only define what percentage of costs are covered by the NHS if we are clear as a sector what a reasonable cost for delivery is. While value-added services can be covered by charity support, clinical salaries and 'on costs' must be covered universally.
- Lead the public reframing: bed closures are not always a sign of decline. They can be a sign of progress.

We ask everyone to:

- Start the conversation – with family, with GPs, with loved ones – about what matters at the end of life, and what kind of care you would want.
- Make an Advance Care Plan to detail what you would want, and to protect your family from having to make impossible decisions without guidance.
- Demand better – of the NHS, of the hospice sector, of government. Death is universal. The care around it should be too. Support the case for a system that reaches everyone, wherever they are and whoever they are.

We ask our charitable supporters to keep donating:

- Essential clinical care must be publicly funded, but our generous supporters remain vital to the quality of care we provide, wherever it is delivered. Our teams care for people day in and day out, making a difficult time in their lives as good as it can be. We want this care to be available to everyone who needs it, and we are committed to changing how we work so that we and the sector can reach more people in the future. We need your help to do this. Charitable donations support the additional time, choice and family support that matter so much: more time with loved ones, more choice about how and where care is provided, and more support for families before and after a death.

A final word

Sue Ryder has been trusted by hundreds of thousands of people at the hardest moments of their lives. We do not take that trust lightly. We will bring everything we have – the skill and care of our staff and volunteers, our national reach, our local roots and the trust people place in us – to challenge the system, make the case for change, and help build what comes next.

The road ahead will ask difficult things of all of us. But at the end of it, more people will receive the care they deserve. Fewer people will die without support. And the system around us will have begun to change – because enough of us were willing to demand it.

Too many people do not get the death they deserve. Together we can change this: death deserves better.

"For everyone to be treated with the dignity and respect they deserve, regardless of their postcode or economic background."

Michael's wish

Appendix. What is good PEoLC?

1. Communication and coordination of care

- Open, honest, and ongoing conversations between patients, families, and healthcare professionals.
- The opportunity to talk to healthcare professionals to explore values, treatment preferences, and goals of care within an Advance Care Planning conversation (where wanted), including regular reviews.

2. 24/7 access to care and single point of contact

- Patients and families can access advice, assessment, and symptom management (including access to medication and equipment) at any time, day or night.
- A single, coordinated access point (for example, a specialist palliative care helpline or community team) that helps with continuity, reduces crisis admissions, and provides reassurance and timely support.

3. Education and empowerment

- Patients and carers are given information about their condition, symptom management strategies, and what local services and benefits are available to them.
- Supports self-management and helps people navigate the healthcare system, ensuring they receive all the care and support they need.

4. Pain and symptom management

- Comprehensive assessment and management of physical symptoms.
- Regular review and adjustment of treatment plans to maintain quality of life and dignity.

5. Psychological and emotional support

- Recognises the challenges of living with a terminal illness beyond physical symptoms.
- Access to bereavement support, psychological therapies, and spiritual or pastoral care as needed, supporting both patients and their families through anticipatory grief and loss.

The story of Sue Ryder

Sue Ryder was founded in 1953 by Baroness Sue Ryder, initially to provide relief and support to survivors of Nazi concentration camps and others left displaced and traumatised by the Second World War. From the outset, the organisation was defined by a willingness to go where need was greatest – and to do so with humanity, directness, and care.

Over more than 70 years, Sue Ryder has evolved continuously in response to the people it serves. In the decades following its founding, the focus shifted toward caring for people living and dying with cancer, at a time when cancer survival rates were poor, and the hospice movement was in its infancy. Sue Ryder became one of the pioneers of specialist palliative care in the UK, establishing a model of care rooted in dignity, compassion and personalisation that remains central to our work today.

As medicine advanced and survival improved for many conditions, Sue Ryder broadened its focus again – providing specialist support for people with complex neurological conditions including Huntington's disease, multiple sclerosis and acquired brain injury, whose care needs were substantial and long-term but whose voices were rarely heard in mainstream services. We also developed one of the UK's largest free bereavement support services, recognising that grief – too often invisible and unsupported – is part of the same continuum of care.

Today, Sue Ryder operates hospices and community palliative care services, and provides bereavement support across the UK. Sue Ryder is thousands of staff and volunteers across our services, communities, and shops, supported by the generosity of millions of people who share our belief that no one should face terminal illness, death or grief alone.

Our history is not our destiny. It is our foundation – and it is what gives us both the confidence and the obligation to call for the change this paper describes.

Thanks

With thanks to authors: James Sanderson, CEO of Sue Ryder, Emma Vasey, Director of Strategy and Corporate Affairs, and Sophie Meagher, Senior Policy and Influencing Officer.

Thanks is also given to the many organisations and individuals who've helped us to shape this paper and to provide valuable feedback, including but not limited to:

- Steve Cabrera – Bective Consulting Ltd
- The NHS Strategy Unit
- Hospice UK
- Sue Ryder's Board of Trustees

Finally, thanks to the sources of information from external publications drawn upon throughout the document and to our wonderful supporters who've shared their wishes for palliative and end-of-life care, helping to illustrate people's lived experience and hopes for the future.

Sue Ryder is alongside people through terminal illness, death and grief. We provide expert palliative and end-of-life care and grief support, offering hope, dignity, and kindness.

For more information about Sue Ryder

call: **0808 164 4572**

email: **engage@sueryder.org**

visit: **sueryder.org**

/SueRyderNational

@suerydercharity

Sue Ryder, 183 Eversholt Street, London NW1 1BU

Sue Ryder is a charity registered in England and Wales (1052076) and in Scotland (SC039578). Registered office: Rebow House, 60 Head Street, Colchester, Essex, CO1 1PB. Ref. SR-00138. © Sue Ryder. November 2026.

Because no one should face death or grief alone