Commission on Palliative and End-of-Life Care: Call for Written Evidence

March 2025

At Sue Ryder, we want to work with the Government to fix the current challenges in palliative and end-of-life care (PEoLC) and create a new ecosystem which supports people to live and die well. Life expectancy is much higher now than when the NHS and the hospice movement started. We have a rapidly growing, ageing population and not only are people living longer, they acquire comorbidities along the way. That is why we need radical approaches to meet the needs of people at the end of life.

Our five-point plan to help build a new ecosystem for PEoLC includes:

1. Greater specialist PEoLC provision in hospitals through the introduction of Sue Ryder Alongside suites.
2. Shifting care into the community through the increase of hospice at home services and virtual wards, funded in line with national currencies and supported by the reform of CHC Fast Track.
3. Ensuring existing hospices are an active part of neighbourhood health infrastructure, utilising the services to effectively improve support to people living with complex multi-morbidities and long-term conditions.
4. An improved national digital PEoLC support offer shaped by experts, providing people with the right tools to plan effectively for their future and share their wishes with everyone involved in their care.
5. Equipping healthcare professionals to have conversations about death and dying through better education and training.

These proposals, detailed throughout our submission, aim to improve outcomes for patients, tackle inequalities and reduce pressure on the NHS.

1. **What is your special interest in Palliative and End of Life Care?**
   For more than 70 years, Sue Ryder's specialist teams have provided expert palliative and end-of-life care (PEoLC) to patients at our hospices, in people's homes and out in the community. We have seven hospice services across five Integrated Care Systems and demand for our services continues to increase year on year.

   Our vision is for a society that supports everyone through dying and grief. To deliver this vision, we want to help people who are dying to live well. PEoLC is integral to this – particularly in an ageing population, where more people are living longer with increasingly complex conditions.

2. **Describe what is working well in the provision of Palliative and End of Life Care**

The hospice sector provides PEoLC to around 310,000 people a year[1], improving patients' and their families' experiences of dying and grief by caring for people in their place of choice, preventing further health deterioration and enabling people to live well with a terminal illness through effective symptom control and holistic interventions.

Most people in the UK want to die at home[2] and hospice services reflect this – in 2023/24, 55% of hospices' total activity was delivered at the person's place of residence.[3] At the same time, hospice inpatient units (IPUs) continue to provide high-quality and holistic care to patients with more complex needs, such as those who need support with symptom control or people nearing the end of life. Hospice IPUs also act as local hubs where people with long-term conditions can receive treatment and support, such as breathlessness management, to relieve symptoms.

Hospices' unique position in the system as independent organisations allow us to be agile and innovative, continuously evolving services to meet the broad range of PEoLC needs. For example, Sue Ryder developed nurse-led beds at Manorlands Hospice in Keighley and medically-light beds at Thorpe Hall Hospice in Peterborough so we can care for a wider range of patients. These services deliver end-of-life care to people who do not need specialist or complex levels of support. Previously, people may not have met the hospices' specialist referral criteria or missed out due to referrals being prioritised on levels of need. These new services mean we can offer more people a choice about where they are cared for and help relieve pressure on hospitals and out in the community.

These are not the only hospice services, however, to reduce hospital use at the end of life. With the right community interventions, emergency admissions can be reduced. In 2023/24 Sue Ryder's hospice at home services in Peterborough and Cheltenham cared for 609 patients. Of those patients, 517 acute admissions were avoided. IPUs also play an important role - in the same year, our Duchess of Kent Hospice IPU recorded 146 avoided acute hospital admissions across 279 patients. Avoidance of emergency admissions not only improves outcomes for patients but represents a significant saving for the NHS - recent analysis from Marie Curie and Nuffield Trust has found that £6.6 billion is spent on emergency hospital care for people in the last year of life.[4]

3. **What steps need to be taken to ensure better service funding and commissioning?**

[1] https://www.hospiceuk.org/about-us/key-facts-about-hospice-care
[2] Marie Curie (2023), Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401b_padd_briefing_final.pdf#:~:text=Most%20people%20in%20the%20UK,their%20preferred%20place%20of%20death.&text=Being%20free%20from%20pain%20and,days%20(38%25)%20of%20life
[3] https://www.hospiceuk.org/about-us/key-facts-about-hospice-care
[4] Marie Curie (2025), Public expenditure in the last year of life. public-expenditure-in-the-last-year-of-life-report

Much of the hospice sector is facing real-terms cuts in the money it receives from government. There needs to be a reset to make sure people get the care they need right now and in the challenging years ahead. At Sue Ryder, we want to work with the Government to create a new ecosystem for PEoLC to improve outcomes for patients, tackle inequalities and reduce pressure on the wider health and care system.

Our PEoLC ecosystem involves Sue Ryder Alongside suites being created on hospital sites. In our model, patients who are expected to be in the last year of life would be transferred to a Sue Ryder Alongside suite from ambulances, A&E and other wards within the hospital.

Once in our care, we can put packages in place to discharge people back to the community, helping contribute to the Government's vision and, crucially, helping people live the rest of their lives to the fullest, and in the place they most want to be – home. In the current system, there are considerable delays and challenges when discharging patients nearing the end of life from hospital. Alongside suites will be in a better position to facilitate efficient transfer to community settings through their links with and knowledge of local hospice services. This is much needed – 8% of people referred to a Sue Ryder IPU between September 2023-October 2024 died before admission, indicating referrals are being left too late.

For people who are at the end of life and cannot be discharged, Sue Ryder Alongside suites provide the "home for home" setting that people so greatly value from our hospices but all on the same grounds as the hospital. This gives families the space they need and gives the patient the compassionate care that hospices do so well.

Each Alongside suite has the potential to care for hundreds of patients every year, rapidly freeing up bed space within the wider acute setting. The bed capacity of Alongside suites could be scaled up or down dependent on need within the acute setting and the landscape of existing services in the area that can support admissions prevention and discharge.

We propose Alongside suites are co-funded by the charitable sector and the NHS on a tariff basis, creating a more sustainable way for both government and hospices to deliver this care. By splitting the cost of this model down the middle – 50:50 – the hospice sector would see a dramatic improvement to the Government income it currently receives. This model does not require additional Government funding. Instead, our proposed funding mechanism is the redirection of some of the existing funding spent on PEoLC within Trusts to pay for Alongside suites on a currency/tariff basis. This ensures that money follows the patient – Alongside suites will take patients directly out of the acute setting.

While this does represent a considerable shift in the approach to PEoLC commissioning, Alongside suites will deliver substantial value for money for the NHS. Our model would provide dying people admitted to hospital with the expert, compassionate care that families value so much from hospices. It would be a more cost-effective use of available funds and would instantly free up beds in our stretched and crowded hospitals. Not to mention, the model would realise wider savings in the system through the early identification of need for bereavement interventions.

Sue Ryder's vision for a future PEoLC ecosystem also involves shifting care into the community through the increase of hospice at home services and virtual wards. Thousands of patients who need clinical support at the end of life could be supported by community hospice services rather than hospitals. However, gaps in community care, particularly out of hours, mean that currently many don't get the right care at home. With appropriate investment, PEoLC expertise and services can be embedded where they have the most impact. This will increase the numbers of people who can be cared for by community hospice services, supporting the NHS 10-Year Health Plan ambition to shift care from hospital into the community.

Sue Ryder is well-placed to lead this change, with 80% of our care already provided in people's homes. In recent years we have shifted towards a community-based model in a drive to meet patient preferences. This has included the transformation of our PEoLC service in South Oxfordshire from an IPU to a mixed-model approach. Our hospice at home service in South Oxfordshire cares for patients in the community and this has been complemented by the establishment of specialist palliative care inpatient beds at Wallingford Community Hospital.

The model would be co-funded by the NHS, with 50% of delivery costs being recovered for the hospice sector by the provision of contracts in line with NHS tariffs based on currencies for equivalent NHS care. We recommend that consideration should be given to the use of Fast Track Continuing Healthcare monies to fund the expansion of hospice at home provision. This is not about new money but about efficient use of existing budgets.

Increasing the provision of PEoLC in the community will bring a significant return on investment for the NHS, with 50% of delivery costs being met by the hospice sector. At the same time, this model of care will help people stay out of acute settings, reach wider communities, improve PEoLC outcomes for patients and drive-up standards in community care delivery.

Specialist hospice inpatient care continues to be an essential component of the community PEoLC delivery model and should be funded through a combination of charitable income and statutory funding, in line with NHS tariffs. Hospice IPUs must

also be considered as a support mechanism for patients facing increasing complexity in their lives as they enter their final 1000 days, working alongside Neighbourhood Health Centres to provide local support with symptom management, respite and holistic care at the right time. However, specialist hospice inpatient care must be complemented with other approaches if we are to ensure everyone has access to appropriate care when needed.

4. **How would you want to address the inequitable access to Palliative and End of Life Care?**

Supporting Alongside suites (as outlined in our response to question three) would significantly improve NHS and hospice service efforts to address health inequalities at end of life due to the diversity of patients in acute settings. The hospice population is still disproportionately White, of higher social economic status and middle-aged.[5] In contrast, 43% of White people who died between 2019 and 2021 died in a hospital setting, compared to 59% of Asian/Asian British people and 52% of Black /African /Caribbean /Black British people who died.[6] As well as addressing inequitable access to inpatient PEoLC, Alongside suites would also help to address inequities in community care as the model would increase referrals from acute services to community PEoLC.

However, referrals from Alongside suites would only be one route into community PEoLC. If care is to be moved into the community in a way that benefits everyone, work must be done to better understand and address inequalities, including through engagement with patients, families and carers.

ICBs should measure and address inequality in order to meet the PEoLC needs of their populations, with a focus on working with local government to address shared vulnerabilities that put people at higher risk of missing out on appropriate care. A gap analysis of every area must be carried out to identify where populations are at higher risk of missing out on care and to identify where PEoLC provision is inadequate. This must be followed by the implementation of a plan to address any identified deficiencies and to ensure a sufficient range of services are available to meet the population's needs.

The Government should commit to strengthening the accountability on ICBs to deliver PEoLC for their population in line with their statutory duty and to ensure guarantees on the minimum levels and types of service that should be expected.

[5] Tobin J, Rogers A, Winterburn I, et al. BMJ Supportive & Palliative Care 2022;12:142–151. https://arc-eoe.nihr.ac.uk/sites/default/files/uploads/files/Hospice%20care%20access%20inequalities%20a%20systematic%20review%20and%20narrative%20synthesis_2.pdf

[6] ONS (2022), Number of deaths by ethnicity, place of death, region and age: England, 2011 to 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/adhocs/14716numberofdeathsbyethnicityplaceofdeathregionandageengland2011to2021

Currently ICBs are not adequately fulfilling their statutory duty and so steps must be taken to guarantee necessary levels of PEoLC delivery going forward.

In addition, a national core data set should be developed for PEoLC, specifying the data that services and providers must collect and report to the Integrated Care System (ICS). This must include collecting demographic data as this is key to an ICS understanding its PEoLC population health needs and in turn acting in line with their statutory duty to address these needs. Currently collation of this information is inconsistent across the system and providers.

5. **What are the top three barriers to delivering optimal Palliative and End of Life Care?**

Priority One

Current funding models are a significant barrier to delivering optimal PEoLC. It costs £1.8 billion each year to run the hospices in the UK and less than £0.5 billion of this comes from the Government.[7] This makes it challenging for the hospice sector to keep up with rising demand and develop new models of care to address inequalities and ensure people get the right care at the right time.

Changing the way hospice services are funded for the care they deliver and introducing Government support for a move to a more efficient model of care delivery would mean that hospices could support many more people nearing the end of life to stay out of hospital and to experience better outcomes.

Currently ICBs are not adequately fulfilling their statutory duty to deliver PEoLC for their population, as outlined in the Health and Care Act 2022, and so steps must be taken to guarantee necessary levels of PEoLC delivery going forward. The Government should commit to strengthening the accountability on ICBs to deliver PEoLC in line with their statutory duty and to ensure guarantees on the minimum levels and types of service that should be expected. This should include changing the way they've traditionally commissioned PEoLC in order to meet more needs.

Priority Two

Overuse of hospitals at the end of life is also key barrier to delivering optimal PEoLC. 43% of deaths still occur in hospital,[8] a third of hospital inpatient care is for people in

[7] https://www.hospiceuk.org/about-us/key-facts-about-hospice-care
[8] Nuffield Trust (2024), What primary and community services do people who die at home receive? What primary and community services do people who die at home receive? | Nuffield Trust

the last year of life[9] and in the year ending August 2023 9% of all emergency admissions were people in the last month of life.[10]

This is harmful to the patient and often means they are not getting the right PEoLC. The majority of people want to die at home and just 6% of people in the UK say they would prefer to die in a hospital.[11] An ONS survey of bereaved people looking at quality of care delivered in the last three months of life found that quality of care rated as excellent was highest where care was provided by hospices (76%), compared to GPs (41%), hospital doctors (34%) and urgent care services (26%).[12]

There needs to be greater recognition of the value that improved PEoLC will bring to the wider system, it can improve patient care, free up NHS capacity and save the NHS money. To ensure that PEoLC can deliver these improvements across the country, care at the end of life must be shifted out of hospitals and into the community and to locations where specialist PEoLC is provided.

Priority Three

A lack of advance care planning is a key barrier.[13] Evidence shows that advance care planning has strong associations with lower rates of hospital deaths, improved quality of care and a reduction in the frequency of avoidable emergency admissions in the last months of life.[14] It can also help people to understand what care options are available to them and support earlier PEoLC intervention. Despite the benefits to both patients and the healthcare system, Sue Ryder polling found that almost nine out of ten people in the UK have not written an advance care plan.[15]

Low uptake of advance care planning is partly down to the fact that many healthcare staff feel unprepared for initiating conversations around the subject, particularly when death and dying remain taboo topics.[16] Even when advance care plans are in place they aren't always shared across the system, for example a Nuffield Trust report found that for people who died in hospital with an advance care plan it was often not shared with the GP record.[17] Additional 2024 research found that while

[9] Clark D, Armstrong M, Allan A, Graham F, Carnon A, Isles C. Imminence of death among a national cohort of hospital inpatients: prevalent cohort study. Palliat Med 2014;28: 474–9 https://pubmed.ncbi.nlm.nih.gov/24637342/

[10] Nuffield Trust (2024), How are hospital services used at the end of life? https://www.nuffieldtrust.org.uk/news-item/how-are-hospital-services-used-at-the-end-of-life-0#:~:text=In%20the%20most%20recent%20study,first%20wave%20of%20the%20pandemic

[11] https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2024/n401_padd_report_final.pdf

[12] ONS (2015), National Survey of Bereaved People (VOICES): England, 2015. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#quality-of-care-by-setting-or-service-provider

[13] McIlfatrick, S., Slater, P., Beck, E. et al (2021). Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. BMC Palliat Care.

[14] https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf

[15] Attitudes to palliative care research conducted by Censuswide and commissioned by Sue Ryder, March 2024

[16] https://www.macmillan.org.uk/_images/missed-opportunities-end-of-life-advance-care-planning_tcm9-326204.pdf

[17] https://www.nuffieldtrust.org.uk/news-item/what-end-of-life-care-do-people-who-die-in-a-care-home-receive-and-how-has-this-changed-over-time

digital systems supported the documentation of advance care plans, they were less helpful in sharing them.[18]

On top of a lack of advance care planning, most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative care approach before they die. This must be addressed as recognising that someone is close to the end of life helps to ensure the right care is provided. Analysis from Nuffield Trust has found that across all causes of death, only 30 to 40% of patients had a palliative care need recorded.[19]

To address this the Government should support the development of improved PEoLC training for healthcare professionals and a digital national support package to help people plan for death. This will drastically improve people's end of life experiences, advance care planning and professional's ability to understand their patients' needs and wishes.

6. **What are the top three things you would change to improve the service?**

Priority One

We need to see government commitment to support new models of PEoLC which help to reduce deaths in acute settings and move more care into the community. As outlined in question three, our vision for a new PEoLC ecosystem would achieve this through the introduction of Sue Ryder Alongside suites, the increase of hospice at home services, virtual wards and more effective use of hospice buildings and IPUs as part of an integrated neighbourhood health approach.

Priority Two

There is too little focus on preventing the crises we see in PEoLC, resulting in pressures across the system and poorer patient outcomes. To address this, there needs to be an improved national digital PEoLC support offer shaped by experts, providing people with the right tools to plan effectively for their future and share their wishes with everyone involved in their care.

Sue Ryder will offer our expertise in the shaping of digital services and digital care plans to support the Government's move from analogue to digital. We will also develop a national PEoLC support package in partnership with patients and professionals to improve public and professional engagement with documenting health and care wishes. The support package will help people to understand their options, enable conversations, document their preferences and directives, put the right plans in place, and leave memories for friends and family.

[18] https://compassionindying.org.uk/blog-post/digital-approaches-advance-care-planning/

[19] https://www.nuffieldtrust.org.uk/news-item/what-primary-and-community-services-do-people-who-die-at-home-receive#:~:text=Recognising%20that%20patients%20are%20at%20the%20end%20of%20life&text=Across%20all%20causes%20of%20death,address%20individual%20and%20carer%20needs.

Priority Three

Healthcare staff, patients and families are often unprepared to have conversations about death and dying, creating a lack of forward planning and system collaboration.

In order to ensure the effective flow of patients in their last year of life, from A&E and other hospital wards into an appropriate palliative setting, Government must support the development of improved PEoLC training for all healthcare professionals.

Sue Ryder is developing an International Academy for Palliative Care, using our expertise in PEoLC and bereavement to ensure that the extensive network of professionals and organisations that impact people's experiences of death, dying and grief are equipped to address an important part of the PEoLC ecosystem – understanding and supporting people with death and grief.

7. **What steps do you believe need to be taken to improve public literacy concerning Palliative and End of Life Care options?**

Equipping healthcare staff to have conversations about PEoLC options with patients early on is a key step to improving public literacy. A 2021 study on public knowledge, attitudes and perceptions towards palliative care found that there are a range of knowledge gaps and misconceptions. It also found that a reluctance to have taboo conversations around death and dying may deter people from accessing integrated palliative care services earlier on.[20] At Sue Ryder we know that people access our services too late, or don't access them at all, because of misconceptions and fears around hospice services.

If healthcare professionals were to discuss PEoLC options with patients earlier on and address any misconceptions the public's literacy would improve and people would be able to make informed choices on the care that is best for them when they reach the end of life.

The Government must support the introduction of a comprehensive training programme for healthcare professionals, so they know how to have conversations about PEoLC and are aware of the full range of care options available.

Furthermore, teaching the public about death and health literacy must start in schools and continue throughout people's lives, through NHS and Government initiatives.

8. **How do you believe that Palliative and End of Life Care provision could be better coordinated?**

[20] McIlfatrick, S., Slater, P., Beck, E. et al (2021). Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. BMC Palliat Care.

The solutions we have proposed as part of the future PEoLC ecosystem would support better coordination of PEoLC provision.

For hospitals, discharging patients who are nearing the end of life to appropriate care can be challenging. Alongside suites will be in a better position to facilitate efficient transfer to community settings through their links with and knowledge of local hospice services. This is much needed – 8% of people referred to a Sue Ryder IPU between September 2023-October 2024 died before admission, indicating admissions are being left too late.

To provide people with seamless and integrated care, and the best possible death, end-of-life wishes must be consistently recorded and made easily accessible to health professionals when needed, so that care and treatment provided is tailored to the individual. The development of improved PEoLC training for healthcare professionals and a digital national support package to help people plan for death will help to achieve this.

High-quality PEoLC in the community is reliant on the availability of a range of healthcare services, including district nursing, GPs and community pharmacy. The Government would need to consider the delivery of these services alongside any increase in hospice at home provision in order to guarantee well-coordinated care for people at the end of life.

9. **If there is research that you would want to draw to the attention of the Commission, which would help to improve Palliative and End of Life Care, please provide or note this here**

Sue Ryder and the University of Birmingham have recently published a report, "Inequity in palliative and end-of-life care and bereavement support: An umbrella review". This report looks at the needs and experiences of disadvantaged population groups and highlights evidence gaps to guide future research.

Findings suggest there is more than links population groups that experience inequities than separates them and socio-economic inequalities increase a person's likelihood of experiencing inequity in PEoLC.

The report sets out a range of recommendations aimed at hospices, Integrated Care Boards (ICBs) and researchers. Key recommendations include:

Hospices and Integrated Care Boards (ICBs)

- Hospices and ICBs should ensure all commissioned care meets the shared needs of population groups who experience inequity in PEoLC and bereavement support.

- ICBs should measure and address the shared vulnerabilities that increase a person's likelihood of experiencing inequity in PEoLC and bereavement support.

Researchers

As research into inequity continues, researchers should:

- Address the evidence gaps identified within this review.
- Ensure research engages with people receiving PEoLC and experiencing bereavement, particularly groups who have historically had less research involvement.

Going forward, we are continuing our partnership with the University of Birmingham. University of Birmingham will use insights from this report to engage with key stakeholders and develop practical tools which aim to support ICBs to overcome health inequities at the end of life.

10. Is there other information that you want to share with the Commission?

Throughout this response we have referenced Sue Ryder's vision for a future PEoLC ecosystem. We have developed a five-point plan that would help to build that ecosystem. For further detail, please find a full copy of this five-point plan attached.