

North East and North Cumbria Integrated Care Board Palliative and End of Life Care Health Needs Assessment

**Supplement 6:
Place Based Summaries of Palliative
and End of Life Care Services**

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Introduction

This section presents place-based submissions from each area across North East and North Cumbria, highlighting the variation in service models and population need described throughout this review. While the preceding analysis outlines system-wide themes, risks, and recommendations, it is recognised that palliative and end-of-life care is delivered within diverse local contexts, each with its own strengths, challenges, and priorities.

The following submissions provide insight into these local nuances, including examples of innovation, service development, and areas requiring further investment or transformation. They are intended to complement the overarching findings of this report, ensuring that recommendations are interpreted and applied in a way that reflects place-specific need, existing infrastructure, and partnership working.

We would like to extend our thanks to all colleagues and teams who contributed to these submissions and shared their insights to support this work.

Together, these contributions support a balanced approach to system improvement—combining strategic direction at Integrated Care Board level with locally informed planning to deliver equitable, high-quality palliative and end-of-life care across the region.

Tees Valley Palliative and End of Life Care Summary

Epidemiology - Demographics

NENC ICB covers a range of geographical areas. This specific response covers the geographical areas of Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton on Tees (herein referred to as 'Tees Valley').

The ICB is responsible for commissioning physical and mental health care for the population residing within the boundaries of Tees Valley. This includes people who are registered with a GP practice and those who are not. Tees Valley has a total combined population of circa 738,054 people, served by 75 GP practices.

Tees Valley faces significant deprivation challenges, with Middlesbrough and Hartlepool ranked among the most deprived areas in England, marked by high poverty rates and health disparities. According to the latest [English Indices of Deprivation \(IoD\) 2025](#), Middlesbrough has been identified as the local authority with the highest proportion of deprived neighbourhoods in England, with 50% of its neighbourhoods falling into the most deprived category. Hartlepool ranks third with 42% of its neighbourhoods classed similarly.

As of January 2026, there were 6,001 patients on the palliative care register in Tees Valley, which equates to 0.8% prevalence (noting the expected target of 1%). It is possible to predict future prevalence and need in the short to medium term, but this is dependent on the ageing population and the increasing prevalence of some diseases such as cancer, dementia and diabetes, which impact on life expectancy and quality of life. Long term projection is complicated by unknown factors such as potential improvements in longevity from improved disease management or emergence of a new condition, such as we saw in the Covid Pandemic.

Although there are exceptions, with over two thirds of the current palliative care register aged over 70 and above, areas with high proportions of their population over 70 tend to have higher rates of their population on the palliative care register.

Around 96,000 people in 2020 were aged over 70 in the Tees Valley. By 2030, this is expected to grow by 18.7% to 114,684 and will reach 136,715 by 2014. This is an additional 40,736 people aged 70 and above in the Tees Valley population, growth of 41.2%. From the above we can ascertain that

the requirement for adequate palliative and end of life care services will increase in the coming years.

PEOLC Service Provision (Adults and CYP)

Adults

Palliative and end of life care is commissioned for the population of Tees Valley from three secondary care providers covering acute and community care, four Hospices and numerous primary care practices and voluntary sector support services. Five local authorities also support the social care needs of patients. Core services, such as primary care, community nursing and pharmacy provision are supported by specialist disease specific services in the community and hospitals, plus specialist palliative care services in the community, hospitals, and hospices. Our local hospice providers also offer a range of pain management services which complement those provided by community and acute care teams, plus a range of complimentary therapy services.

During the development of the Tees Valley Palliative and End of Life care strategy there was an opportunity to map local PEOL care services. It was noted that there was variation in the way in which palliative and end of life care services were commissioned and funded, largely down to historic ways of working. Some hospice providers were funded through grant agreements and other providers were contracted through Standard NHS Contracts. Different providers who offered the same services also had differing service specifications and therefore different pathways of care depending on which locality a patient resided in. Subsequent work programmes linked to implementation of this strategy have looked to transform care pathways, contractual arrangements and funding arrangements across all PEOL services commissioned from a number of providers, including our hospices.

Specifically from a Tees Valley perspective, the ICB has been working closely with all hospices for a number of years in relation to palliative and end of life care provision, and the important role hospices play in providing access to high quality care as close to home as possible, to support our patients and their families to have a personalised, positive experience wherever they wish to be cared for. The Tees Valley Local Delivery Team (part of the ICB) commenced a piece of work, utilising the information included within the local strategy and national guidance to review and update service specifications for the specialist palliative care teams across the area to better reflect the locally commissioned pathways and include work towards the future state for better PEOLC in the Tees Valley.

The tables below aim to describe the current PEOLC service provision across Tees Valley.

Specialist Inpatient bed provision

Location	No of Specialist palliative care inpatient beds commissioned for Tees Valley patients as of 1st April 2025:
Teesside Hospice Care Foundation	10
Butterwick House	8
Alice House Hospice	10
St Teresa's Hospice	6

Specialist Palliative Care Teams

Location	
North Tees Hospitals NHS Foundation Trust (part of the Tees Hospitals Group)	<p>The SLPC Team is made up of Senior Doctors, Nurses, Physiotherapists, Occupational Therapists and Therapy Technicians, with further multi-Disciplinary support from Chaplains and Clinical Psychologists</p> <p>Patients may be seen in a variety of settings, in hospital, in their home or care home, in clinic or at a hospice.</p> <p>9am-5pm 7 days a week (urgent advice only by a clinical nurse specialist over weekends)</p>
South Tees Hospitals Foundation Trust (part of the Tees Hospitals Group)	<p>The SLPC Team is made up of Senior Doctors, Nurses, Physiotherapists, Occupational Therapists and Therapy Technicians.</p> <p>8.30am – 4.30pm 7 days a week. Weekend/ bank holiday service is limited nursing staff who will manage triage advice and have some limited capacity to visit patients in order to prevent admission/facilitate discharge</p>
County Durham and Darlington Foundation Trust	<p>The SLPC Team is made up of Senior Doctors, Nurses, Physiotherapists, Occupational Therapists and Therapy Technicians</p> <p>9am-5pm 7 days a week</p>

OOH advice (5pm till 9am) via Tees-wide consultant on call rota- health professionals seeking advice to phone the switchboard at the hospitals and ask for the palliative medicine consultant on call.

Advice and support also available via the Single Points of Access (iSPA) services provided by each Trust

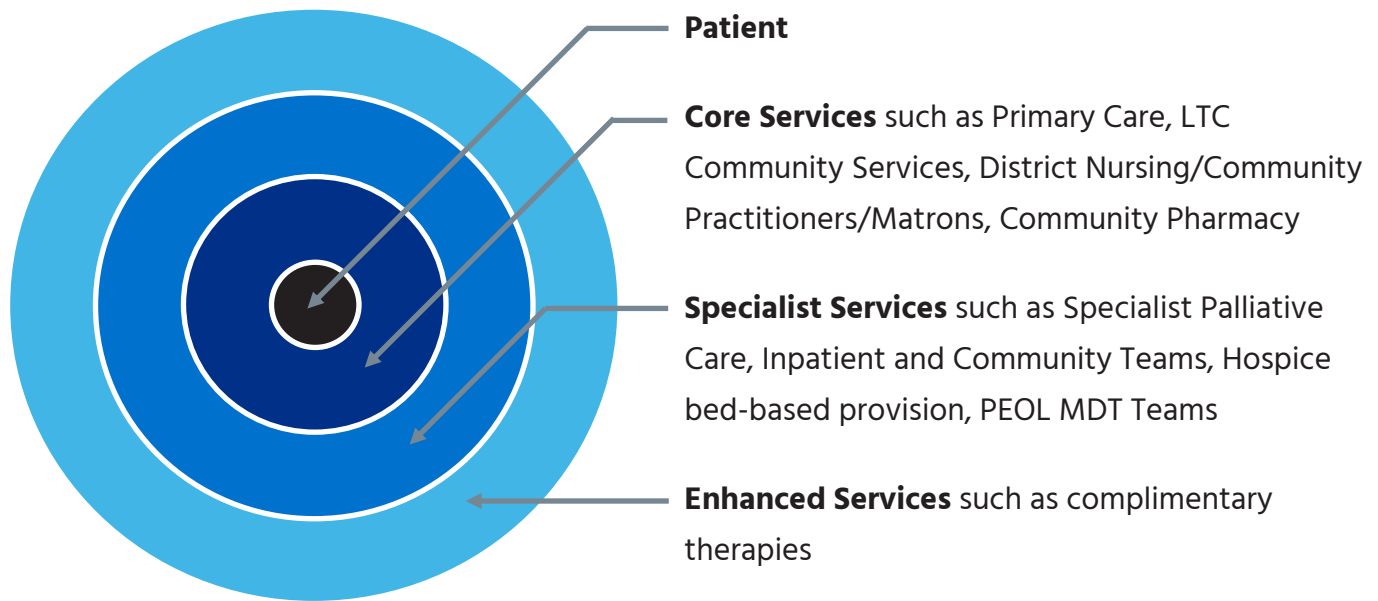
Other teams providing palliative and end of life care:

Location	
GPs across Tees Valley	GPs provide palliative and end of life care to their patient population, seeking specialist advice where needed from specialist palliative care services. GPs identify patients approaching the end of life, carry out assessments, care planning and anticipatory prescribing
Community nursing across Tees Valley	Provide evidence-based care and support to patients in their own homes. Predominantly providing diabetes care, general wound care (including pressure ulcer and leg ulcer management), administration of medications via a variety of routes, intra venous antibiotics, palliative and end of life care, diagnostic testing and phlebotomy, catheter care and complex patient management

Our hospices and voluntary sector organisations provide a number of complimentary therapies and wellbeing services provided via charitable income. These are as follows:

- Bereavement Services
- Day Hospice Services (such as symptom management, group support)
- Emotional and Psychological support for patients and families.
- Holistic/Complimentary Therapies (such as aromatherapy, reflexology, massage)

Fig 1. Tees Valley ICP Vision for PEOLC



Children and Young People

There are currently no commissioned specialist palliative and end of life care services for children and young people (CYP) across Tees Valley. Specialist clinical input is provided by the regional Children’s Hospices in Paediatric Services (CHIPS) team, with clinical supervision from consultants based in Newcastle.

Two hospices within Tees Valley provide support to children and young people with palliative care needs. Funding for these services was historically provided directly by NHS England; this now flows through the ICB via grant agreements. However, in the absence of clearly defined Schedule 1 specifications and associated key performance indicators, there is limited transparency regarding how this funding is utilised. As a result, these grants are not linked to defined service specifications, activity reporting, or performance monitoring and are understood to contribute primarily to overall hospice running costs.

For both hospices, the majority of activity relates to planned respite care, funded on a daily basis through NHS Children’s Continuing Care for eligible children. While the specific use of ICB grant funding cannot be fully evidenced, informal discussions with providers indicate that it is used to support general operational costs rather than discrete palliative and end of life care provision.

- 1. Butterwick Children’s Hospice** – has 6 beds and activity is predominantly planned respite. Schedule 1 of the agreement consists of 1 sentence - ‘Specialist Palliative and end of life services to children and young people’. There is no requirement to provide data to the ICB for

this service so actual activity is unknown, including bed availability, staffing numbers, bed days used or waiting lists etc.

- 2. Zoe's Place Hospice** – provides PEOL care to children under the age of 8 and is predominantly for planned respite care. Schedule 1 of the agreement is as follows:

Service Development Funding (SDF) for 2025/2026 has been disseminated from NHS England to the North East and North Cumbria ICB to support children and young people's hospice provision. The allocation of the Children's Hospice Grant for Zoe's Place Baby Hospice is detailed in Schedule 2. The service specification for specialist palliative and end of life care services for children and young people is below (followed by link to national service spec).

Funding is paid to the Zoe's Place Trust, a registered charity which consists of 3 hospices (Birmingham, Liverpool, Middlesbrough). We understand that the entirety of the NENC funding is passed to the Middlesbrough unit and is utilised towards the running costs of the hospice. The majority of the support offered by the unit is for respite care on a day-visit basis, funded by NHS CCC on a spot purchase arrangement. There is no requirement to provide data to the ICB for this service so actual activity is unknown, including bed availability, staffing numbers, bed days used and waiting lists etc.

Gaps in Service Provision (CYP)

- There is no ringfenced funding/commissioned service for CYP PEOL inpatient care.
- On account of the absence of NHS Standard contracts for these services, there is no mechanism for formally assessing activity levels, actual costs, staffing levels, availability of the services to patients, duration of admissions any gaps in service provision etc.
- Most children with NHS Children's Continuing Care funding are over the age of 5 because children with complex needs under the age of 5 are not deemed to require more support than their peers. This means that these families cannot access such support unless it is provided through hospices' charitable funding. It may be that some of the grant monies go towards this, but there is no mechanism for finding this out.
- Transition age CYP - There is no consistent transition process in place for supporting those CYP who will need to transition to adult services.
- The local councils are responsible for commissioning respite facilities for these patients. Initial discussions took place with all Local Authorities within Tees Valley around the potential of reviewing respite provision as a collective 18 months ago, however due to limited capacity these discussions have not progressed as yet.
 - See an example in this link for 1 of the 5 councils within the Tees Place Footprint.
[Specialist Short Breaks Directory.pdf](#)

- There are multiple reasons why CYPs with palliative needs are not identified as such and as a result GPs are often unaware of them. This can lead to a failure to develop advance care plans with the patients and poor preparedness for death for the families.

Stakeholder and Community Engagement (Adults)

As part of developing the Tees Valley Palliative and End of Life care Strategy, Tees Valley launched a period of engagement with both the public and stakeholders to look at how services provided to people who are in the last months of their life, known as end of life and palliative care services, are currently delivered, what currently works well and what can be done to improve them, so they are patient centred, offering individuals and their families access to collaborative, co-ordinated care.

Although the information shared was wide ranging, some key themes emerged. These were:

- A need to improve communication with patients, families and carers, both at diagnosis, during the provision of care and at the end of life
- Improved ways for patients, families and carers to make contact with services, helping them to navigate the system to gain access to care in a quick and easy way when this is needed and provide improved co-ordinated care to them.
- Opportunities to reflect on the way care is provided to patients, increasing continuity where this is possible and, in some cases, increasing the compassion provided to patients, families and carers.

To further expand the survey work undertaken, Tees Valley also offered respondents the opportunity to attend 1-1 sessions to share their story in more detail. 5 individuals came forward, and individual sessions were arranged where the experiences and thoughts of the family member or carer were collated. The detailed feedback gathered in these 1-1 sessions was in depth and varied, but some common themes were drawn out which were:

- A need for improved communication
- Improved points of contact for the families and carers
- More co-ordinated care across health professionals
- Continuity of care from health care professionals

Locality specific activity and initiatives (Adults)

Specialist Palliative Care Inpatient Provision

A significant proportion of the work undertaken over the last 3 years has specifically reviewed the way in which the ICB commissions Hospices across Tees Valley, what pathways of PEOL we commission from these providers and the financial arrangements in place for provision of such pathways, in line with national guidance such as the Commissioning and Investment Framework for Palliative and End of Life Care (March 2022). This work has resulted in agreement across the Tees Valley system that the ICB will commission specialist palliative and end of life care inpatient provision from all four Hospices across the Tees Valley, recognising they have the relevant skills and expertise to deliver this pathway comprehensively to meet the needs of our patients, and to complement other services across primary care and in our communities that are commissioned from other providers such as GP Practices and community providers.

This work has resulted in the ICB co-designing a specialist palliative and end of life care inpatient pathway with all Hospices, agreeing consistent admission criteria, developing and agreeing a financial framework for the model based on national tariff information and agreeing detailed implementation plans with each provider. For a number of Hospices across Tees Valley, including Butterwick, this also included a detailed investment programme which was implemented over a 2-year period.

During this process, the ICB worked with Hospice providers and broader partners in relation to mapping all PEOL commissioned services in line with NHSE guidance and concluded that the ICB needed to focus on the commissioning of specialist palliative and end of life care provision from Hospices for Tees Valley. This did mean that for some Hospices in Tees Valley, the ICB moved away from grant arrangements and/or vague block arrangements that contributed towards the organisation's running costs. It was agreed as part of this process that the ICB would focus on this commissioned pathway, and Hospices would continue to offer any additional enhanced services they felt they wanted to focus on as charitable organisations, from charitable income. The ICB committed to raising awareness of the enhanced services that Hospices offer as part of their charitable income via partnership forums and with GP Practices.

Specialist Palliative Care Teams

Engagement with stakeholders identified variation in the way in which palliative and end of life care services were commissioned and funded, largely down to historic ways of working. Different providers who offer the same services also have differing service specifications and therefore different pathways of care depending on which locality a patient resides. Tees Valley (which came

together in 2020) is made up of previous separate Clinical Commissioning Groups (CCGs) - Darlington CCG, Hartlepool and Stockton-on-Tees CCG and South Tees CCG. This coming together as a Tees Valley highlighted differences in the delivery of services across each area, different delivery models of care with differing staffing models and in some cases, differing outcomes. The Tees Valley Local Delivery Team commenced a piece of work, utilising the information included within the local strategy and national guidance to review and update service specifications for the Specialist Palliative Care teams across the area to better reflect the locally commissioned pathways and include work towards the future state for better PEOLC in the Tees Valley.

Education and Training

The findings from the engagement work undertaken with patients, families and carers whilst our local strategy was developed, alongside the findings from the NENC workforce confidence survey, demonstrated that more needs to be done to ensure all staff (not just specialist palliative care teams) who come into contact with someone who has palliative care needs or is reaching the end of their life are competent and confident in engaging in honest conversations and understand the role they can play in developing patient centred care plans, to make a difference to someone's life at such an important time.

To progress this important action, a number of task and finish groups were established with key stakeholders across our system, one of which has been an Education and Information Group. This group has focused on undertaking a local training needs assessment and scoping out potential training courses and resources that would support our local system in the delivery of good quality palliative and end of life care.

This training needs analysis highlighted a need for further training on communicating with patients/ and or families and advance care planning. To support this the local delivery team utilised a small amount of personalised care funding to work with the Gold Standards Framework to develop two roadshows in early 2025. These half day sessions focused on how to initiate care planning conversations with patients, and how to use the resources available such as deciding right templates. The roadshows were well received, with 87 delegates attending over the two sessions, including GPs, HCAs, care coordinators, nursing staff, volunteers, specialist palliative care teams.

A list of recommended palliative and end of life care training resources based on exploratory work the group has undertaken has been compiled. The list shares these recommended resources, recommended staff groups who would benefit from accessing the training and how regularly it is recommended they refresh this knowledge.

LDT specific recommendations

Adults

Improved System Interoperability

- Support our local organisations to enable data to flow between providers to support patient care
- Continue to promote the use of consistent regional templates for palliative and end of life care, with regular training
- Encourage hospices to consider how they can access shared patient care systems.

Coordination of care

- Ensure PEOl services utilise where available efficient referral routes i.e. Single Points of Access across each locality to co-ordinate pathways of care.
- Vision: To enable patient-centred care across all sectors for people with progressive, life-limiting conditions, from diagnosis to death. Supporting our palliative and end of life care system to feel appropriately equipped to deliver high quality palliative and end of life care to our population. Providing greater integration and seamless journeys for patients through primary, community, hospital, or hospice-based care at the end of their lives.
- Services will wrap around the needs of patients, with patients, their families and carers at the heart of everything we do. Services will build around the needs of the patients, enabling access to more complex care as required throughout the patient journey, plus being supplemented by enhanced services as and where these are available across our system.

Education and information

- Review the information available to patients and their families and improve this where required. This could be in the form of updating leaflets etc to provide consistent patient facing information
- We recognise there is further education needed to support professionals in advance care planning and initiating conversations with patients about death and dying.

CYP

- Implement formal contracts to replace grants for the children's hospices based on a co-produced service specification with KPIs which can act as levers for service improvement and consistency.

- Further work to understand the accuracy of GP records relating to CYP life limiting conditions and EOL, review the outcome and consider if a mechanism needs to be considered to ensure this is accurate and therefore CYP needs are being identified and met.
- Liaise with local councils to understand the full scope of respite provision for each LC area and consider opportunities for joint commissioning provision.

County Durham Palliative and End of Life Care Summary

Epidemiology - Demographics

County Durham specific demographics to note may include:

- Mortality from cancer in under 75s is statistically higher than England average
- Almost 60% of over 65s are living with at least one long term health condition; County Durham has the highest old age dependency ratio in NE and England and is rising year on year
- Ageing population especially in rural areas
- Highest ethnic minority population is GRT community
- County Durham geography is mix of rural and urban towns and villages, large rural areas, public transport links poorer in rural areas

PEOLC Service Provision

County Durham and Darlington NHS Foundation Trust (CDDFT) provides an integrated Specialist Palliative and End of Life Care (PEOLC) service offering 7-day face-to-face specialist palliative care assessment delivered in both hospital and community settings. There is 24/7 specialist telephone advice from consultants and senior palliative care doctors and has a Single Point of Contact (SPOC) for many , but not all, elements of the palliative care service.

The community service has almost 3000 referrals each year (an increase of 25% since 2019). The Acute Hospital Palliative Care Team provides support to 65% of patients dying in the acute hospitals and sees 3600 referrals per year. CDDFT is rated by the Care Quality Commission (CQC) as outstanding for palliative care.

While the NHS service does not provide inpatient SPC beds, patients can access inpatient care at all the local hospices (Willowburn, St Cuthbert's and St Teresa's) , which provides commissioned beds for County Durham with out-of-hours medical cover through the Specialist Palliative Care Advice line and out of hours GP service. Further commissioned beds are available in St Benedict's Hospice and Alice House Hospice. These hospices represent the inpatient SPC provision available to County Durham and Darlington residents, although their access models and reliance on charitable funding create variability in availability.

Across the wider PEOLC system, there is no formal Hospice at Home service though the excellent community nursing service delivers many elements of such provision. There are two specialist Occupational Therapists who work as discharge facilitators and a dedicated education post. Other AHP provision is supported by relevant services.

The locality has little day hospice or outpatient palliative care provision. Bereavement services are not well coordinated. In common with the rest of the region there is no EPaCCS system due to lack of development of both local systems and GNCR.

The service continues to develop feedback through the Friends and Family Test, VOICES and NACEL. There is strong commitment to quality improvement activity including NCEPOD and NACEL national audits, achievement of preferred pace of death (over 90% in both specialist palliative care and care homes service) and participation in the NEAS SPN audit. The previously well-established PEOLC oversight group has been challenged by recent reorganisation, and the absence of a Transitions Lead represents an additional service gap.

Stakeholder and Community Engagement

- In County Durham, a follow-up Voices Survey was commissioned in 2022/23 (repeat of survey in 2018)
- Carried out patient and public engagement as part of a joint procurement exercise in 2023 (Durham and Tees Valley) of Rapid Response Hospice at Homes Services – can share findings summary
- Hospice engagement pieces carried out by individual hospices

Locality specific activity and initiatives

County Durham specific initiatives include:

- Hospice collaborative working group in last two years has been focused on service integration and sustainability between local trust (CDDFT) and Durham-based hospices St Cuthbert's and Willow Burn. An integrated specialist palliative care staffing model is under development that will see shared resources working across hospital, community and hospice settings to improve patient experience, service sustainability and quality and staff satisfaction.
- County Durham patients follow pathways in and outside of the county in all directions, due to transport links, geography, socio economic factors, availability of specialist services. Our two hospices based in Durham are relatively central, but also commission services outside of area

following flow of patients e.g. IP beds in Hartlepool for Eastern corridor, IP beds and OP services in Darlington for South patch; former DDES locality served by Butterwick Hospice in Bishop Auckland.

- Durham Dales area and Sedgefield have strong referrer relationships with community hospital teams.
- Historical contracts with hospice providers are partly due to legacy of former commissioning boundaries and other factors e.g. former DDES (Durham Dales, Easington and Sedgefield)

LDT specific recommendations

- Continue development of the integrated specialist staffing model between local trust and hospices and broaden scope to include all commissioned hospice services used by County Durham patients
- Review of all contracts and service specifications in line with national guidance, together with all NENC localities

Northumberland and North Tyneside Palliative and End of Life Care Summary

Epidemiology - Demographics

Integrated Summary: Northumberland & North Tyneside

Socio-economic Deprivation

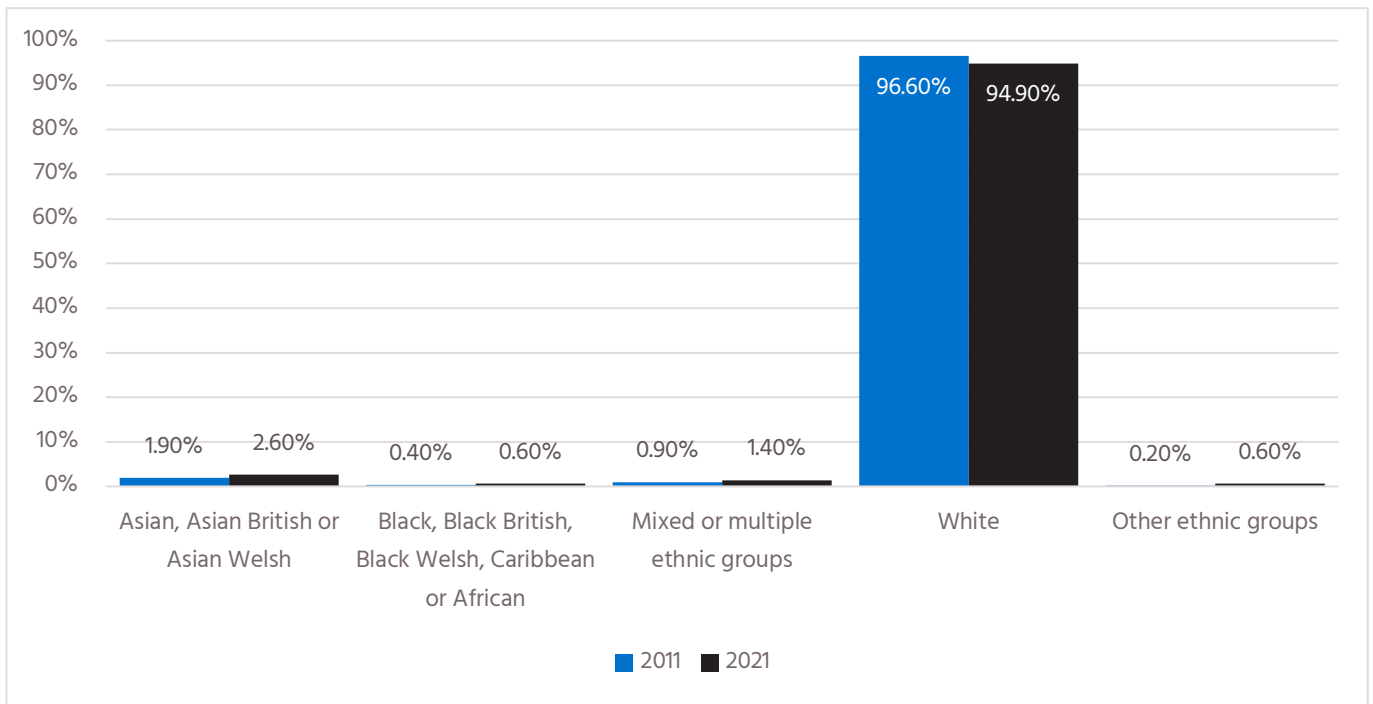
- **Northumberland** - Residents in the most deprived communities live significantly shorter lives, with around a 12-year gap in life expectancy compared to those in the least deprived areas. Healthy life expectancy shows an even wider inequality, with a gap of roughly 17 years. Social determinants are also a concern, as nearly half of adults using social care report not having as much social contact as they would like.
- **North Tyneside** - A clear social gradient in health exists, with higher mortality in deprived areas from heart disease, cancer, chronic respiratory disease and injury-related causes. Life expectancy has stalled over the last decade in line with national patterns.

Life Expectancy & Healthy Life Expectancy

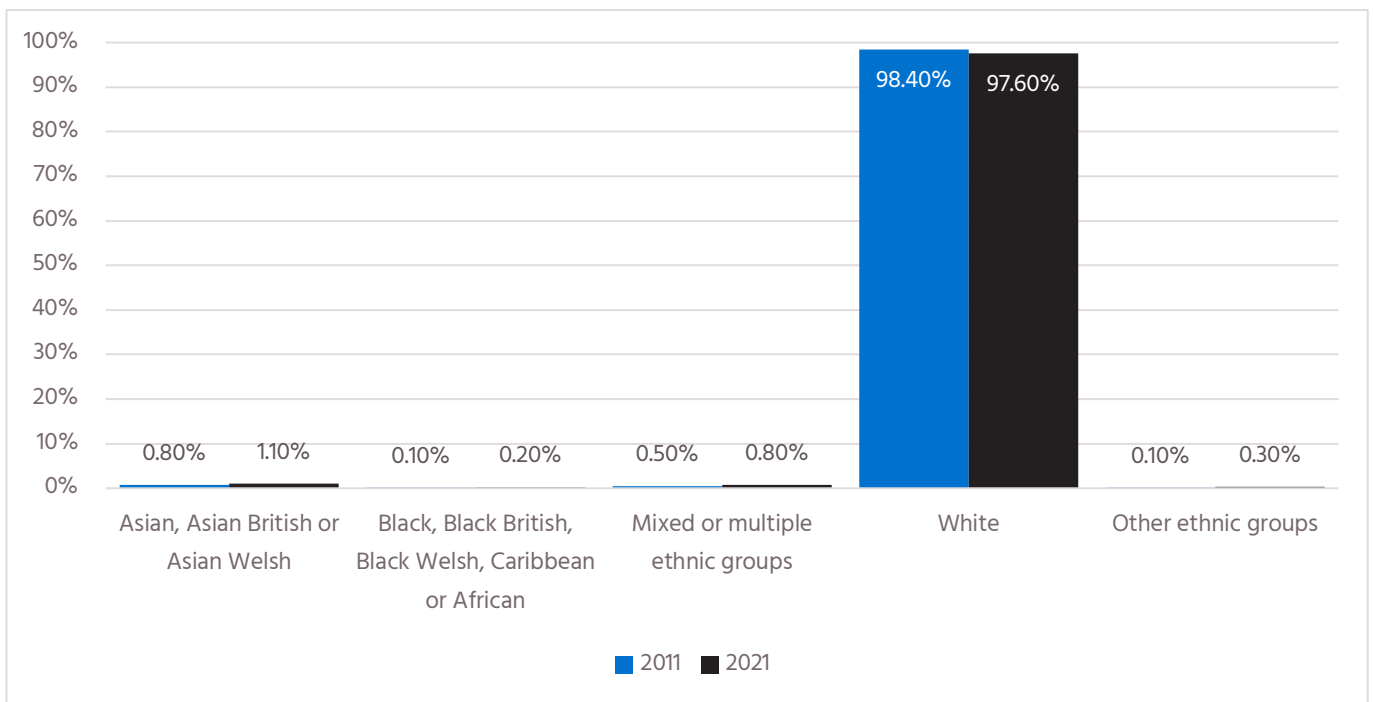
- **North Tyneside** - Male life expectancy is 77.7 years and female life expectancy is 82.1 years. Healthy life expectancy is 61.6 years for men and 57.2 years for women. Inequality gaps are notable: 12.3 years for males and 9.9 years for females. Graphical data shows that women spend around 20 years in poor health and men spend around 18 years in poor health, highlighting a significant period of life lived with long-term conditions.
- **Northumberland** - Large inequalities between communities result in substantial differences in both overall and healthy life expectancy. Visual indicators suggest favourable winter mortality and circulatory disease mortality compared with national averages.

Ethnicity Profile

Percentage of usual residents by ethnic group, North Tyneside



Percentage of usual residents by ethnic group, Northumberland



Learning Disabilities

- North Tyneside** - The prevalence of learning disability in North Tyneside is slightly higher than average, but most adults with a learning disability live in stable, suitable accommodation, and uptake of annual health checks is strong. However, employment levels remain very low and the number of adults needing long-term support is higher than nationally, indicating significant ongoing support needs.

Mortality – Leading Causes of Death

- **North Tyneside** - Major contributors to early mortality and inequality include heart disease and stroke, cancers (particularly lung cancer), chronic lower respiratory diseases including COPD, and injuries, poisoning and suicide—especially among men.
- **Northumberland** - Circulatory disease mortality is lower than national averages. However, frailty-related harm is more prominent; hospital admissions due to falls in older adults are significantly higher than the England baseline. Winter mortality among those aged 85+ is lower than the national rate.

Population Projections

- **Northumberland** - Approximately 26% of residents are aged 65 or older, higher than both the England and North East averages. This older population is projected to rise to 33% by 2043. The Old Age Dependency Ratio is already higher than regional and national levels and is expected to increase further.
- **North Tyneside** - Although specific projections were not provided, demographic trends follow the same pattern of an ageing population with increasing complexity of need.

Morbidity & Mortality Projections

- **Northumberland** - Rapid ageing will increase pressures from frailty, multimorbidity, falls and social care needs. Improving circulatory mortality means more older adults are living longer with chronic conditions, increasing demand for long-term care and community support.
- **North Tyneside** - Projected increases in long-term condition prevalence are driven by high levels of musculoskeletal conditions, obesity and chronic respiratory disease. The widening gap between life expectancy and healthy life expectancy suggests growing pressure on primary care, community services and long-term condition management frameworks.

PEOLC Service Provision

Palliative and end-of-life care across Northumberland and North Tyneside is delivered through a wide network of GP practices, community teams, include inpatient Palliative Care Units, which are very uncommon, hospices, care homes, voluntary organisations and acute services.

Both areas use palliative and supportive care registers to identify people early, coordinate multidisciplinary input and support proactive planning. North Tyneside has particularly high register completeness, with around 0.9% of the population recorded on its palliative care register—almost double the national position. Primary care use colour-coded palliative registries, regular MDT

reviews and Gold Standards Framework principles. These systems support more coordinated care, reduce emergency admissions and strengthen the ability to respond to changing needs.

There are notable local differences in care provision shaped by geography and workforce. North Tyneside has seen strong progress in enabling people to die in their preferred or usual place of care, with around 39% fewer hospital deaths than the national average. More than half of all deaths occur in the person's usual place of residence, and around 60% of palliative patients die in their preferred place of death. In Northumberland, approximately half of all deaths occur in hospital, with around one in ten taking place in specialist palliative or community hospital beds. Travel to place of death has improved over time, with average distances reducing to around 4–5½ miles, indicating more people are receiving care closer to home.

Advance care planning continues to strengthen across the LDT footprint. In North Tyneside, uptake of DNACPR decisions has risen from under 40% to around half of all patients on the palliative register, and the proportion with Emergency Health Care Plans or Advance Care Plans has increased to more than 75%. Practices with strong ACP use also show reduced emergency admissions during the final year of life. In Northumberland, EHCPs are routinely shared between GPs, NEAS, community nursing, out-of-hours services and hospitals, although consistency is affected by rurality, variable digital interoperability and limited specialist availability outside core hours. Both areas continue to focus on reducing inequalities for people who face additional barriers to accessing good PEOLC, including people with learning disabilities, those who are homeless, travellers and people with limited capacity.

The Specialist Community Palliative Care service has undergone recent significant restructuring, building on the impact and effect of the North Tyneside extended service, to address the inequalities in service provision across North Tyneside and Northumberland. We now have a 7-day model of planned care delivery, utilising nursing and AHP staff. This incorporates more integrated and cohesive working practices with the hospital-based team and Palliative Care Units, along with other community services. We have a Clinical Nurse Specialist on duty daily, 9am-7pm, to act as a coordinator for professional advice and support calls across the footprint, who has oversight of the availability and capacity of staff to address any urgent needs, can link with the other services to coordinate care, as well as an understanding of the patients at home with the most complex needs, wherever they live. Appropriate patients are now admitted directly to PCU on both sites at weekends rather than just North Tyneside, avoiding ED admission

Together, the combined system provides a strong foundation for the NENC Health Needs Assessment. The HNA will further examine place-of-death trends, the completeness and quality of GP palliative and supportive care registers, and the uptake and consistency of advance care

planning. It will also help identify the extent to which geographic variation, deprivation, care-home density, urgent care responsiveness and hospice access influence outcomes across Northumberland and North Tyneside.

Stakeholder and Community Engagement

Engagement activity covering the population of Northumberland was completed in May–June 2021 and involved a large-scale mixed-method approach to ensure residents' voices shaped end-of-life priorities. A total of 282 residents completed an online survey, providing statistically robust insight into perceptions, preferences and barriers around end-of-life care.

Alongside this, a five-week Citizens Panel of 16 members was convened to gather deeper qualitative views. Respondents represented a broad demographic mix, including a wide age range and individuals with and without professional involvement in end-of-life matters. This ensured the findings reflected a genuinely representative cross-section of the population.

Key findings included that 56% of residents felt uncomfortable talking about death, with discomfort significantly higher among younger adults. While 46% of respondents felt home was the best place to die, priorities were centred on being pain-free, retaining dignity and being with family. Engagement showed strong support for the developing end-of-life strategy, with 93% agreeing with its ambitions and 91% supporting its overall aims. Residents also provided clear suggestions on how to improve conversations about death and dying, including more public information, community-based initiatives like Death Cafés, and better communication training for staff.

The engagement also informed the co-creation of a future End-of-Life Agreement, outlining responsibilities for individuals and care providers. Residents felt their role was to communicate wishes clearly, plan ahead, and share preferences with family, while providers were expected to ensure dignity, respect, pain relief and honest communication. These insights provide a strong evidence base for shaping future services and ensuring end-of-life care across Northumberland aligns with local values, expectations and needs.

Locality specific activity and initiatives

Across Northumberland and North Tyneside there is a strong emphasis on building compassionate communities and strengthening the role of local people, voluntary organisations and community assets in supporting those approaching the end of life. Northumberland has well-developed

community-based initiatives, including an active network of voluntary sector partners such as Tynedale Hospice at Home, North Northumberland Hospice and a bereavement support service, all of which provide practical, emotional and social support. The area has also implemented Death Cafés, which received positive feedback and have been used to help normalise conversations about dying, grief and planning ahead—an important step given that over half of local survey respondents reported discomfort talking about death. The strategy prioritises building “compassionate, resilient communities,” emphasising public engagement, early conversations, and community groups that create supportive environments for people and families facing end-of-life challenges.

Bereavement support is a core component of PEOLC provision in the areas. In Northumberland, bereavement services are delivered through a wide partnership model, local hospices, specialist palliative care teams and voluntary-sector organisations. The services provide emotional support, practical guidance and group-based peer support for adults, carers and children. Bereavement support offer across nursing homes, community teams and specialist services, with a structured bereavement policy aligned across primary and secondary care. Many care homes receive education and support from Specialist Palliative Care services to strengthen their bereavement practices. Both localities recognise bereavement as a critical element of compassionate end-of-life care and are investing in widening access, improving consistency and ensuring support is available before and after death.

LDT specific recommendations

- **24/7 access to palliative and end of life care (PEoLC) services and beds:** Improve round-the-clock access to palliative care, including clear pathways to access community hospital palliative beds and inpatient palliative care units at all times, not only in core hours.
- **Consistent advance care planning and digital sharing:** Standardise and improve advance care planning so that personalised care plans (including DNACPR/EHCP/EPaCCS where used) are routinely offered, recorded, and shared electronically across primary care, community teams, hospitals, social care and care homes via interoperable systems—moving away from paper-based plans.
- **Person-centred care environments and preference recording:** Increase single room availability for end of life care where possible, and strengthen the recording, visibility and honouring of patient preferences across settings.
- **MDT coordination and reduced crisis admissions:** Strengthen MDT working and system coordination (GPs, community teams, hospital liaison, social care, care homes) to improve

continuity, reduce crisis admissions, and support rapid response and timely discharge/fast-track pathways.

- **Workforce development and training across all sectors:** Expand workforce education and training for all relevant staff groups across health and social care (including care homes), with a focus on communication skills, symptom management and confidence in PEO LC delivery.
- **Equity of access and tailored approaches for underserved groups:** Address inequalities through targeted, inclusive service design for harder-to-reach / socially excluded groups (e.g., ethnic minorities, rural communities, LGBTQ people, people with dementia, learning disabilities, homelessness, and prison populations (continued provision for HMP Northumberland including working to provide inpatient support with the Hospital Liaison Team and also care for prisoners on the PCUs)), ensuring equitable access to high-quality PEO LC.
- **Community-centred and voluntary sector partnership:** Expand community-centred approaches and strengthen collaboration with hospices, charities and community assets to support PEO LC delivery, engagement and local capacity.
- **Bereavement and emotional support as routine provision:** Improve the consistency, availability and quality of bereavement and emotional support across care homes, hospices, primary care, community services and the voluntary sector.
- **Earlier, culturally acceptable conversations about dying:** Enable and normalise earlier discussions about death and dying—making conversations easier, more culturally acceptable and more routinely embedded in care.
- **Use of evidence, outcomes and lived experience to guide improvement:** Increase system-wide use of local data, outcomes measures and patient/community stories to guide improvement priorities, evaluate progress and support continuous learning.

South Tyneside and Sunderland Palliative and End of Life Care Summary

Epidemiology – Demographics

South Tyneside and Sunderland support populations with some of the highest levels of deprivation in England, contributing to earlier mortality, poorer healthy life expectancy, and higher prevalence of multiple long-term conditions. Life expectancy remains below the England average, with a significant gap between the most and least deprived wards.

Disease burden is characterised by high rates of cancer (particularly lung cancer), cardiovascular disease and chronic respiratory disease such as COPD. These conditions are closely associated with industrial legacy, smoking prevalence and socioeconomic deprivation, and frequently result in complex symptom burden and prolonged end-of-life trajectories.

The population is ageing, with a projected increase in people aged 65+, particularly those aged 85 and over. This demographic shift is expected to further increase demand for palliative and end-of-life care, particularly community-based support.

Together, deprivation, ageing, multimorbidity and preventable mortality create sustained pressure across the palliative and end-of-life care system in South Tyneside and Sunderland. While specialist services are involved in a minority of deaths, the majority of people approaching the end of life are supported by core and generalist services across primary care, community nursing, care homes and acute settings, underlining the importance of timely specialist advice, coordination and advance care planning to support safe, person-centred care.

PEOLC Service Provision

- Sunderland and South Tyneside have access to a Single Point of Contact (SPOC) for Specialist Palliative Care (SPC) Nursing services Monday–Friday, 09:00–17:00. An advice line is also available for all health professionals 24/7 via St Benedict’s Hospice IPU. Work is ongoing to review this process in line with the new Care Coordination Hub.
- Seven-day face to face access to Specialist Palliative Care on hospital sites (available 8hrs a day) is not currently part of the commissioned specification for Sunderland and South Tyneside. However, it is a national recommendation which has regularly not been met in the

'National Audit of Care at the End of Life (NACEL)'. NB – 70% of hospitals nationally do have this service provision.

- An out-of-hours (OOH) community nursing service is available in Sunderland and South Tyneside from 16:00–08:30.

Inpatient Palliative & End of Life Care

- Specialist palliative and end of life inpatient care for Sunderland and South Tyneside is primarily provided by St Benedict's Hospice, which operates 14 specialist inpatient beds commissioned via South Tyneside and Sunderland NHS Foundation Trust. These beds serve a wider cross boundary population including Sunderland, South Tyneside and parts of north east Durham, creating ongoing capacity pressure.
- South Tyneside does not have a consultant led hospice inpatient unit within the borough. However, six commissioned nurse led end of life care inpatient beds are provided at Cedar Unit, Haven Court, delivering 24 hour nursing care. While this provision supports local need, it is not clinically equivalent to consultant led hospice inpatient care.
- When local capacity is exceeded, patients may access inpatient hospice beds at Marie Curie Hospice, Newcastle through spot purchase arrangements.

Community & Hospice at Home Services

- There is no comprehensive, fully responsive 24/7 Hospice at Home service across Sunderland and South Tyneside. However, limited planned and overnight Hospice at Home type provision is commissioned, including locality specific overnight services.
- Continuing Healthcare Fast Track packages are used to support people at home at the end of life, but these arrangements do not replace a dedicated specialist Hospice at Home model. As a result, community provision remains fragmented and contributes to variation in patient experience and place of death.
- The SPC workforce includes AHPs: Physiotherapy, Psychology, Complementary Therapy, Occupational Therapy, and Pharmacy (Pharmacy provision is Sunderland only).
- South Tyneside has access to Occupational Therapy only.
- There are 4.25 WTE education posts dedicated to meeting the needs of the service and the education programme for palliative care (Currently there is a 1.00 WTE vacancy which has been held due to the financial constraints of the Trust)
- Day and outpatient services include Specialist Palliative Care Day Service provision Monday–Friday for specialist input and MDT support (including consultant oversight) as part of the core contract. Palliative Care Consultants also provide outpatient clinics in their localities.

South Tyneside has access to Palliative Care Day Service via Marie Curie at Haven Court. This has no SPC consultant oversight.

- Bereavement services for adults are provided via Sunderland Counselling Services, funded by St Benedict's Charity.
- Sunderland and South Tyneside have access to Specialist Palliative Care Nurses across community and acute settings, with support from SPC Consultants. Vital regular involvement in Primary Care Palliative Care MDT meetings has been hampered by low staffing levels and increasing clinical demand.
- Sunderland hosts a Lymphoedema Service, which is also accessed by north east Durham. Lymphoedema in South Tyneside is commissioned through St Oswald Hospice in Newcastle which offers a satellite clinic locally.
- Access to a limited EPaCCS system is available, but currently only used in Sunderland; South Tyneside staff have not yet received training. Regional work on the Great North Care Record and its capabilities for helping Palliative Care patients continues to develop.
- Patient and family feedback is collected via the Friends and Family Test.
- A well-established Steering Group is in place within the hospitals with clear reporting into senior leadership structures. No such community equivalent is currently meeting given the ICB restructure, as the ICB used to convene the group.
- There is currently no allocated Transitions Lead.

Workforce and Sustainability Challenges

- The staffing model for the Inpatient Unit has not been reviewed since contract inception. The commissioned resource no longer meets the increasingly complex needs of patients accessing hospice beds. The Service Specification for SPC in Sunderland has not been reviewed since 2012.
- The current staffing deficit required to maintain safe staffing is unfunded, with the organisation absorbing financial risk.
- There is a lack of parity across both localities, impacting service equity. For example, there is no Specialist Palliative Care inpatient unit or Specialist Palliative Care Day Unit in South Tyneside.
- The workforce is ageing, and there is no ready-made pipeline to support succession planning.
- Education provision is under increasing pressure; additional funding is required to meet growing demand across multiple providers.

The current model is under increasing workforce and financial pressure. Several service specifications have not been formally reviewed for over a decade, and staffing models no longer reflect the complexity of patient need. A number of mitigation actions are reliant on unfunded

temporary arrangements and organisational goodwill, which presents sustainability and safety risks without longer-term funded solutions.=

Together, these factors create sustained and growing pressure on the 'core/generalist', 'specialist', and 'enhanced' palliative and end-of-life care system across South Tyneside and Sunderland, reinforcing the need for responsive, community-based, and culturally competent models of care.

The Commissioning and Investment Framework for Palliative and End of Life Care highlights the key areas within 'Core', 'Specialist' and 'Enhanced' Services which the ICB, St Benedict's Charity and STSFT need to consider, in the context of available resources.

Mitigation Actions

- Additional shifts have been implemented, although these remain unfunded.
- A Band 6 development post has been created to support succession planning within the SPC Nursing Team.
- Wellbeing work is embedded across all teams and supported by Clinical Team Managers.
- Regular team meetings and joint service development meetings are held across both localities.
- Staff are supported to develop within their roles to aid future progression.

Recent Quality Improvement / Service Development

- A joint Vision Event was held, supporting shared learning across both localities.
- Funding for Project ECHO was successfully secured. The programme has now commenced to support streamlined education and training across the region, informed by recent findings from a training needs analysis

Stakeholder and Community Engagement

Report Summary: Improving Palliative and End-of-Life Care for Sunderland's BAME Communities

In collaboration with Macmillan Cancer Support, the Sunderland Bangladesh International Centre (SBIC) has undertaken significant work to understand and improve the palliative and end-of-life care experiences of Sunderland's local Black, Asian and Minority Ethnic (BAME) population. Evidence indicates that disparities in end-of-life care within BAME communities are complex and influenced by a range of cultural, religious, linguistic, and socio-economic factors. These barriers can lead to reduced access to services, delayed referrals, and unmet care needs at the end of life.

This study has focused particularly on the Muslim Bangladeshi and Pakistani communities, highlighting the importance of care models that are culturally sensitive and reflective of the values, beliefs, and identity of BAME Muslim populations in Sunderland. Engagement with religious leaders, alongside community focus groups and survey responses, has provided meaningful insight into the specific concerns and needs of these communities.

Key themes emerging from the work include the need for:

- Culturally appropriate education and information, ideally delivered by trusted religious figures.
- Stronger communication pathways between healthcare providers and religious or community leaders.
- Improved understanding of cultural and religious needs among professionals working in palliative and end-of-life care settings.

The work also emphasises the importance of partnership and co-production. Alongside the BAME-focused initiatives, significant progress has been made in other areas of equitable palliative care:

Learning Disability Collaborative Work

A collaborative project has been undertaken to clearly document a joint care pathway for individuals with learning disabilities who require palliative or end-of-life care. The most recent outcome is the development of the Deciding Right EHCP accessible information suite, including:

- Easy-read patient stories
- Easy-read Emergency Health Care Plan (EHCP) materials
- An easy-read EHCP video

All resources are now hosted on the Deciding Right website and were co-produced to ensure accessibility and inclusivity.

Friends and Family Test – “You Said, We Did”

Feedback from patients, carers, and families has driven tangible improvements. A recent example includes responding to requests for more bariatric seating, which has now been successfully implemented.

Locality specific activity and initiatives

Data highlights that Sunderland's integrated Specialist Palliative Care service is involved with around 17% of all deaths in Sunderland and that, when involved, 85-90% of patients will die in their preferred place of death. This means that around 83% are covered by core/ generalist services (in hospital and community). Specialist Palliative Care support of these core teams is vital and requires

- Strategic, consistent, and regularly funded multi-modal education.
- 7-day face to face hospital SPC services on both hospital sites.
- Workforce planning to allow Specialist Teams to support/ attend primary care MDTs
- Consistent and agreed data streams to inform ICB of service delivery, capacity, and how to better support and develop Core, specialist, and enhanced Palliative Care services.
- Advice line reconfiguration to make sure of timely advice to colleagues and to avoid missed calls.
- Better interfacing of computer systems and information sharing (e.g. for Advance Care Planning).

Bereavement Services

- Bereavement support is delivered locally through Sunderland City Council, funded by St Benedict's Hospice Charity.
- The service provides emotional, practical, and signposting support for individuals and families following a bereavement.
- This partnership enhances access to community-based bereavement care and complements the hospice's wider remit in supporting people affected by life-limiting conditions.

Epinay School Partnership (South Tyneside)

- Collaborative work with Epinaay School supports pupils and staff in understanding death, dying, and bereavement.
- This programme provides age-appropriate education, resources, and guidance to help manage conversations around loss.
- The initiative is specifically delivered within South Tyneside and contributes to early-years public education about palliative and end-of-life issues.

Gold Standards Framework (GSF) Regional Training Centre

St Benedict's Hospice has been a Gold Standards Framework Regional Training Centre (RTC) since 2016. With all the changes in education staff it is unclear whether this still applies or is actually able to be delivered.

National Context

- GSF is the leading UK programme supporting generalist frontline staff to deliver high-quality end-of-life care.
- The Framework focuses on improving care quality, organisation, communication, and proactive planning.

Local Status

- As of the Feb 2024 national review, St Benedict's Hospice was one of only two remaining RTCs nationwide, reduced from 12.
- This highlights the hospice's recognised expertise and ongoing commitment to delivering high-quality training.

Scope of Delivery

As an RTC, the hospice is licensed to deliver:

- Care Home Programme
- Domiciliary Care Provider Programme
- Retirement Village Programme

Contractual Responsibilities

- The hospice (as RTC) provides services related to implementation and assessment of GSF programmes on a sub-contract basis.
- The relationship is governed by a formal agreement with GSF, outlining responsibilities for programme delivery, assessment, and quality assurance.

Project ECHO Programme

Complementing our established programmes, Project ECHO provides a validated, scalable approach to virtual learning. By adopting ECHO as our preferred delivery model, we are extending the reach of specialist palliative care expertise to a wider network of professionals across health and social care. The methodology supports case-based learning, peer support, and knowledge dissemination, building resilient, community-based palliative care capacity.

Project ECHO (Extension of Community Healthcare Outcomes) is an international education approach that uses virtual learning to broaden specialist knowledge through a hub-and-spoke model.

Local Application

- The Education Team aims to extend palliative and end-of-life care training beyond the classroom by adopting Project ECHO as its preferred model.
- ECHO enables real-time case-based learning and promotes shared expertise across health and social care.
- The methodology supports the delivery of specialist knowledge to a wider audience, building community-level capability.

LDT specific recommendations

Night duty staffing on the St Benedict's Hospice inpatient unit has been confirmed as unsafe through two independent Workforce Reviews, both of which highlighted significant deficits in the current staffing establishment against local safe staffing standards.

The service is formally recorded on the organisational Risk Register as operating with an unsafe night-time model, requiring regular reliance on NHS Professionals (NHSP) bank nurses to maintain minimum cover. This reliance on temporary staff is not only clinically unsafe due to reduced continuity and variable skill mix, but also financially unsustainable as it sits outside the agreed establishment and was not budgeted for within current financial plans. The ongoing requirement for bank staffing to maintain basic safety demonstrates that the current night staffing model is no longer fit for purpose and poses a continued risk to patient safety, workforce wellbeing, and regulatory compliance. There is a clear need for an urgent, funded, and sustainable staffing solution to mitigate these risks and ensure safe, high-quality care is consistently delivered overnight. There are plans in place to ensure this happens.

Gateshead Palliative and End of Life Care Summary

Epidemiology - Demographics

Gateshead has a population of approximately 199,100 people living in around 89,000 households. The population is projected to increase to 216,750 by 2043

The population profile is ageing. By 2043, it is estimated that there will be an additional 12,316 people aged 65 years and over, representing a 29% increase. In contrast, the population of children and young people aged 0–15 years is expected to decrease by approximately 3,529 (10%).

Gateshead is the 47th most deprived local authority in England (out of 317). Around 32,700 people (16%) live in areas ranked within the 10% most deprived nationally, and approximately 62,600 people (31%) live within the 20% most deprived areas.

Among those living in the most deprived areas, 47.6% have at least one long-term condition. Healthy life expectancy in Gateshead is significantly lower than the England average, with a marked gap in life expectancy between residents living in the most and least deprived postcodes.

Gateshead is also home to one of the UK's largest and fastest-growing strictly Orthodox (Haredi) Jewish communities, with a population estimated at approximately 2,900 to over 3,000 in recent years.

PEOLC Service Provision

Gateshead provides an integrated Specialist Palliative Care (SPC) service across community, acute hospital settings, and St Bede's Inpatient Unit. The service is delivered by a broad interdisciplinary team.

Core Service Components

- St Bede's Inpatient Unit
 - 10-bed specialist palliative care unit
 - 24-hour nursing care
 - Specialist medical cover Monday–Friday, 08:30–17:00
 - Out-of-hours medical cover provided by general medicine overnight and at weekends
- Specialist Palliative Care Nursing

- Hospital and community coverage, 08:30–17:00
- 8 WTE Band 7 SPC nurses
- End of Life Care Facilitators
 - 1.6 WTE establishment
 - Currently operating at 0.8 WTE due to secondment
- Medical Staffing
 - Consultants in Palliative Medicine: 2.8 WTE
 - Specialty Doctor: 0.9 WTE
- Leadership and Specialist Roles
 - Nursing Operations Manager (Band 8a): 1.0 WTE
 - Specialist Pharmacist: 0.3 WTE (0.2 WTE rotational on IPU)
 - Chaplaincy: 0.5 WTE
 - Clinical Psychologist: 0.5 WTE
- Community Link Worker
 - 21 hours per week
 - Employed by Edberts House, a local voluntary sector organisation
 - Supports patients with social issues including finance, housing, and social isolation
 - Pilot has demonstrated strong outcomes and secured funding for the next financial year
- Hospice at Home Service
 - Band 7 Team Lead: 1.0 WTE
 - Band 6 Nurses: 2.6 WTE
 - Healthcare Assistants: 14.96 WTE
 - Supports patients in their preferred place of care, reduces hospital admissions, and facilitates end-of-life discharges from hospital
- Administrative Support
 - 2.6 WTE

The Community Rapid Response Team supports out-of-hours palliative care provision, with:

- Two nurses available from 20:00–08:00 7 days a week
- Occupational Therapist with a special interest in palliative care

In 2023, a 12-week pilot extended SPC nursing support to weekends and bank holidays (08:00–20:00). This included a Band 7 SPC nurse based on the acute site during these periods. Options for securing ongoing funding are currently being explored

Marie Curie and St Oswald’s Hospices provide a 24/7 SPC out of hours telephone advice line for professionals which is currently under review.

There is currently no specialist palliative care physiotherapist, OT or Social Worker but this is under review. There are sessions from both a specialist pharmacist and a psychologist however these are not sufficient for the need identified.

Support for generalist services

The SPC team works closely with colleagues across primary and secondary care, including frailty services, community teams, and care homes.

- Each care home in Gateshead has a Community Nurse Practitioner (CNP) linked with a specialist palliative care nurse
- Regular involvement in frailty care home multidisciplinary team (MDT) meetings
- Attendance at GP palliative care register meetings
- Ongoing education for GPs through TITO teaching

The SPC team has developed an education prospectus outlining training opportunities for all staff involved in caring for people at the end of life, including domiciliary care providers. This includes:

- A range of courses covering symptom management and advance care planning
- Sage and Thyme communication skills training
- Advanced Communication Skills Course
- Serious Illness Care Programme, a multicomponent, structured communication intervention designed to identify patients, train clinicians to use a structured guide for advanced care planning discussion with patients, 'trigger' clinicians to have conversations, prepare patients and families for the conversation, and document outcomes of the discussion in a structured format in the electronic medical record.

Stakeholder and Community Engagement

Avoidable admissions project

Gateshead have a high rate of emergency admissions in the last year of life and the lowest proportion of patients on the palliative care register across the region.

A multifaceted project run jointly between the SPC team and the frailty team aimed to understand and address these issues. Key elements included;

- Education session for CNP's on the use of the SPICT Tool and Prognostic Indicator guidance to help guide patients selected for the Palliative Care Register.
- Supporting a pilot exploring the use of the SPICT tool for patients within a care home in a local GP practice

- Focussed SPC support for care home staff, CNPs and GPs in identification of patients eligible for palliative care register with a fixed term secondment of one of the SPC nurses.
- Audit of admissions by GATDOC of patients from care homes in conjunction with CBC with feedback discussions and plan for ongoing review
- Professional questionnaire (96 responses) from a wide range of professionals identified multiple barriers to following an EHCP. They identified several potential ways to address these challenges including training, support with decision making at the time of the decision, clearer plans accurately representing patient and family wishes and better communication between organisations.
- EHCP workshop based on these responses was a huge success with attendance from multiple organisations including NEAS, CNPs, DNs, SPC team, Community rapid response team, GATDOC, Consultant from ED, Frailty Team and care home staff. This has been repeated with plans for ongoing engagement.

Dying Matters National Campaign

During Dying Matters Week, the team delivers events aligned to the national theme. Activities have included:

- Staff and public engagement across hospital and community sites
- Survey exploring what matters to people spiritually, religiously, and culturally at the end of life
- Community outreach via the Metrocentre Hub and town centre event with Melissa bus.

Schools project

The SPC team has a longstanding relationship with local schools, originally developed through Dying Matters Week engagement. While direct school visits are no longer feasible due to clinical pressures, collaborative work continues.

The SPC team has been working with Emmanuel College and Dr Kathryn Mannix to develop a series of curriculum resources for three year groups in the school. These resources were delivered during Dying Matters week last year with plans to further develop and share more widely this year.

A joint research project with Northumbria University, Emmanuel College and Gateshead SPC team has facilitated focus groups for both students and teachers at the school to inform future development.

Compassionate Gateshead

The SPC team are working to embed a public health approach to palliative care within Gateshead.

There is currently a pilot of Compassionate Gateshead, aiming to establish a network to improve people's experiences of death, dying, and grief in Gateshead, it includes Local Authority colleagues, voluntary and community groups, businesses, volunteers and local community members.

The network is led by a partnership between the Palliative Care Team at the Queen Elizabeth Hospital and Edberts House (a Community Development Charity in Gateshead).

The pilot, that has been running since April 2025, has proven the need, appetite for the programme and engaged public, private and VCSE sector organisations and individuals who are keen to work in a more collaborative way. The following activities and impacts have been achieved so far

- Consulted with over 250 people in both a professional and personal capacity on their views for the need for a network to support end of life care
- 668% increase in the use of the Our Gateshead website 'death dying and grief page'
- Influenced the inclusion of End-of-Life support in the Health and Wellbeing Strategy
- Hosted successful vision launch at the Glasshouse attended by a wide range of stakeholders in Gateshead including the MP, the local authority, healthcare leaders and multiple voluntary sector organisations.
- Gateshead Council unanimously passed a motion of support for Compassionate Gateshead
- Festival of Compassion launched with over 30 different activities and events that was featured on BBC Look North, The Chronicle, BBC Radio and multiple other online and social media platforms
- Facilitated a partnership between Winston's Wish and Emmanuel Schools Foundation to become an 'early adopter' for their 'ask me' manifesto that provides training and support to teachers and students who are bereaved
- Delivered presentations, training and support to over 20 organisations / networks
- Convened a cross sector regional Special Interest Forum for people providing end of life support to explore shared learning and explore future collaboration

In the second year of Compassionate Gateshead, new workstreams will focus on Children and Young People, Workplaces and Community Development, expanding the programme's reach across the borough. A cross-sector steering group will also be established, bringing together representatives from health, public health, VCSE organisations, education, employers and community groups to guide delivery, strengthen partnerships and support sustainable development of the programme.

Bereavement Surveys

We are keen to learn from the experiences of patients and their families are currently reviewing the most effective way to collect bereavement feedback.

Feedback is currently sought as part of the NACEL audit and we have given respondents the opportunity to provide additional information to get a greater depth of feedback.

We also regularly review the results from the trusts friends and families feedback that is used by the teams,

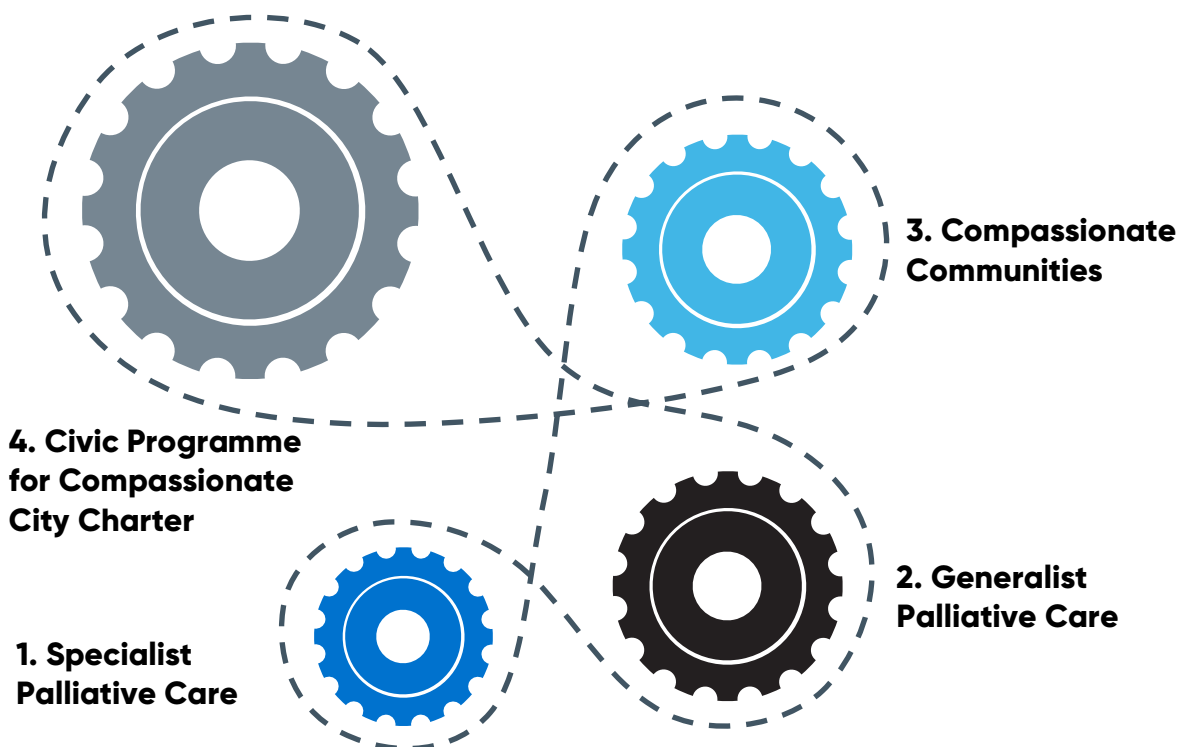
Locality specific activity and initiatives

Palliative and End of Life Steering group

Gateshead PEoL steering group has developed a wide reaching strategy that was launched in October 2023 to coordinate and focus Gateshead based initiatives.

This strategy was informed by recent national publications and the trust values, with input from major stakeholder groups including the entire Specialist Palliative Care (SPC) team and a trust wide consultation.

Palliative Care: The New Essentials



New initiatives are strengthened by a robust work plan that is set out by the End-of-Life Steering Group. Three work streams have met bimonthly, in between the bimonthly end of life steering group meetings working towards an individual work plan. The workstreams are

- Service effectiveness and risk
- Service development
- Education and public engagement

Their highlights are presented below

Service Effectiveness and Risk workstream

- Developing palliative care discharge checklist to improve coordination and planning of hospital discharges
- Exploring options for 7 day admissions to St Bede's
- Care of the Dying Patient nervecentre observations module to improve care for patients in the last days of life
- Alerts for patients who are approaching end of life in hospital and patients known to the community SPC team admitted to hospital to allow earlier specialist assessment
- Review of coding and EMIS templates

Service Development workstream

- Development of business case for 7 day service with specialist AHPs
- Pilot of End of Life Volunteers on St Bede's
- Development of research capacity
- Development of Public Health Palliative Care approach
- Butterfly bereavement café for those linked to patients on St Bede's

Education and Public Engagement

- Improving identification of death and dying on wards and in community including use of SPICT prognostic indicator tool
- Developing prospectus and reviewing engagement and evaluation
- Development of SIM training
- Compassionate Gateshead project
- Schools project
- Link nurse project
- Care home support

LDT specific recommendations

- 7-day service for all to reduce inequality of access to care across the region
- Ongoing funding for community link worker to allow this role to develop and cascade learning back to primary care link workers
- Ongoing funding for Compassionate Gateshead and continue to build network to facilitate mutual support to develop a public health approach across the region.
- Strengthen MDT working and system coordination (GPs, community teams, hospital liaison, social care, care homes) to improve continuity, reduce crisis admissions, and support rapid response and timely discharge/fast track pathways.
- Expand workforce education and training for all relevant staff groups across health and social care (including care homes), with a focus on communication skills and symptom management.

Newcastle Palliative and End of Life Care Summary

Epidemiology - Demographics

Newcastle Adults

The Newcastle Upon Tyne Hospitals NHS Foundation Trust (NuTH) is one of the largest NHS teaching hospital trusts in the UK. It provides a comprehensive range of acute, specialist, and community services to patients across Newcastle, the wider North East region, and beyond. The Trust operates two major hospital sites—Royal Victoria Infirmary (RVI) and Freeman Hospital and is internationally recognised for its research-led clinical care, particularly in areas such as cancer, transplantation, and neurosciences. It has a workforce of over 16,000 staff and serves a population of approximately 1.5 million people. It has a strong academic partnership with Newcastle University and is a leading centre for medical education and innovation.

- The Trust managed an annual budget exceeding £1.7bn in 2024/25.
- The current number of acute beds open across the trust is 1492.

The Palliative Care Service at NuTH covers a tertiary centre that serves a large geographic area from the Scottish Borders down to Teesside and from east to west coast. NuTH offers services and care to patients from all of these localities.

50% of those the Palliative Care Service support are from Newcastle/Gateshead, with even less than this from Newcastle specifically. This makes direct comparison in service, workforce and needs with other providers in the region very challenging. In addition, patients are often transferred to NuTH for a specialist opinion (such as those with acute vascular issues) but then deteriorate or are deemed too unwell for intervention. Moving them back to a hospital close to home or to a preferred place of death locally is often extremely challenging with delays in acceptance by local hospitals. These patients then sadly die in a NuTH hospital, some of them in pursuit of treatments that were not available at their local hospital.

Clinical Activity

The hospital and community data is gathered from the Palliative Care Dashboard - Power BI Report Server. The data is harvested from the eRecord system in the hospitals and System One in the community, and the Palliative Care Service have attempted to replicate reporting styles for both, however, in some domains this has not been possible. The Palliative Care Service continues to work

closely with colleagues in information analysis (IA) to improve collection and understanding of data.

Hospital Referrals

The number of referrals into the hospital Palliative Care Service is consistent with previous years. Most referrals led to a full assessment from the Service.

Cancer remains the most common underlying diagnosis for patients seen by the Palliative Care Service. However, there are increasing appropriate referrals coming in for patients with non-cancer diagnoses. Palliative Care Service responds promptly across the hospice settings to new referrals. Across all settings, the same day/next day response rate is 90.10%.

Anticipatory Medication Alerts - Hospital

As well as the reactive assessments in response to referrals, the hospital palliative care service has a proactive model of reaching out to ward teams where a patient in hospital is prescribed the Trusts pre-set 'Care of the Dying' medication order sets through a well-established Standard Operating Process. A message is sent via the system to the team to say a patient has these medications prescribed which triggers a nurse specialist response to review the notes and either attend or contact the ward to work through a pre-populated template inserted into the notes. This process enables patients who require timely specialist palliative care advice or assessment to receive this, it supports the teams dedicated end of life care HCAs to attend the patients who are dying comfortably with nursing oversight and it leaves prompts in the notes for teams to access if needed (for example Out Of Hours advice contact information and amber discharge advice).

The team's data collection relating to the anticipatory medication alerts, and end of life HCA activity, is limited while we await a digital solution to how we can measure impact of the anticipatory medication alerts.

Improving data collection for alerts is a priority (covered in the 4+1 strategy below), and we are exploring a similar alerts model for proactively supporting patients recognised to be dying in their own home or care home with our community nursing colleagues using reports in SystemOne.

Community Referrals

Community Contacts, Length of Spell and Response Times: The average community length of spell is 25.94 days. This is just one indicator that demonstrates the differences between the community and hospital service.

100% of accepted referrals in the community are seen within three days, with the majority of patients receiving input same or next day.

NuTH also provides secondary 'DGH' type care for the residents of Newcastle and we need to carefully navigate the equity in focus between these two elements. Newcastle includes areas of both very high and very low socio-economic deprivation.

NuTH PCS actively works to address the inequity in care into underserved populations-including via our PEOLC 'Equity and Engagement' group. We have previously worked into a 'Complex Needs' MDT in which those with intersectional issues such as problematic substance use, mental health challenges and those experiencing homelessness in the context of palliative and EOL care. This was chaired by a local GP with a specialist interest in supporting these patients and was attended by third sector partners-Changing Lives. The funding for this successful endeavour has sadly ended.

NuTH PCS attend all LeDeR review panels to provide input and share learning. The trust learning disability team sit on our trust wide PEOLC strategy group.

Newcastle Children's

The Newcastle Children's Community Nursing Team take referrals based on GP locality and not patients home address. They take referrals for patients age 0-19 from a range of services.

The service operates Monday -Friday 8:30-16:30.

The Newcastle Children's Community Nursing Service is a nurse-led team. The team provides support for children and young people with both complex and acute nursing needs including those with life limiting and life threatening conditions. The team do provide support around end of life care within the service hours and with support from the CHIPS team. The service also has a Health Play Specialist who is able to provide bereavement support for children and young people to include siblings of patients within our care.

The service includes a team of Registered Nursing Associates and a healthcare assistant who can provide short-term care packages in the community.

PEOLC Service Provision

Deciding Right/Advance Care Planning

With ongoing commitment from the Trusts executive team to the end of the financial year NuTH have now established a well-attended, bimonthly, Deciding Right Group meeting. This reports to the Trust via the Clinical Outcomes and Effectiveness Group. A workplan has been agreed by the group.

Newcastle Palliative Care Registers

Newcastle GP Palliative Care multidisciplinary team meetings revolve entirely around the GP palliative care registers and these are regularly attended by all the Community Palliative Care Nurse Specialists and sometimes also by Consultants in Palliative Care based within the Community Palliative Care Team. The Palliative Care Consultants within NUTH regularly attend MDT's including Atypical PD CRESTA Clinic recommending palliative care registers in that clinic where appropriate. Also Heart Failure MDT and Interstitial Lung Disease clinic.

Newcastle Care Homes and Palliative Care Registers Quality Improvement Pilot

Care homes implemented a register based on Gold Standards Framework (GSF) principles to identify residents approaching palliative and end-of-life care, enabling proactive planning and better support for residents and families. Maintained by care home staff and supported through ongoing education and bimonthly reviews by a palliative care educator, the initiative improved recognition of disease trajectories, reduced unnecessary hospital admissions, and supported achievement of preferred place of death. An audit confirmed its effectiveness. Additionally, the Palliative Care Service (PCS) funded regional sessions within the Teenagers and Young Adults (TYA) service to support palliative and end-of-life care for young people with cancer

Palliative and End of Life Care Masterclass for Newcastle Care Homes

NuTH's Palliative Care Service organised a Palliative & End of Life care Master class for Newcastle Care Homes in September 2025. This was a free event for care home staff. Stakeholders who agreed to participate in the educational event included NEAS, Specialist Care Home Support Team, Community Palliative Care, Palliative Care Service HCA, Consultant from RVI ED, Virtual Frailty Team, End of Life Care Managers, MCA Practitioner and one of our Clinical Psychologists. Evaluation from candidates was incredibly positive especially regarding the presentations from NEAS and the ED Consultant. Care home staff reported that the information was eye opening and it will encourage them to think carefully before ringing 999 in the future.

Stakeholder and Community Engagement

Dying Matters National Campaign

Dying Matters is a national campaign run by Hospice UK who work with organisations, decision makers and to public to make improvements for dying people or those who are grieving. Every year in May Hospice UK recommend that we all collectively use that awareness week to encourage communities to get talking about death. In NuTH we begin planning of Dying Matters week in January. We invite our collaborators – both internally and externally - to regular meetings, and we

plan our timetable of events. For the past couple of years, we have promoted Dying Matters in both our acute hospitals and within a venue within our community. Our Palliative Care Educational Facilitator has also promoted the Dying Matters campaign within Newcastle Care Homes and has had excellent engagement from Care Home Managers, Care Home Staff and patients and their relatives.

Bereavement Surveys

Newcastle have prioritised seeking the views of bereaved families on the care the patient received and also the care they received at the time of and after the death. The team have worked hard to put systems in place to offer this opportunity in both an internal version and as part of contributions to the National Audit of Care at the End of Life (NACEL), in collaboration with hospital bereavement officers and the Trust patient experience team.

In September 2024 when the Medical Examiner (ME) service became mandated, and bereavement services were reviewed, the role of contacting families after a death for all patients transitioned to the ME officers. The content of those calls was reviewed and refined to essential ME roles/responsibilities and the inclusion of a question around bereavement surveys was not possible as part of this.

In response the teams have worked hard in hospital to make the survey information available as part of the 'Information for the Bereaved' leaflets/packs families are given after a death when they leave the ward, but uptake in this method is low. For this reason Newcastle opted out of the NACEL bereavement survey in 2025, as there was a recognition we had more work to do to increase uptake of a survey during that time and we wanted to prioritise our internal survey with this as the narratives we were able to receive this model provided much more scope for quality improvement, over the NACEL outputs on balance. Newcastle is looking to incorporate the 8 essential NACEL bereavement survey questions for the 2026 round I hope enough surveys will be returned to contribute, while maintaining what works well for our own internal processes in the narrative.

Community bereavement surveys are well established; they are a modified version of the original hospital survey and are included in all of the community Caring for the Dying Patient Document packs. They are included as a link/QR code on the bereavement leaflet and also as a printed paper copy with a pre-paid envelope for return. The community palliative care team monitor all returned surveys throughout the year, sharing with teams directly positive feedback or addressing concerns directly with families who report these including their contact information, and they summarise all surveys returned annually into a report which gets presented at a community nursing forums,

palliative care meetings and with GPs. On the whole survey feedback is positive across families responding where patients die in their own home or a care home which is reassuring.

RVI and Freeman Hospital Haven Facilities

The RVI Haven for relatives of patients receiving end of life care at the RVI was opened on 27th November 2019. Following on from the success of RVI Haven, a location for a similar facility was agreed for the Freeman Hospital on Level 1 in the former Finance Office overlooking the Restaurant Courtyard. The Freeman Haven was opened in November 2024 and for patient's relatives in January 2025. Haven spaces have received funding through A Gift of Kindness Charitable Fund – part of Newcastle Hospitals Charities.

The Haven facilities are designated quiet spaces for families/friends of patients receiving end of life care in the hospital.

Access is via a swipe card provided by our Healthcare Assistant teams. Feedback from patients' families is highlighted below:

March 2025: *"I don't know what we would have done without this space. It has made a very difficult time more bearable"*

March 2025: *"A true haven in a sad time. Just being able to have a shower and sit down is so precious. The kindness of others is really apparent here."*

April 2025: *"Thank you so much for letting us use this beautiful room to freshen up at this sad time for us."*

May 2025: *"An excellent facility, catering for all family needs, allows for time to reflect at such a sad period, compliments to the professionalism of the team."*

Hydrangea Symbol

The hydrangea symbol has been introduced into many ward environments within Newcastle Hospitals to indicate that a patient is receiving end of life care. It acts as a visual reminder for all staff to tailor their activities around the bed space or cubicle to suit the sensitivity of the situation. Consent to use the hydrangea symbol is sought from patients' families.



Hospices

Two charitable hospices serve the area these are Marie Curie (18 inpatient beds) and St Oswalds – 15 adult inpatient beds plus 6 beds that flex for children/young adults (adult commissioning via Health; children via Health & Social Care). Commissioned funding is enhanced by charitable income.

Locality specific activity and initiatives

In 2025, the Palliative Care Service (PCS) identified a set of clear strategic priorities. The '4+1 Palliative Care Service Priorities' was co-produced with stakeholders and is cognisant of Trust, regional and national priorities and pressures. We have continued to take all opportunities to collaborate, engage and support teams and partners from around the region in pursuit of these. We are keen to raise awareness of the 4+1 across the Trust and welcome opportunities to do so at board level meetings.

Review of community palliative care service around Integrated Neighbourhood Teams with a focus on proactivity:

We have worked closely with community stakeholders including the GP Clinical Director for the community to develop a better understanding of what is working well in the delivery of community palliative care and what could be revised or improved. Through these connections, the PCS has participated in city-wide GP forums and discussions around palliative care provision for those with life-limiting conditions including the frail elderly. We are optimistic that these relationships will continue to allow effective progress in this area.

Two community-based innovations we are actively exploring are:

- Establishment of a 'Single Point of Access' for healthcare professionals, patients, and caregivers. This model is supported by national drivers such as the Marie Curie/Kings Fund report 'The Night Times Are Frightening' and the National Commission for Palliative and EOL Care Report 2025. Community partners have expressed strong support for this initiative.
- Piloting of a 'Community End of Life Alert' system, enabling the PCS to proactively contact teams caring for patients recognised as approaching the end of their life.

This is being looked at in collaboration with the community nursing team and would mirror a system that is well established in the hospital settings. There may also be opportunities for this to integrate with a 'virtual ward' model for efficient remote care.

We continue to seek opportunities to be involved in all evolving conversations around the formation of Integrated Neighbourhood Teams and believe there will be significant opportunities with this model of working as we strive for excellence in palliative care delivery

Review of delivery of 'Front door' palliative care in the ED/Assessment suite setting, with a focus on proactivity:

We have engaged with colleagues in the Assessment Suite and Emergency Department to better understand perceived barriers to delivering person-centred palliative care at the front door and baseline data analysis is underway.

One of our PCS nurse specialists has been supported to apply for an NMHAP research internship with a proposal involving qualitative research to better understand staff perceptions of opportunities and barriers to the delivery of palliative care in these settings.

The PCS has participated in regular Medicine and Emergency Care Front Door Engagement events to share insights into the unique needs of this vulnerable patient group as they seek to access unplanned care.

Review educational offer to all teams and services delivering palliative & end of life care:

Recognising the challenges that our internationally educated colleagues tell us they can face in the delivery of culturally sensitive palliative & end of life care in the UK, we are working toward the creation of a co-designed PEOLC education session for staff who trained internationally. Support from the Equality, Diversity and Inclusion managers has been invaluable, and we aim to launch this initiative next year.

Plans are also underway to host a regional symposium for Palliative Care Nurse Specialists, providing education and showcasing innovation and excellence across the network. The trust communication and marketing manager has provided useful support and guidance.

Maximise our impact in supporting the delivery of care in the last days of life:

Supporting non-specialist colleagues in delivering end of life care remains a key focus. The PCS continues to offer support for the Trust's Accrediting Excellence (ACE) programme which affords us opportunities to re-emphasise the priorities of end-of-life care and their documentation across a wide range of ward areas.

Optimise data gathering and utilisation in the shaping of ongoing service improvement:

We continue to explore pertinent KPIs to ensure we are delivering the most effective and impactful service possible. We are optimistic that the upcoming digitalisation of the Caring for the Dying Patient Document will allow more effective and meaningful real time patient data to help shape and inform service delivery.

Digitalisation of the Caring for the Dying Patient Document

Since the move to a 'Paperlite' EPR system in 2019, the palliative care team has worked to integrate the Caring for the Dying Patient Document into eRecord. Early implementation was delayed due to limitations in printing and transferability, leading to continued use of paper versions with inconsistent uptake. Following senior escalation, the project regained momentum in 2024, with a planned go-live in Spring 2026. The updated digital version includes improved functionality, such as in-house Comfort Observations and enhanced printing templates, developed in collaboration with regional partners to optimise usability and support continuity of care.

NuTH have secured Newcastle Hospitals charities funds to appoint a full time Band 6 Clinical Educator for 1 year to support the implementation of the digitalised version of the Caring for the Dying Patient Document working into the palliative care, digital health and with the Trustwide clinical educator workforce with the aim of making the education sustainable beyond the 1 year fixed term post. The role will be about educating the MDT workforce across all of the adult inpatient areas on all aspects of good end of life care, whilst demonstrating how the digital system can support evidence of this.

Ward Accreditation with Palliative and End of Life Care standards

In 2024 NuTH began to introduce a new accreditation framework across the organisation. The Accreditation Team developed a set of Accreditation Standards, in alignment with Trust strategy, hoping it will form a comprehensive assessment of clinical and professional standards.

The Palliative Care Service were approached to create End of Life Care Standards reflecting an assessment of end of life care delivered in an area. These standards were incorporated into the accreditation framework. Palliative Care team members work collaboratively with the ACE team to visit clinical areas when they are being accredited. The Palliative Care Service have been participating in ACE for 12 months now and it is positive to see the excellent standard of end of life care being provided across the organisation.

The ACE team have recently approached the Palliative Care Service to slightly revise our End of Life Care standards for outpatient areas as this will be the next focus for accreditation.

LDT specific recommendations

- Nil

North Cumbria palliative and End of Life Care Summary

Epidemiology – Demographics

North Cumbria presents a distinct and complex population health profile that directly shapes the demand for palliative and end-of-life care.

With a registered population of over 330,000, the area is characterised by an older age structure, high multimorbidity, and widening health inequalities, all of which intensify care needs at the end of life.

Life expectancy in North Cumbria remains below national averages, with males living 78.1 years and females 82.2 years, but crucially, healthy life expectancy is far lower—only 58.4 years for men and 59.1 years for women. This means residents spend a significant proportion of later life living with illness, frailty, and disability, increasing both the volume and complexity of palliative care demand.

Multimorbidity is a defining feature with a significant number of people living with three or more long-term conditions, including high prevalence of respiratory disease, cardiovascular conditions, diabetes, cancer and moderate to severe frailty. These conditions are leading contributors to early mortality and are closely linked with higher palliative care need.

North Cumbria also experiences significant premature mortality, with an under-75 all-cause mortality rate of 379.1 per 100,000 (England 329.4), and higher than national average mortality from cancer and cardiovascular disease (CVD) with CVD mortality rates at 87.9 for North Cumbria compared to the England rate of 74.3. Suicide rates remain high at 19.4 per 100,000, significantly above the England average of 10.9, reflecting both the mental health burden and socioeconomic adversity experienced across the area.

Socioeconomic inequality plays a major role in shaping end-of-life need. While the overall proportion of residents in the most deprived quartile is relatively modest, some neighbourhoods—most notably within Workington, Carlisle, and Copeland—experience considerable concentrations of deprivation. These inequalities influence disease burden, emergency care use, late diagnosis, and care access in the final months of life.

Hospital activity reflects the need for more care to be available in the community: across 2022/23–2024/25, there were 2,699 elective and vs 2,868 emergency inpatient spells for patients who were recorded as palliative. The high emergency activity suggests people may be presenting late or struggling to access community alternatives at end of life.

End-of-life hospital utilisation data further demonstrates the intensity of need, following the journey of a group of 3000 now deceased palliative patients, we saw 7,854 A&E attendances and 5,658 emergency admissions occurring within the 12 months prior to death.

These hospital-based spells are not only frequent but often recurrent- over 1,880 people accounted for 6,187 A&E attendances, and 1,269 patients required 3,254 emergency admissions, indicating significant instability and unmet needs in the community.

The distribution of emergency activity also highlights variation across the system, with the highest shares occurring in areas of high multimorbidity and socioeconomic disadvantage. Clinical drivers for these final-year admissions are dominated by neoplasms and circulatory and respiratory disease, conditions closely associated with complex symptom burden and late-stage decline. Notably, the vast majority of emergency admissions (93%) originated from the usual place of residence, underscoring gaps in rapid response, anticipatory care, and community-based management that might otherwise prevent crisis-driven hospital care at the end of life.

North Cumbria's rurality amplifies these challenges. Large geographies with dispersed populations make it more difficult to deliver home-based end-of-life care and support. Service utilisation patterns show how some neighbourhood areas rely heavily on Type 1 A&E, while others have high Urgent Community Response demand signalling unmet need and limited alternatives in highly rural communities.

The combination of high multimorbidity, earlier onset of poor health, uneven deprivation, rising frailty, and rural service barriers positions North Cumbria as a clear outlier in population health. These factors collectively drive a higher and more complex demand for palliative and end-of-life care, with particular pressure on community services, urgent care pathways, integrated hospice services and carer support. Strengthening advanced care planning, earlier identification, and access to home-based and community palliative services will be essential to meeting our current and future needs.

PEOLC Service Provision

Community Nursing and General Practice

The majority of PEoL care is undertaken within generalist community teams supported by specialist advice where needed and available.

General Practitioners identify patients approaching the end of life, carry out assessments, care planning and anticipatory prescribing.

Palliative and end of life care which often involves managing housebound, highly complex patients in their home environments, is undertaken by highly skilled generalist nurses within the NCIC (North Cumbria Integrated Care NHSFT) Community Nursing teams. Each team is based within one of seven ICC (Integrated Care Community) Hubs which broadly match PCN/Neighbourhood footprints. Each ICC Hub operates an in-hours Single Point of Contact (SPoC) for Community and Urgent Community Response services using a lead clinician of the day model. Access to the Specialist Palliative Care Team is also via these ICC SpOCs and will receive referrals from clinicians or share messages with the team from patients / relatives / carers or advocates.

Out of hours nursing (8pm-8am), and out of hours GP services (6.30pm - 8am) is delivered by Cumbria Health and is accessed via 111.

North Cumbria Integrated Care Specialist Palliative Care Service

The NCIC Specialist Palliative Care (SPC) service operates from Monday to Friday 9:00 and 17:00. Clinically led by 3 part time consultants, with a team of Clinical Nurse Specialists to provide SPC across the North Cumbria community and two acute hospital sites Cumberland Infirmary (Carlisle) and West Cumberland Hospital (Whitehaven).

The SPC service is classed as a liaison service and works in conjunction with Community Nurses, Hospital Teams and General Practice surgeries to provide care to those with complex specialist care needs including one of more of the following:

- Complex / refractory symptoms (physical / psychological / emotional / social)
- Rapidly escalating / uncontrolled symptoms particularly at end of life
- Complex advanced care planning or support needed with complex end of life decisions (e.g. withdrawal of treatment)
- From hospital setting: complex discharge planning or rapid discharge for end of life care

NCIC also operates the Loweswater Suite from West Cumberland Hospital, a 4 bed inpatient unit which provides Specialist Palliative Care Non-complex patients can also be accepted for end of life

care support into any of the inpatient Community Hospital beds in Penrith, Brampton, Workington or Cockermouth Community Hospitals if needed, on a step-up or step-down basis.

As part of NCIC End of Life Strategy and delivery plan, there is a dedicated Clinical Nurse Improvement lead (0.65 wte) working alongside medical lead 1 day per week. The service also have two dedicated end of life Clinical Educators (1.4 wte) to develop PEOLC skills across the workforce.

At the time of this report the service in the early stages of service remodelling in line with the NHS 10 year plan, to ensure that the service is sustainable, resilient, and responsive to growing and increasingly complex patient need. The proposed remodelling aims to:

- Strengthen the educational and advisory function of the service
- Introduce an enhanced skill mix to support workforce development and career progression
- Improve IT functionality and data collection to better evidence activity, outcomes and value, while maintaining high quality patient care

24/7 Advice and Guidance

A 24/7 helpline for professionals requiring specialist palliative care advice outside of standard working hours is provided by Eden Valley Hospice. However, as an unfunded service, it is limited and as such is not widely available.

Close monitoring of use shows increasing use by acute hospital teams. With resilient funding, this service could be made widely available, enabling access to colleagues in care homes, out of hours generalist services and emergency services which could prevent unnecessary hospital admissions, and support preferred place of death. This service could be further made available to family members, knowing that reliable, expert advice is available at any time can reduce the fear and panic that can arise from unexpected changes in a patient's condition, confidence that they can access guidance on managing changes in symptoms, and reducing the burden on unpaid care givers.

Eden Valley Hospice Specialist Inpatient Unit

Specialist Palliative Care for complex patients aged 18+ is provided by Eden Valley Hospice Adult Inpatient Service. The Hospice provides eight specialist care beds for symptom control or end of life care for North Cumbria residents with progressive, life threatening, incurable illnesses who have complex needs.

Services are delivered by a multi-professional team, including doctors, nurses, advanced clinical practitioners, nurse associates, counsellors, social workers, spiritual care team, therapists and

pharmacists, with recognised training in palliative care and for whom palliative care is their core speciality.

Hospice at Home Nursing Services

Additional complementary palliative and end of life nursing care is provided across the footprint by two Hospice at Home (Hospice at Home Carlisle and North Lakeland - HHCNL and, Hospice at Home West Cumbria - HHWC) nursing services, for adults with a life limiting palliative diagnosis approaching the last 12 months of life.

Nursing teams include Senior Registered Nurses, Registered General Nurses, Assistant Practitioners and Healthcare Assistants with specific training in end of life care, who work closely with a patient's GP, Community Nurse, Specialist Nurse and other health and social care professionals. HHWC also have a Service Level Agreement for a Medical Advisor (Consultant in Palliative Care).

Teams provide palliative and end of life one-to-one support overnight, or for an agreed number of hours during the day. Care includes personal care, symptom management, support for family carers and can be provided in the patient's home, residential and nursing homes, and community and acute hospitals, with the aim to support patients in their preferred place of care.

In addition to delivering high-quality clinical and personal care they generate significant social value by strengthening trust in care services and supporting emotional resilience of family carers. Their compassionate engagement, emotional support and practical guidance enables families to cope with bereavement, reduce carer stress, avoid crisis and sustain confidence in community based end of life care across all of North Cumbria

Periods of respite care can also be arranged, with Carlisle and North Lakeland also offering a specific Respite Care Service for Neurological Conditions.

Hospice at Home services also deliver a support at home service to people who are eligible for 'fast track' discharge which is supported by Continuing Healthcare Funding. Lymphoedema services are also provided for cancer and non-cancer patients both at home and in clinic settings across North Cumbria.

Additional occupational therapy services are available from Carlisle and North Lakeland which can be accessed via self referral.

Jigsaw, Cumbria's Children's Hospice

Jigsaw covers all of Cumbria supporting a small cohort of babies, children and young people with medically complex life shortening conditions. This includes palliative symptom management and end of life care for children. We also provide after death care in our Butterfly Room for children

who are not necessarily previously known to Jigsaw. We mainly provide short respite breaks to support families providing nursing care, support and activities. Care is provided in a home from home setting and each young person's care is personalised towards their own needs, in partnership with the children and young adults, their family, carers and other professionals.

Specific Challenges in service delivery affecting North Cumbria

- West Cumbria also experiences significant staffing challenges in Community Nursing teams which have left gaps in accessing responsive palliative nursing overnight - increasing a gap in overnight response already felt across North Cumbria.
- No sustainable or widely available 24/7 specialist advice for generalist health and social care colleagues, leaving out of hours support for symptom management limited and unpredictable.
- No access to specialist nurse or consultant assessment out of hours, crises can occur at any time, particularly nights, weekends, and bank holidays.
- Multiple challenges in the delivery and accessibility of services across a geographically large, predominately rural area.

Stakeholder and Community Engagement

Collaborative Palliative Care Learning Event – Reconnecting, Rebuilding and Respecting across North Cumbria, November 2023

Around 150 health and care professionals came together with the aim of developing palliative and end of life care across North Cumbria. Supported by Dr Kathryn Mannix, the event at the Greenhill Hotel in Wigton, looked at the ingredients which support a 'good death'. Those who attended spent time considering the gaps, and how we could better work together to make improvements for patients.

The objective for the day was to gain a shared understanding of the current palliative/end of life landscape in North Cumbria and identify where we can work together for the benefit of our patient population. Professionals talked about what they heard from patients and also reflected on their own personal experiences. It was clear a good death meant that families were involved, and the patient's views were heard, there was good planning especially around managing pain, and other professionals were brought in in a timely way, and the patient had the care in the most appropriate place. There was also reflection that this list may have been different with more patients in the room.

Hospice at Home Carlisle and North Lakeland 360 Review

H@H Carlisle and North Lakeland commissioned Cumberland Healthwatch to undertake a 360 review which provided qualitative evidence from 13 service-user, carer, professional, trustee and bereaved family case studies to inform understanding of palliative and end-of-life care needs, service impact, and unmet need within Carlisle and North Lakeland.

The feedback shared gives insight into key population needs:

- Early and ongoing palliative support, not solely end-of-life care.
- Support for unpaid carers, many of whom experience exhaustion, isolation, and declining health.
- Rapid response during crises, particularly following hospital discharge
- Psychological, emotional and spiritual support for patients and families
- Bereavement support, including proactive follow-up after death.

Hospice at Home Carlisle and North Lakeland LEAF - Lived Experience Advisory Forum

Feedback from patients about the experiences of bereavement and support received from H@H Carlisle and North Lakeland provides insight into how patient need is not just about symptom control at the end of life — it is about preparedness, safety, dignity, emotional security, and sustained support for families before, during and after death.

This feedback shows that patients and families need:

- Clear, kind communication in plain language
- Earlier anticipatory care planning
- Safe, supported transitions from hospital to home
- Adequate, predictable respite for carers
- Equitable access despite rurality
- Proactive emotional and bereavement support
- Specialist input for complex conditions
- Clear signposting and awareness of services

Eden Valley Hospice and Jigsaw Children's Hospice - [Bringing care closer to home: Improving palliative care in remote, rural and island communities](#). Hospice UK 2025

Case studies ("Supporting complex care packages" and "Rafferty's story") from families who have worked with Eden Valley and Jigsaw Hospices formed part in the report, which explored the unique challenges of accessing palliative care in rural communities. Key themes from these case studies outlined:

Rurality Intensifies Inequity and Access Challenges

- Remote and rural geography leads to long travel times, limited local services, and difficulty accessing specialist care.
- Fragile infrastructure (e.g., road closures, lack of care workers, workforce shortages) directly impacts patient safety and quality of life.

Hospice Care is a Stabilising Force for Families

- Hospices provided specialist, consistent, relationship-based care that families and systems could not sustain alone.
- Their involvement reduced risk, prevented care-package breakdowns, and supported preferred place of care and death.
- Hospices offered vital family-centred support, not just patient care.

System Pressure and Workforce Limitations

- Complexity of needs in rural areas exposes system vulnerabilities—lack of carers, overstretched community teams, and limited local facilities.
- Without hospice involvement, many cases risked escalation to high-cost or out-of-area placements.

Personalisation, Continuity, and Trust Matter Deeply

- Relationships built with hospice teams increased people's confidence in their care, supported dignity, and strengthened emotional resilience for families.
- Services that view patients "as part of a family, not just a case" deliver profoundly meaningful impact.

Locality specific activity and initiatives

Patient and Family Support Services

Eden Valley Hospice

- Counselling
- Social Work
- Living Well Services
- Bereavement support
- Spiritual Care

Hospice at Home West Cumbria

- Complementary therapies from Specialist Therapists
- Agreement for sessions for patients with MND
- One-to-one and group emotional support for adults (for patients, families and those bereaved)

Hospice at Home Carlisle and North Lakeland

- Complementary therapies
- One-to-one and group emotional support support for adults (for patients, families and those bereaved)
- Respite project for patients with long term neurological conditions
- Befriending Service

North Cumbria Integrated Care NHS FT

- Bereavement service providing staff, patient and family support

Death, Dying and Bereavement Resource Bags

In order to improve access to information and meaningful conversations about death and dying for those with learning Disabilities, colleagues in CNTW (Cumbria, Northumberland, Tyne and Wear NHSFT), NCIC (North Cumbria Integrated Care NHSFT) and Eden Valley Hospice collaborated to develop a resource pack, filled with easy read supportive documents to help encourage conversations around death and dying.

Members of organisations supporting people with learning disabilities and those with lived experience have reviewed and selected all of the resources inside the bags, which will be available to health and care organisations in North Cumbria in Spring 2026.

Staff Confidence and Competence Survey 2025

In 2025, the North Cumbria End of Life Education and Collaboration Subgroup undertook a survey of staff confidence and competence in delivering End of Life Care within their roles. The survey gathered 243 responses from colleagues across the system with significant responses from GPs, paramedics and nurses giving insight into the experiences of generalist health and social care staff in delivering PeoLC. These included:

- Staff are highly confident communicators, with strong skills in sensitive conversations and involving people in decisions about their care

- Confidence drops in clinically critical areas: recognising when someone is imminently dying, managing pain and symptoms, and discussing nutrition/hydration
- System navigation is inconsistent. Many staff—especially in community and residential settings—are unsure how to access specialist palliative care advice, particularly out of hours
- Staff report a need for practical, role-specific training, clearer escalation pathways, and improved information sharing

LDT specific recommendations

The top three gaps in North Cumbria were agreed as:

24/7 – Professional Palliative Care Advice / support better symptom control

- This would support better and more responsive care and reduce inappropriate admissions.
- Specifically – out of hours, 7-day access to advice, single point of access, connectivity into wider services. Specialist palliative advice to generalists. Supporting patients to better manage symptom control. Ambition to go further and offer access to patients and family/carer.

Communication and Collaboration

- This would increase timely care, and time to care, by reducing wasted time chasing other professionals and repeating conversations.
- Across teams – knowing what else is on offer, patient skills, accessing records, single point of access, a discharge pathway, doing more through co-production (a working together culture approach), advanced care planning and earlier conversations.

Education

Upskilling the generalist and the specialist workforce (at all levels) will improve patient experience and learning together will build more effective integrated networks.

In a range of areas:

- Early conversations
- Recognising the dying patient
- Generalist support – end of life is the responsibility of all clinicians
- Advanced care planning – having an ACP that goes with you all your life (An ACP for everyone from early on) / Training and support for early conversations with patient and family.
- Better understanding of other services

Local Priorities are established and coordinated by the North Cumbria End of Life Partnership Group. The Partnership is a collaborative which works to plan and deliver improvements on behalf of the North Cumbria Integrated Care Partnership Sub-Committee in line with the North Cumbria PEoLC Strategy.

Led by the three Hospices in North Cumbria, the group works to strengthen existing collaborative working to allow us to meet our aspiration that "Health and care system partners will work together to improve, innovate and deliver joined up services that meet the needs of people at end of life in North Cumbria."

In order to achieve this vision, the group work together as a committed partnership, continually reflecting and improving to design and deliver a programme of work which aligns with the agreed system priorities: improved communication, enabling a good death, developing choice and staff development.

Following the completion of a baseline self-assessment against the National Ambitions for Palliative and End of Life Care Framework, the group are working towards securing the following recommendations for North Cumbria:

- 24/7 specialist palliative advice line for professionals
- Rapid response service for West Cumbria initially
- Standardised approach to shared electronic care records
- Standardised approach to personalised care planning
- Central access information on services
- Improving digital maturity across providers for integration with the Great North Care Record
- Improved training offer for generalist, learning disability and social care workforce (and unpaid carers)
- Increase opportunities to promote death dying and bereavement across communities