

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

Supplement 5: Children & Young People Specialist Palliative Care Review

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Introduction

The purpose of this report is to summarise need, current provision (system view), access and equity, experience/outcomes, and priority system requirements for CYP who may benefit from specialist palliative and end of life care, aligned to national benchmarks and available population evidence.

In Scope

Areas in scope for this report included:

- Babies, children and young people (birth to 19) with life-limiting or life-threatening conditions who may benefit from specialist palliative care.
- Whole-pathway needs spanning identification, pathways, community and hospice support, end of life care and bereavement, including antenatal and neonatal.
- System themes: access, equity, coordination, experience/outcomes, and care closer to home.

Out of Scope

- Detailed provider-by-provider description
- Detailed workforce modelling

Key Findings

- **Need for CYP specialist palliative care across NENC is substantial, increasing and long-term**, driven by rising prevalence of life-limiting conditions, improved survival and growing clinical complexity, with many children requiring support over extended periods rather than only at end of life.
- **Palliative care involvement is not consistently embedded from diagnosis**, including antenatal and neonatal pathways, limiting anticipatory planning, continuity and coordinated support over time.
- **Current provision operates through a complex, multi-provider landscape**, with important contributions from specialist, community and hospice services, but without consistently formalised coordination, shared planning or escalation arrangements at system level.
- **Access to specialist advice and escalation is not consistently available 24/7**, reducing the system's ability to safely support care at home, particularly out of hours, and limiting genuine choice for children and families.
- **Variation in access persists by diagnosis**, with children with non-malignant life-limiting conditions experiencing less consistent access to specialist palliative care than oncology pathways, despite similar levels of need and complexity.
- **Geographic inequity remains a significant challenge**, particularly for families in rural and dispersed areas, where distance, travel time, medicines access and out-of-hours support can compound barriers to care.
- **Seven-day community support is not consistently available across NENC**, increasing reliance on hospital care during deterioration and reducing flexibility to support care closer to home.
- **Transition from children's to adult services is a system-level gap**, with few providers having named transition leads, limited shared expectations and inconsistent planning, placing young people at risk of fragmented care and loss of continuity.
- **Multidisciplinary and holistic support is incomplete**, with gaps in psychological, emotional, play and bereavement support limiting the system's ability to meet the full needs of children and families in line with national expectations.
- **System-wide assurance and outcomes monitoring are limited**, with no single, shared framework to measure access, equity, responsiveness and experience across CYP palliative care pathways.

Key risks

The gaps identified above give rise to the following key system risks and impacts:

Risk	Impact for CYP & Families	Impact on the System
Inconsistent palliative care involvement	Increased symptom burden, avoidable crises, reduced opportunity for shared decision-making and care aligned to family preference	Reactive rather than planned care, increased emergency admissions and inefficient use of acute services
Fragmented coordination	Patchy family experience, repeated storytelling and uncertainty about who to contact during deterioration	Duplication, gaps at handover points and reduced system resilience
Lack of reliable 24/7 specialist advice	Reduced ability to manage symptoms at home, increased distress during crises and limited choice of place of care	Increased unscheduled care use, hospital admissions and pressure on urgent and emergency services
Inequitable access by diagnosis,	Unwarranted variation in experience and outcomes based on diagnosis rather than need	Misalignment with national guidance and population-based planning principles
Geographic inequity and rurality challenges	Reduced access to timely support, increased family burden and constrained choice of care setting	Persistent place-based inequality and difficulty delivering consistent standards across NENC
Inconsistent seven-day community support, with variable availability of community and specialist support	Greater reliance on hospital care during deterioration and reduced continuity of care	Reduced effectiveness of care-closer-to-home models and increased acute demand

Unclear boundaries between specialist palliative care and related services	Confusion for families navigating services and inconsistent access to specialist input	Inability to identify unmet need can lead to displaced demand and inefficient use of resources
Incomplete multidisciplinary and holistic support	Unmet psychosocial needs for children and families before and after death	Failure to meet national quality expectations and increased long-term impact on family wellbeing
Weak transition arrangements to adult services	Loss of continuity, reduced support and increased anxiety for young people and families	Increased risk of crisis presentations and fragmented engagement with adult services
Limited system-wide assurance and outcomes monitoring	Ongoing “postcode lottery” for families	Reduced ability to identify variation, target improvement and demonstrate compliance with national standards

Background

National policy and quality guidance are consistent that palliative and end of life care for babies, children and young people should be needs-led, equitable, proactive and coordinated, beginning early in the disease trajectory and continuing alongside active treatment. NICE NG61 frames palliative and end of life care for children and young people as a long-term process that may start at diagnosis, including antenatally where relevant, and extend over many years. It emphasises shared decision-making, advance care planning, symptom management and enabling care in the child or young person's preferred place, rather than focusing solely on the final phase of life.

NICE Quality Standard QS160 sets out the core components of high-quality services, including coordinated leadership, multidisciplinary team involvement, access to emotional and psychological support, bereavement care, and 24-hour access to specialist advice and children's nursing support for those cared for at home at the end of life. Together, NICE guidelines establish a clear expectation that children and young people's palliative care should be embedded across pathways and settings, and should not be limited by diagnosis, prognosis or proximity to death.

Through the Service Specification for Specialist Palliative and End of Life Care for Children and Young People (January 2023) NHSE reinforces this approach, describing an integrated specialist model from identification of need through to end of life and bereavement. The specification recognises increasing prevalence of life-limiting conditions and highlights the importance of interdependencies between specialist palliative care, acute paediatric services, community children's services, hospices and primary care.

National policy direction further strengthens the case for assessing children and young people's palliative care need as part of wider system delivery. NHS England's Standardising community health services guidance (2026) positions palliative care as a core component of community health service models and reporting, while 'Fit for the future: towards population health delivery models' emphasises organising services around defined populations and strengthening CYP palliative care, particularly in supporting anticipatory planning, crisis responsiveness and care closer to home.

National benchmark

National guidance outlines that CYP Palliative Care should deliver:

- **Early and longitudinal palliative care** - Palliative and end of life care as a long-term process beginning at diagnosis, potentially antenatally, running alongside active treatment and incorporating day/night planning.
- **Core Service features** - Measurable expectations, include: ACP involvement, named medical leadership, MDT input (including specialist palliative care), emotional/psychological support, grief support, and 24-hour access to nursing care and consultant advice for children cared for at home at end of life.
- **Integrated model and interdependencies** - An integrated specialist model “from identification of need through to end of life and bereavement”, including interdependencies across acute, community, hospice and primary care.

The NHS England CYP Service Specification requires a consultant-led specialist multidisciplinary team (MDT) with representation from paediatric palliative medicine consultants, specialist palliative care nurses, named care coordination, and access to allied health professionals, psychological support, social work and spiritual care. The specification expects this MDT to operate across all care settings, provide 24/7 specialist advice, and work as part of an integrated system alongside acute paediatrics, community children’s services, conditions-specific teams, hospices, social care and education. While these requirements set a clear benchmark for function and availability, the specification intentionally does not prescribe MDT size or staffing ratios, placing the onus on systems to assure that the model of care is capable of meeting population need.

In December 2025, an Expert Panel Evaluation of Palliative care in England report found that commissioning of palliative care, especially services that sit across NHS, hospice and voluntary sector provision, is fragmented and opaque, with insufficient clarity about baseline expectations. This is particularly problematic for children’s services, which:

- serve smaller but highly complex cohorts
- often rely on blended funding models
- are more vulnerable to instability than adult services

The Panel concludes that ICBs have not yet translated their statutory duty to commission palliative care into consistent, needs-led provision for all population groups, including CYP, demonstrating

that children's palliative care services are structurally disadvantaged in commissioning prioritisation, increasing the risk that CYP needs are under-planned relative to adult services.

Population need

Population-level evidence demonstrates a substantial and growing level of need across the region. NENC data from the Make Every Child Count study show that the prevalence of children living with life-limiting conditions more than doubled between 2001 and 2017, rising from just over 30 per 10,000 to around 69 per 10,000, equating to more than 4,000 children and young people living with life-limiting conditions at any one time. This confirms that demand is not driven solely by mortality, but by a large and persistent cohort of children requiring ongoing, specialist and coordinated support over many years.

The age profile of need highlights the importance of early and longitudinal palliative care involvement. Prevalence is particularly high in infancy, with rates exceeding 220 per 10,000 among children aged under one year, demonstrating that need frequently begins antenatally or in the neonatal period. However, elevated prevalence is sustained across childhood and adolescence, reinforcing that children's palliative care should be understood as a long-term process running alongside active treatment and wider paediatric care, rather than as support restricted to the final stages of life.

The diagnostic profile of children with life-limiting conditions, is dominated by congenital and neurological conditions, reflecting improved survival and increasing complexity rather than short episodes of terminal illness. This pattern underlines that the majority of children requiring palliative care support in NENC have prolonged, multi-system needs that require coordination across acute, community and specialist services over extended periods. As a result, service models focused primarily on end-of-life episodes or condition-specific pathways alone are insufficient to meet the full spectrum of identified need.

There is clear evidence of inequality and unwarranted variation in need across NENC. Prevalence of life-limiting conditions is highest in the most deprived communities, demonstrating a strong overlap between palliative care need, deprivation and wider health inequalities from early childhood onwards. In addition, there is marked variation between local authorities, with prevalence ranging from the low 60s to over 80 per 10,000 children. Combined with the region's mix of urban, rural and coastal geography, this indicates that a one-size-fits-all approach will not adequately address need, and that a clear understanding of place will be essential to develop responsive models of care to ensure equitable access across NENC.

System Overview of Current Provision

CYP palliative care across NENC is delivered through a distributed landscape of services, including a regional specialist palliative care team, condition-specific oncology pathways, community children's nursing teams, and hospice-based provision. While this offers a wide range of support, providers describe variable access and coordination across localities, with community children's nursing not consistently available on a seven-day basis and specialist palliative care advice not routinely accessible 24/7.

Hospice inpatient or end-of-life care options are reported to be limited in some parts of the region, meaning that, despite a significant number of families choosing home or Hospice as the preferred place of care, the system can struggle to offer flexible alternatives or timely escalation, particularly out of hours. Providers highlight that these features make it difficult to consistently meet national expectations for integrated, round-the-clock specialist support across all settings.

At the same time, providers report active and ongoing quality improvement, recent developments include strengthened referral pathways and standard operating procedures, expanded training and education programmes delivered regionally and through hospices. Providers also identify inequity across the wider CYP palliative care system, and that current variation in access reflects differences in service configuration and investment rather than differences in underlying need.

Evaluating children's palliative care as a unified system rather than through the lens of individual providers is essential for several critical reasons:

- **Complexity of Care:** Seriously ill children have multifaceted needs that no single organisation can meet in isolation.
- **Equity:** By assessing the entire local landscape, gaps can be identified to address the "postcode lottery." This ensures that 24/7 specialist support is available to all families, regardless of which specific provider they first encounter.
- **Sustainability:** The current model relies heavily on the voluntary sector, with children's hospices often self-funding 80% of their costs. A systemic perspective allows statutory partners to recognise these contributions and develop sustainable, long-term funding models that distribute responsibility across the sector.
- **Facilitating Choice:** True patient choice is only possible if the wider system provides the necessary infrastructure, including specialist community nursing and out-of-hours consultant advice.

Ultimately, shifting the focus from "per provider" to "per system" moves the priority to holistic family outcomes, ensuring that care models are fit for purpose as the prevalence of life-limiting conditions continues to rise.

Presenting a clear picture of CYP SPC provision across NENC however, is further complicated by variation in service models and funding arrangements across place systems, and by blurred boundaries between specialist palliative care, Continuing Healthcare (CHC), hospice care and local authority-funded short breaks or respite provision. In many localities, elements of specialist palliative support are delivered alongside or embedded within other services, and consultant oversight may be provided remotely or through wider paediatric or hospice arrangements. As a result, this section focuses on describing the current landscape of provision and function, rather than attempting to produce a definitive account of capacity alone.

With multiple providers contributing, there needs to be significant focus on and investment in developing interfaces, shared planning, escalation routes, consistent standards and outcomes assurance to effectively meet needs of CYP and families.

Children's Holistic Integrated Palliative Care Service (CHIPS)

CHIPS, based at the Great North Children's Hospital in Newcastle, operates as a regional specialist paediatric palliative care function across NENC designed to address longstanding inequity in access to specialist support for children and young people with life-limiting and life-threatening conditions. The service was established in 2020 to ensure that access to specialist palliative care is needs-led and not dependent on diagnosis, particularly improving provision for children with non-oncological conditions who have historically experienced more variable access.

CHIPS provides specialist expertise across the disease trajectory, including antenatal and neonatal pathways, long-term complex conditions and end-of-life care, and interfaces with acute subspecialty teams, general paediatrics, community children's nursing, and condition-specific services. Its role is to support coordinated, anticipatory and responsive care across settings, rather than functioning as a standalone service, and it forms a core part of the wider system through which children's palliative and supportive care need is met in NENC.

Currently, the service does not currently operate a 24/7 specialist nursing or medical rota, meaning that children and families (non-cancer) do not have continuous access to specialist palliative clinical advice or symptom management outside core hours. The service has identified that extending to a fully resilient 24/7 model would require significant additional capacity and expertise.

It has also identified gaps within the MDT that limit the ability to deliver fully holistic, family-centred palliative care, however, this report notes that through additional investment and service development, administrative support has been bolstered, along with the addition of a WTE Psychologist and part time psychology assistant, bringing support for complex psychosocial need, and improving the quality and consistency of bereavement care. At the time of writing, the service is also currently recruiting senior nursing and medical roles in order to develop a resilient model with out of hours access.

Wider CYP Palliative and Supportive Care Provision Across NENC

CYP palliative and supportive care across NENC is also delivered through a range of hospice and community-based providers, including services such as Jigsaw (North Cumbria), St Oswald's Hospice (North of Tyne, South Tyneside, Sunderland, Durham and Gateshead), Zoe's Place and Butterwick Hospice (Tees Valley).

These services provide critical elements of care and support for children and families, often focusing on respite, symptom support, and end-of-life care, with varying access to specialist medical oversight. However, it is not always clear which elements of this provision constitute specialist palliative care as defined by national guidance, and consultant-led oversight is frequently delivered through external or shared arrangements. This reinforces the complexity of defining specialist capacity and demand, and highlights the importance of system-level coordination rather than service-by-service comparison alone.

Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS)

Although condition-specific and therefore outside the formal scope of this review, the NENC Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS) service provides an important role within the system. CYPOONS delivers specialist palliative care to babies, children and young people with cancer across NENC and consistently meets expectations for seven-day face-to-face care, 24/7 on-call access, prescribing capability and senior clinical support, with consultant oncology input available at all times.

At the same time, CYPOONS exposes significant inequity within the wider CYP palliative care landscape. Comparable levels of access and responsiveness are not currently consistently available to children with non-malignant life-limiting conditions.

This reinforces that current variation across NENC is driven by service configuration and historical investment decisions rather than underlying need, and that addressing this imbalance will be critical to delivering an equitable, system-wide CYP specialist palliative care offer aligned with national benchmarks.

Transition from Children's to Adult Services

Transition from CYP to adult services represents a critical and consistently vulnerable point for young people with life-limiting and life-threatening conditions across NENC. National guidance is clear that palliative care for children and young people should be continuous and coordinated across the life course and expects integrated working across services to avoid disruption to care at transition.

Providers report variation in how transition is planned, led and experienced, with limited system-wide consistency. While some local services have established informal relationships or condition-specific arrangements, transition is often dependent on individual clinicians rather than embedded pathways. Few providers have named transition leads, and there is no consistent expectation across the system regarding ownership, coordination or accountability for transition planning. This creates a risk that young people with complex, long-term palliative care needs experience fragmented handovers, loss of continuity and reduced access to specialist support at a time of heightened vulnerability.

The absence of clearly defined transition leadership also limits the system's ability to deliver early, proactive transition planning, particularly for young people with non-malignant conditions who may have prolonged and fluctuating palliative care needs. Where transition is not planned well in advance, families report uncertainty about future care, changes in relationships with trusted professionals, and anxiety about adult service readiness.

From a system perspective, transition gaps reflect broader challenges in coordination across multiple providers and settings. Children and young people receiving palliative care often interface with multiple specialist and community paediatric teams, community children's nursing, hospices, education, social care and voluntary sector support. They also often transfer to multiple adult specialist services and need to rely more on primary care services to hold a holistic overview of their care. Without a named lead or agreed transition framework, responsibility for coordinating across these interfaces can become unclear, increasing the risk of duplication, omission or delayed engagement with adult services. This undermines national expectations for seamless, person-centred care and can drive avoidable reliance on crisis services during deterioration.

As adult specialist palliative care services are configured differently, with different eligibility criteria, much more general palliative care is delivered by primary care services. Transition planning should include primary care and must identify current and anticipated specialist palliative care needs to ensure appropriate and timely referral to specialist palliative care services even if this is not needed at the time of transition.

There are also equity implications. Young people in rural or dispersed areas, or those with complex neurological and non-cancer diagnoses, may be particularly affected by inconsistent transition arrangements. Where adult services are less visible or harder to access, the absence of structured transition planning can exacerbate existing geographic and diagnostic inequities identified elsewhere in this review.

Overall, transition represents a system-level gap rather than a provider-specific issue. The limited presence of named transition leads, lack of shared expectations and absence of consistent pathways mean that continuity of palliative care support cannot be reliably assured for young people moving into adult services across NENC. Addressing this gap will be essential to delivering an equitable CYP palliative care system that supports young people and families across the full trajectory of care.

Without explicit system ownership of transition, continuity of palliative care support for young people moving into adult services cannot be reliably assured.

Conclusion

This needs-led review demonstrates that demand for children and young people's specialist palliative and end of life care across NENC is substantial, increasing and long-term, driven by rising prevalence of life-limiting conditions, improved survival and growing clinical complexity. National guidance is clear that palliative care for children and young people should begin early, run alongside active treatment and be delivered through coordinated, equitable systems that support care closer to home, continuity across settings and responsive escalation when needs change.

NENC has a wide and committed provider landscape delivering important elements of care and support for children and families. However, when assessed at a system level, current arrangements do not consistently deliver the core features expected by national standards. Variation in early identification, coordination across providers, access to 24/7 specialist advice, seven-day community support and transition to adult services means that families' experience and outcomes remain dependent on diagnosis, geography and local service configuration rather than underlying need.

The review highlights that these challenges are systemic rather than provider-specific. Fragmentation arises where multiple organisations contribute to care without shared expectations, consistent escalation routes or clear ownership, particularly at points of vulnerability such as deterioration, out-of-hours care and transition to adult services. The limited presence of named transition leads and the absence of consistent transition pathways further undermine continuity for young people with long-term palliative care needs.

Importantly, the findings do not point simply to a need for more specialist input in isolation, but to the need for an assured, coordinated system offer. This includes clear minimum access standards, early and proactive identification, consistent advance care planning, defined interfaces across services, and equitable models that explicitly address rurality, deprivation and diagnostic variation. Without this system-wide focus, the ability to deliver genuine choice, care closer to home and equitable outcomes for children and families will remain constrained.

Addressing the gaps outlined in this review is essential to ensuring that CYP specialist palliative care across NENC is consistently needs-led, equitable and resilient, and that system leaders can be assured that national expectations are being met for children, young people and their families across the full trajectory of care.

Recommendations

Recommendation 1. Agree and implement a system-wide CYP palliative care model for NENC

Establish a shared system framework that defines minimum expectations for access, coordination, escalation and continuity across all providers and settings, aligned to national guidance.

Recommendation 2. Embed early and proactive palliative care involvement across pathways

Strengthen identification and referral from diagnosis, including antenatal and neonatal pathways, to enable anticipatory planning, continuity and coordinated support over the full disease trajectory.

Recommendation 3. Strengthen system coordination and shared planning

Develop consistent expectations for shared care plans, escalation routes and communication across specialist, community, hospice and acute services to reduce fragmentation and variation in family experience.

Recommendation 4. Improve access to 24/7 specialist advice and escalation at system level

Ensure that children, families and professionals have reliable access to specialist palliative advice out of hours, supporting safe care at home and genuine choice of place of care.

Recommendation 5. Address inequity by diagnosis and geography

Use population-level evidence to assure equitable access to specialist palliative care regardless of diagnosis, deprivation or rurality, explicitly addressing variation for children with non-malignant and neurological conditions.

Recommendation 6. Strengthen seven-day community support to enable care closer to home

Improve consistency of community-based support across the week to reduce avoidable hospital admissions and support families during deterioration.

Recommendation 7. Clarify roles and interfaces across CYP palliative, CHC, hospice and respite provision

Agree clear system-wide definitions and interfaces to improve navigation for families and enable more consistent assurance of specialist palliative care provision.

Recommendation 8. Enhance multidisciplinary and holistic support

Strengthen access to play and bereavement support across the pathway to ensure care is fully holistic and aligned with national quality expectations.

Recommendation 9. Establish a consistent, system-wide approach to transition

Introduce clear expectations for transition planning, including named transition leads, early preparation and joint working between children's and adult services to ensure continuity of care.

Recommendation 10. Develop system-wide assurance and outcomes monitoring

Implement a shared framework to monitor access, equity, responsiveness and experience across CYP palliative care pathways, enabling identification of variation, targeted improvement and assurance against national standards.

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