Classification: Official

Publication reference: PR1675

Specialist palliative and end of life care services

Children and young people service specification

18 January 2023

Contents

This document provides a children and young people service model for delivering specialist level palliative care (SLPC) services from identification of need through to end of life.

[We have provided guidance for commissioners in square brackets through the specification.]

1. Population needs

1.1 National context

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (Fraser et al, 2020). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030.

Palliative care is provided to infants, children and young people with a wide range of life-limiting or life-threatening conditions (in excess of 300). Some will have severe disabilities and multiple and particularly complex healthcare needs related to their condition, as well as palliative care needs. However, up to 15% of children and young people with palliative care needs do not have a definitive underlying diagnosis.

Access to palliative care should not depend on diagnosis or overall prognosis and can be provided at any stage of a child or young person’s illness.

Services with the competencies to offer paediatric palliative care will support and care for children and young people and their families at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement.

The needs of children and young people living with more complex and/or long-term conditions that are life-limiting or life-threatening cannot be met by the capabilities of their core team alone. They need input from a workforce with specialist palliative care skills and experience.

See Appendix 1 for common definitions of palliative and end of life care (PEoLC).

1.2 Local context

[Commissioners should detail local strategies, responses to national guidance and relevant local data, including patient feedback.]

2. Outcomes

[Using the NICE quality standard (QS160) and the ambitions framework, commissioners and providers should agree and define the outcomes that demonstrate each of the following is met for their local areas:

- Each child and young person is seen as an individual:
  - evidence of a personalised approach to care
  - example: person-centred outcome and experience measures.
- Each child and young person gets fair access to care:
  - evidence of steps to establish how equitable access to the service is and any measures to improve this.
- Maximising comfort and wellbeing:
  - evidence of effective efforts to maximise the person's comfort and wellbeing using established validated outcome measures.
- Care is co-ordinated:
  - extent to which the service provider engages with local systems to share information that supports better co-ordination of care, eg through participation in electronic palliative care co-ordinating systems (EPaCCS) or equivalent as they are established.
- All staff are prepared to care:
  - evidence from outcome measures, uptake of education and training, other staff support measures and appraisal systems for own staff, and contribution to the education and training of wider PEoLC teams in the locality.
- Each community is prepared to care:
  - evidence of actions the service has taken, or plans to take, in relation to community engagement and understanding of PEoLC.]

3. Scope

3.1 Aims and objectives of service

[Commissioner to include relevant key aims and objectives for the service provider(s). They should specify:

- the key services to be provided
- key workforce with specific characteristics, ie level of skill and training
- an integrated approach to PEoLC services with structures and systems that improve communication and co-ordination between service providers, including seamless transitions of care
- a multidisciplinary team (MDT) model of delivery and one that includes personalised approaches such as personalised care and support planning, including anticipatory care planning; and supported self-management approaches and personal health budgets
- holistic approach to care with links to social prescribing, assessing and addressing the needs of children, young people and families, clear referral pathways to other services such as child and adolescent mental health services (CAMHS)
- use of IT systems such as EPaCCS (or equivalent)
- participation in a managed clinical network approach
- a local training offer that targets specific groups, including those across health, social care, education and the voluntary sector
- approaches to ensure delivery is in keeping with the principles of diversity, inclusion and equality.]

3.2 The service model structure

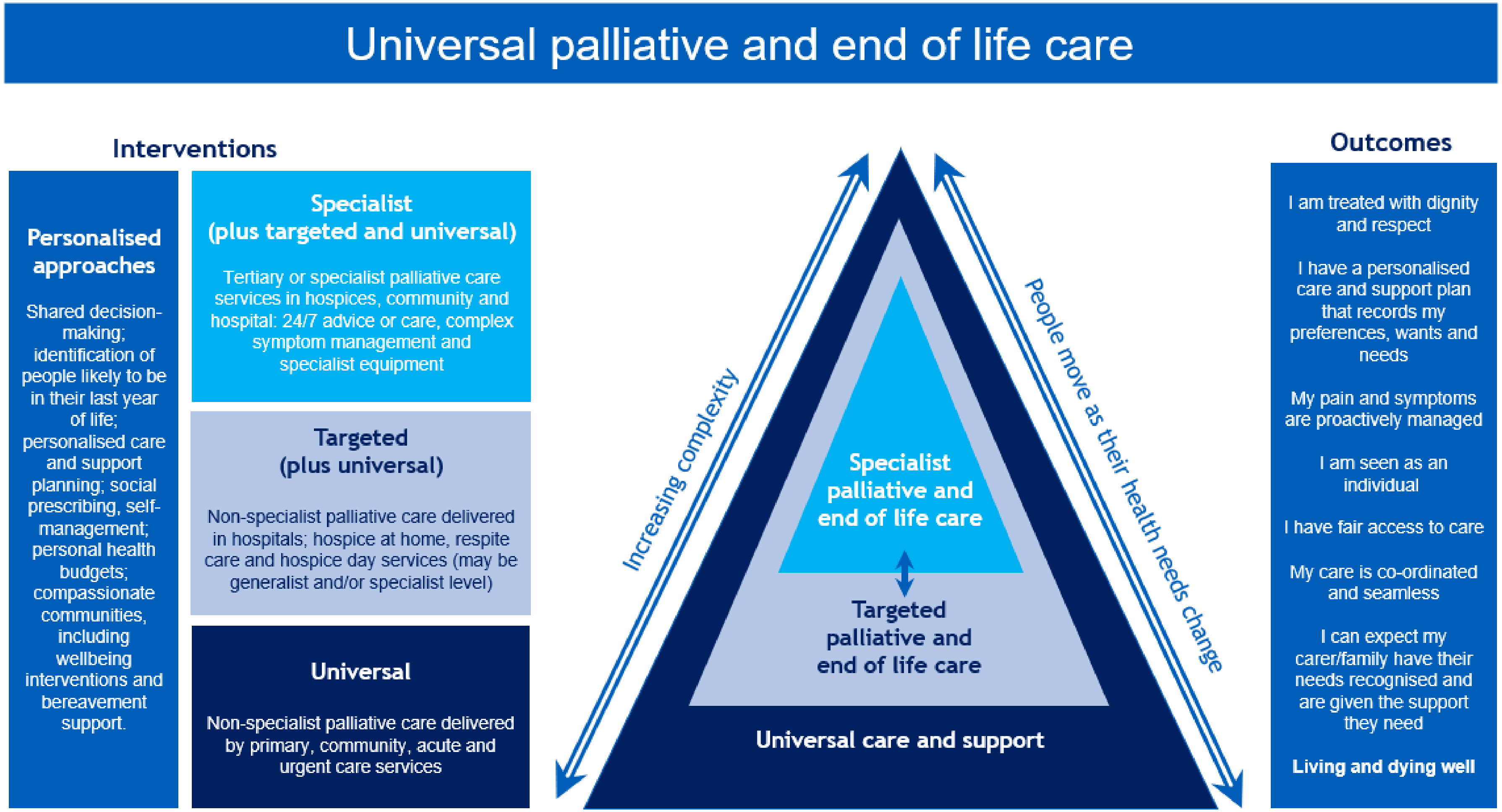
[Figure 1 shows the whole system approach. Commissioners should ensure that appropriate services are available to children and young people from universal services, through to core services and to specialist provision. The tiers of provision are not compartmentalised but joined for a seamless patient journey. The right professional should provide care and support at the right time and in the right place, with no opportunities for support missed and specialist provision targeted where it is needed most.

The model is tiered only to help commissioners plan development; not create barriers to integrated working. Close engagement between tiers is vital to ensure the child or young person's story does not need to be told more times than necessary; key health and wellbeing needs are identified and addressed effectively; and all professionals involved in the child or young person's care are aware of personalised plans agreed with the child, young person, their family and/or carer.

The model is not a stepped approach. It is flexible with each service area's involvement fluctuating through a child or young person's journey in response to need. Each tier of provision depends on the others to ensure a holistic approach to the health, wellbeing, emotional, social and spiritual needs of the child or young person and their families and carers. No single provider can provide for all these needs.

Commissioner to insert detail on the locally agreed service model.]

Figure 1: Relationship between services



Universal palliative and end of life care

Interventions

Personalised approaches

Shared decision-making; identification of people likely to be in their last year of life; personalised care and support planning; social prescribing, self-management; personal health budgets; compassionate communities, including wellbeing interventions and bereavement support.

Specialist (plus targeted and universal)

Tertiary or specialist palliative care services in hospices, community and hospital: 24/7 advice or care, complex symptom management and specialist equipment

Targeted (plus universal)

Non-specialist palliative care delivered in hospitals; hospice at home, respite care and hospice day services (may be generalist and/or specialist level)

Universal

Non-specialist palliative care delivered by primary, community, acute and urgent care services

Increasing complexity

Specialist palliative and end of life care

Targeted palliative and end of life care

Universal care and support

People move as their health needs change

Outcomes

I am treated with dignity and respect

I have a personalised care and support plan that records my preferences, wants and needs

My pain and symptoms are proactively managed

I am seen as an individual

I have fair access to care

My care is co-ordinated and seamless

I can expect my carer/family have their needs recognised and are given the support they need

Living and dying well

3.3 Delivering the integrated model

[This section describes the individual tiers of the integrated service model (Figure 1). The tiers of universal and core services are covered for completeness, but this specification largely focuses on the requirements for specialist PEoLC provision.

Commissioners may wish to highlight the information relevant to their provider and/or detail how each tier will be achieved locally.]

3.3.1 Universal services

[**'Universal services'** are those that all children, young people and their families have access to. The key services within this category are primary care, health visitors, social care and education. It also includes wider community groups. These services are embedded in the communities they serve and can play a key role in the development and promotion of palliative care approaches.

The universal services structure will vary from place to place but the support they offer to the child or young person and their families includes:

- Primary care: This includes GP services and dental care. GPs are key partners. The primary healthcare team can provide advice at times of intercurrent illness, routine health checks for certain long-term health conditions, continuous care during transition between services and support to the whole family in bereavement. GPs can share information with and receive information from the MDT. They should be in close communication with core teams, especially those delivering care at home.
- Health visiting/school health nursing: These professionals play a leading role in ensuring the child or young person can access the local Healthy Child Programme (HCP) offer.
- Local authority social services: These services can provide any non-specialist mobility equipment as required to enable a child or young person to live at home or to move around their environments safely. Also, the local authority often works alongside the integrated care system to deliver safeguarding services and co-ordinate care for Looked After Children.

- Education: All children and young people should continue to be able to access education, with learning and physical need adaptations made where appropriate. An Education and Health Care Plan (EHCP) is an important requirement for the child or young person. A SENCO ensures the EHCP is completed by, and is shared with, the relevant people around the child or young person. School nursing services ensure health needs are addressed and catered for within the school environment.
- Community groups: These voluntary or charitable groups can provide leisure and recreation, social networks, financial and benefits advice, or support groups. Social prescribing may be developed within a place to meet the needs of children and families with palliative and end of life needs.

Commissioner to insert detail on the agreed service model.]

3.3.2 Enhanced services

[**'Enhanced services'** are predominantly provided and funded by children's hospices and other charitable organisations. This arrangement may include activities such as:

- bereavement support for non-complex grief
- emotional and practical support, including advocacy
- parent/carer support and groups
- sibling support including activities
- complementary health.

These services are not routinely funded by NHS commissioners but may form part of a wider commissioned offer. Where they are not available, commissioners should look to alternatives to ensure an offer is available in their area.

Commissioner to insert detail on the agreed service model.]

3.3.3 Core services

[**'Core services'** provide targeted and skilled support in a range of settings. Most children and young people's palliative care is provided at this level by a range of organisations, including community services, acute hospital services or hospices.]

Core palliative care multidisciplinary team

Core services for children and young people diagnosed with a life-limiting or life-threatening illness will be delivered around an MDT model.

The provider must ensure services communicate to achieve seamless care that works to the agreed personalised care and support plan.

The key objectives of the core PEoLC MDT are: [delete/add as required]

- ensure a personalised care and support plan, and where applicable an advance care plan, are offered, agreed and followed by all services in regard to care and support
- plan and deliver symptom control
- for each child or young person identify a care co-ordinator or key worker who is responsible for co-ordinating their care
- all relevant services to meet the needs (physical, emotional and psychological) of the child or young person are engaged and available for access as appropriate
- the equipment and resources needed to support the child or young person are available at the right time and in the right place
- all medicines and prescribing are available when needed, with appropriate specialist support as required
- all transfers of care are planned and plans communicated, eg discharge planning
- short breaks or respite within age appropriate settings are offered
- professionals (universal and core) have the relevant training and skills, and know when to seek specialist advice.

Core respite services

[Short breaks are a key part of service provision (NICE NG61) and there are a variety of models for providing these. ‘Standard short break’ services give parents/carers a much-needed break from their caring responsibilities, and also a break and benefits for the child or young person; for example, by supporting their independence and giving them the opportunity to socialise with peers.

These can range from a few hours in the child or young person's home to longer stays away from the family home in specially equipped respite facilities such as a hospice. Short breaks can also be to give parents help with the day-to-day looking after of their child or young person so that families can spend quality time together, rather than apart, but without this time being dominated by caring duties (as these are taken care of by staff).

Commissioner to insert detail on the agreed service model for core respite services.]

Core multidisciplinary team staffing models

The provider must ensure provision for: [delete/ add as required]

- healthcare professionals from primary, secondary or tertiary services, including specialists in the child or young person's underlying life-limiting or life-threatening condition and members of the specialist palliative care team, and where available hospice professionals or members of palliative care charities
- social care practitioners
- education professionals
- family representatives
- spiritual advisors
- allied health professionals (eg physiotherapists, occupational therapists and psychological therapists)
- short breaks and respite providers
- voluntary sector groups and services
- children's continuing care nurses or assessors
- equipment services
- carer services
- equality inclusion leads.

The make-up of the MDT should be adjusted as appropriate to the changing needs of the child or young person.

3.3.4 Specialist services

[‘Specialist services’ support children and young people with a range of life-limiting or life-threatening conditions. They are experts in their field with knowledge and experience about the conditions and the issues they present.

A specialist children and young people palliative care team is defined as one that is supported by a doctor with specialty training (a consultant) in paediatric palliative medicine. They are supported in providing expert care and support to children, young people and families by specialist level professionals such as specialist nurses, pharmacists and psychologists where this is needed.]

The provider must ensure the delivery of the components of a specialist palliative care team, which include: [delete/add as required]

- advanced symptom management:
  - complex symptom management skills
  - knowledge of the dying process
  - understanding of rare disorders and their pathways
- parallel planning and enhanced supportive care
- support for advance care planning, including emergency care planning and accessing children’s continuing care
- support for end of life decision-making, including preferred place of care
- rapid discharge for end of life care, including fast track to hospice or home
- specialist medical and nursing support, available 24/7, for hospices, acute trusts, community palliative care teams and tertiary centres
- specialist equipment in the home (where not included in children’s continuing care arrangements) [may be commissioned on a case-by-case basis where unique needs are identified]
- input into MDTs, ‘team around the child’ (TAC), pre- and debriefs relating to a child or young person’s death, and other professional meetings, at hospitals, hospices and in the community
- identification of those with complex grief and at ‘high risk’, and their signposting/referral to appropriate local and/or specialist bereavement services
- education and training programmes across care settings, including bespoke patient-specific training of professionals in the use of specialist paediatric

palliative care equipment, eg community patient-controlled analgesia and drug infusion devices.

Specialist respite services

[‘Specialist short breaks’ provide sometimes urgent extra care in an appropriate setting or programme for medically complex or technology dependent children who may otherwise be excluded from standard short breaks. This may include symptom management and assessment.

Such breaks may take place in the child or young person's home or away from home in a setting such as a hospital, long-term care facility or hospice.

Commissioner to insert detail on the agreed service model for specialist respite services.]

Specialist palliative care multidisciplinary team

SLPC is delivered by an MDT with the requisite qualifications, expertise and experience in offering care for children and young people with life-limiting or life-threatening illness, with or without co-morbidities. The specialist team should be involved in the early stages of planning palliative care and then may be involved at different stages of the child or young person’s journey as required.

The provider must ensure that a specialist children and young people’s palliative care team can provide the workforce to support children and young people on a 24/7 basis [this may be remote support or as part of a wider regional offer]. The workforce must include at a minimum (NICE NG6):

- a consultant in paediatric palliative medicine
- a clinical nurse specialist (Band 7 and above) with expertise in paediatric palliative care
- a pharmacist with expertise in paediatric palliative care
- experts in child/young person and family support, including provision of psychosocial support in the context of PEoLC and bereavement (eg social, practical, emotional, psychological and spiritual support).

[Commissioner to include relevant detail from the below to reflect local arrangements.]

[**Specialist outreach teams** provide disease-specific or palliative care outreach to children and young people at home. These teams are usually multidisciplinary. As well as providing home care, outreach palliative care teams usually play an important role in consultation, liaison and provision of direct care. The teams advise healthcare professionals, including about symptom management, provide counselling and education for the child or young person and family, participate in discharge planning, liaise with community services and support a family through to bereavement.

Nurses specialising in palliative care. Where a nurse leads a service or has a role with a significant autonomous advisory component, such as in a community or hospital liaison setting or nurse-led outpatient clinic, they should be a clinical nurse specialist in palliative care or consultant nurse in palliative care. They may be responsible for or supervise lower grade nurses and non-registered staff. In other settings such as inpatient units, nurses who have been trained in SLPC training are part of the specialist MDT.]

3.4 Key service characteristics

[The service characteristics below are structured so as to make clear the links to Ambitions for palliative and end of life care: a national framework for local action 2021-2026.

These should be adapted to available or planned local services.]

The provider must:

Service characteristic	Link to ambitions framework
Referral	
1. Have defined referral criteria that include specialist level palliative care (SLPC) for: a. the child or young person with progressive life-limiting illness and with or without co-morbidities, where the focus of care is on quality of life, including complex symptom control b. the child or young person with unresolved needs that cannot be met by the current team. These needs may be physical,	Ambition 2

Service characteristic	Link to ambitions framework
psychological, social and/or spiritual, eg complex symptoms, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions c. the specialist service can be offered alongside the active treatment of an underlying condition.	
2. Have a referral process that includes an auditable system for prioritisation linked to patient outcomes.	Ambitions 2 and 4
3. Accept referrals based on need rather than diagnosis.	Ambition 2
Assessment and care	
4. Provide medical and nursing cover to allow assessment, advice and active management seven days a week, and 24-hour telephone advice. This may require a collaborative arrangement between a number of service providers and joint commissioning, working towards provision of 24-hour access to SLPC advice from a consultant in palliative medicine, including face-to-face assessment where necessary.	Ambitions 2, 3 and 4
5. Have timely access to the medication and equipment needed for specialist-level inpatient or home-based care. [Commissioner to include specific parameters.]	Ambitions 2, 3 and 4
6. Work in partnership with the child or young person, those important to them and their carers to develop and support personalised care planning, including identifying and recording personal preferences, and helping them navigate to services that will deliver the required information and care, at any time of day or night it is needed.	Ambitions 1 and 4
7. Identify and assess the needs of the family and those important to the child or young person, including their psychological and social needs; support and prepare them for the caring role at whatever level; and facilitate access and signposting to other services, including pre-bereavement and bereavement.	Ambitions 1, 3 and 6
8. Respond to those with protected characteristics in a sensitive and inclusive way, including by providing access to advocacy, translation and interpretation services.	Ambitions 1 and 2

Service characteristic	Link to ambitions framework
9. Use a multidisciplinary approach to care, with a competent workforce with recognised expertise in SLPC and using evidence-based best practice. Children and young people must be regularly reviewed and discussed by the MDT, as defined by local operational policy.	Ambitions 3 and 5
Co-ordination and partnership working	
10. Work in partnership with other services and the third sector to meet the child or young person's needs, ensuring that assessments and personalised care planning are reliably communicated to and co-ordinated with other services involved with the child or young person in a timely fashion.	Ambitions 1 and 4
11. Access and use an electronic palliative care co-ordination system to facilitate this co-ordination, as such systems become available locally, and where the individual agrees to its use.	Ambitions 1 and 4
12. Have a defined operational policy for multidisciplinary and partnership working to include arrangements for MDT meetings, and communication across care settings and organisational boundaries within a quality and governance framework.	Ambitions 4
Leadership and governance	
13. Have specialist level and diverse palliative care clinical leadership at senior strategic level within the organisation (eg senior management team level).	Ambition 5
14. Have a suitably resourced quality, IT and governance framework, which should include: • audit and quality improvement methodology • patient-centred outcome and experience measures and user feedback (in keeping with the requirements of the Accessible Information Standard) • data collection and sharing to aid service improvement at local and national level • adequate access to electronic clinical information, including pathology and imaging • arrangements for engagement in research in line with the service's objectives	Ambitions 1, 2, 4, 5 and 6

Service characteristic	Link to ambitions framework
- arrangements for all staff and volunteers to be appropriately trained and supported to give competent, reliable, confident and compassionate care.	
15. Be configured and established to lead and/or contribute to the delivery of education, training and continuing professional development to the wider workforce regarding best practice in palliative and end of life care.	Ambition 5
16. Use the growing evidence base to enable the development of innovative practice; share and celebrate good practice.	Ambitions 3 and 5
17. Contribute to and encourage public involvement and engagement in developing compassionate, understanding communities, including through raising local awareness, practical support and planning for future care.	Ambition 6

[Commissioners may wish to highlight the sections relevant to their provider and/or add details of how each tier will be achieved locally.]

3.4.1 Care planning

[**Personalised care and support planning (PCSP)** involves a series of facilitated conversations with children and young people, or those who know them well, to explore the management of their health and wellbeing within the context of their whole life and family situation. This process recognises the individual’s skills and strengths, as well as their experiences and the things that matter most to them. It identifies issues and actions to resolve these.

PCSP should be central for children and young people receiving PEoLC services. It is an essential tool to integrate the services the child or young person accesses so they have one joined-up plan that covers their health and wellbeing needs.]

The provider must:

- implement a process for recording conversations, decisions and agreed outcomes in a way that makes sense to the child or young person and their family
- ensure personalised care planning is proportionate, flexible, inclusive, equitable and co-ordinated. and adaptable to a person's health condition, situation and care and support needs
- ensure what matters to the individual is documented, their plan is directed towards these concerns, and all the necessary elements that would make the plan achievable and effective are included.

[NICE (NG61 and QS160) recommends consideration of **advance care planning (ACP)** for every child and young person with a life-limiting condition. This should be offered to all families and completed where agreed appropriate to do so. The key principles of a PCSP apply but with additions pertinent to supporting a child or young person in palliative care.]

The provider must implement processes for:

- collecting demographic information about the child or young person and their family, including up-to-date contact information for:
  - the child or young person's parents or carers
  - the key professionals involved in care
- providing a statement about who has responsibility for giving consent and evidence of parental responsibility
- providing a summary of the life-limiting condition
- agreeing an approach to communicating with and providing easy read and jargon-free information to the child or young person and their parents or carers
- summarising an outline of the child or young person's life ambitions and wishes; for example, for:
  - family and other relationships
  - social activities and participation
- including education preferences and an Education, Health and Care plan if relevant

- incorporating religious, spiritual and cultural beliefs and values into their care
- agreeing a treatment and prescribing plan and objectives
- providing a record of significant discussions with the child or young person and their parents or carers including:
  - preferred place of care and death
  - organ and tissue donation
  - management of life-threatening events, including plans for resuscitation or life support
  - specific wishes, eg for their funeral and care of their body
- providing details of any systems that provide early help, to avoid a crisis or handle an emergency
- agreeing a distribution list for the advance care plan
- agreeing a record of parallel planning (where applicable)
- agreeing discharge planning agreements from acute hospital to community
- use of social media accounts.

[Note on decision-making

All decision-making must be within an ethical and legal framework. In the UK clinicians are bound to follow the 2010 General Medical Council guidance on treatment and care towards the end of life. This includes specific guidance on decision-making for children and young people. Furthermore, specialist teams can support families and clinical teams in decision-making processes.]

3.4.2 Personal health budgets

[All children and young people in receipt of children and young people’s continuing care have a right to a personal health budget (PHB). For continuing care this is often a mechanism to implement one team of carers to build relationships and trust with the family.

Opportunities for a PHB are not limited to continuing care activities; numerous other opportunities may exist such as respite provided by carers already known to the family, or creative therapies to improve psychological wellbeing. The benefits of a PHB can be realised during the PCSP process and will allow funding to follow the individual.

Commissioner to include any relevant local PHB offers for children and young people in palliative or end of life care, including the pathway and relevant criteria.]

3.4.3 Family and carer needs

[Quality PEoLC includes giving appropriate and responsive care and support to families, friends, carers and all those who are important to the dying child or young person. This must encompass good bereavement and pre-bereavement care.

The needs of the family (including siblings) need to be assessed and where possible addressed. Ensuring carers are adequately supported is important to enable the child or young person’s management in a home environment where desired.]

The provider must ensure:

- processes are in place to assess the needs of the family and loved ones and, where possible, to address them
- the carers are adequately supported to enable management in a home environment where desired
- where there are opportunities to do so, the family is offered training to enable self-management within the family.

3.4.4 Care of the team

[Supporting a child or young person and their wider family will at times be emotionally challenging.]

The provider must ensure every member of the team receives support and an opportunity to feedback and discuss what is happening [eg access to professional psychological support for staff and standards for debriefs]. Professionals as well as volunteers should have access to ongoing health and wellbeing support and supervision.

3.4.5 Communication

[Good communication is vital to ensure that the child or young person and their family understands their condition, their plan, their key points of contact and what they may expect in their journey.]

The provider must ensure:

- there is a key contact for the child or young person and family who knows them and the system well
- the child or young person's story is only told once to each service
- professionals communicate well with each other and work well as a team
- the child or young person and their family are listened to about what works for them and what is important (in keeping with the requirements of the Accessible Information Standard)
- next steps in treatment and care are always well communicated in advance
- arrangements are accessible for those whose first language is not English.

3.4.6 Transition requirements

[It is important that teams at all levels – universal, core, enhanced and specialist – are aware of the transition needs of children and young people. Transition points can be identified for health, education or any other significant change that a child or young person may need support with.

This specification does not set out how transition should be managed as local services will vary in regard to age criteria, but it is important that local commissioners and providers ensure transition processes are in place for children and young people with palliative needs. The process of transition into adult services should begin, where appropriate, at the age of 14. NICE (NG43) makes recommendations for transition.

The provision of palliative care to adults aged 18 years and over is covered in a separate specification, but it is important that young people at a transitional age are catered for within both the specifications.]

The provider must ensure there are mechanisms and processes in place to support the transition of young people into adult services.

3.4.7 Information and data sharing

[Choice and decision-making must be underpinned by good information. The child or young person and their family need to have this and to be supported to use it. Information can support self-management if provided in the right way and at the right time. As such, professionals should appropriately share information, as well as direct children and young people to support organisations that can provide further relevant information and support.

A child or young person and their family need to have a copy of any plan they have agreed to, so that they can review, change and update it to ensure the plan guides a person-centred approach. Subject to the child or young person’s consent, or if they lack mental capacity in their best interests, the plan should also be shared with all those who may be involved in their care.

All electronic systems for sharing health-related preferences must be able to record and then share an individual’s preferences at the end of life. There should be ambitious local targets for the rollout of systems for sharing digital records and electronic patient care co-ordination systems (EPaCCs or equivalent) should be implemented to support this.

Commissioner to include details of the provider requirements.]

3.4.8 Complex decision-making

[On rare occasions, cases in paediatric palliative care are contentious, e.g. because of issues about treatment or access to services that are not routinely funded, or where clinical judgement and family choice do not align. Processes for reaching agreement may include consensus building meetings, medical mediation, second opinions or alternative pathways for difficult decision-making.

The relevant commissioner will support families and providers in reaching a consensus where funding is the issue, such as by using individual funding request processes.

Commissioner may include any specific requirements for complex decision-making.]

3.5 Population covered

Paediatric palliative care is concerned with providing palliative care to children and young people (and their families) with life-limiting or life-threatening conditions who are considered unlikely to reach their 18th birthday.

Different services will have different acceptance criteria for age. The recommendation is that all services use the definition of age as up to 18th birthday as a minimum standard, but where appropriate they work towards implementing services for those up to 25. This is especially important when considering service users with learning disabilities and transition requirements.

[Commissioner to include any relevant criteria and may wish to consider additional population requirements to help reduce health inequalities.]

3.6 Acceptance criteria

Paediatric palliative care services should be accessible to infants, children and young people with life-limiting conditions.

[There are no nationally agreed criteria for accessing specialist palliative care due to the complexities. These stem not only from the child or young person's level of need, but also social aspects such as safeguarding or family issues; and the inter-relationship with the confidence and skills of the non-specialist practitioner (core services).

Life-limiting or life-threatening conditions can be categorised into broad groups (see Appendix 2 for child and perinatal categories). These illustrate the wide range of conditions children and young people can have who are likely to benefit from a palliative care approach and/or support from children and young people's palliative care services. The groups are neither exclusive nor fixed; children can move between them or be in more than one at any time.

The concept of parallel planning is important, where palliative care is offered throughout a child or young person's life in parallel with and alongside curative treatment or treatment to significantly prolong life. The palliative care approach should be taken from diagnosis or recognition that curative treatment is not an option or may fail (Together for Short Lives, 2018).

Commissioner to include any relevant local criteria. Providers of SLPC services will often have clear acceptance criteria that need to be shared with potential referrers.

Commissioners may wish to consider:

- what happens where children or young people are not eligible for referral?
- what information is needed locally about services available and how is this are accessed?
- what assurances are in place about reducing inequity of access for underserved groups?
- discharge criteria
- support for integrated cross-sector/agency working.]

3.7 Interdependence with other services/providers

3.7.1 System-wide working

[All services – both statutory and voluntary – within and between the tiers of the model need to work collaboratively and closely together to deliver a truly integrated service model.

In the delivery of an integrated service, interdependence exists between the SLPC services and:

- primary and community providers – GPs, district nurses and out of hours services
- other multidisciplinary specialist teams
- rapid response team
- social care services – both in hours and out of hours
- other providers of children and young people PEoLC services: statutory and voluntary
- providers of acute care
- urgent and emergency care services, including NHS 111 and ambulance services
- providers of adult palliative care
- providers of services for individuals with long-term conditions

- local authority services and education
- equality and inclusion leads.

Commissioner to include any relevant local partnerships or working arrangements.]

3.7.2 Palliative and end of life care clinical networks

[One effective way to achieve more integrated working is through clinical networks, which can bring together different organisations to share best practice and provide a structure through which providers and commissioners can strategically plan service development, with an understanding of patient pathways. They also provide a forum to hear the voices of service years and the benefits of managed co-production.

Informal children and young people's palliative care networks currently operate in almost all regions and are to varying degrees achieving this potential. These networks will benefit from having clear linkages with the palliative strategic clinical network for their region.

A key NICE (GC61) recommendation is the development of managed networks, which would have a more formal management structure to support the delivery of care, with defined objectives and a clear governance framework.

Commissioner to specify how the provider will contribute to the local arrangement for the managed network(s).]

Appendix 1: Definitions of key terms

Infants, children and young people	Refers to everyone up to their 18th birthday as specified by NICE guidance (NG61, NG43) and the Children and Families Act (2014), and is used as the definition of children and young people in this specification. Different services will have different acceptance criteria for age. The recommendation is that all services use the definition of age defined above as a minimum standard but where appropriate they work towards implementing services for those up to 25. This is especially important when considering service users with learning disabilities and transition requirements.
Palliative care	Children and young people's palliative care is an active and total approach to care, from the point of diagnosis or recognition to death and bereavement. It embraces physical, psychological, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, anticipatory planning, parallel planning, complexity and crisis provision through death and bereavement. Palliative care is not dependent on diagnosis or prognosis and can be provided at any stage of a child or young person's illness, not only in the last few days of life.
End of life	The end of life stage begins when professionals caring for the child or young person and their family recognise that death may be imminent. End of life care is care that helps all those with advanced, incurable illness to live as well as possible in the final stages of their illness. This includes care during and around the time of death and immediately afterwards. It enables the supportive and palliative care needs of both the child or young person and their family to be identified and met throughout the last phase of life and into bereavement.

‘Core’ services	Key palliative and end of life activities that are commissioned and funded by integrated care systems (ICSs) or local authorities. These are essential services.
‘Enhanced’ services	These are services that make an important contribution to the health and wellbeing of children, young people and their families. These may be funded by charitable monies and will not be routinely commissioned.
‘Specialist’ services	Specialist palliative and end of life care is required for people (all ages) living with more complex and/or long-term conditions that are life-limiting or life-threatening. The needs of this group cannot be met by the capability of their core team alone. This care requires a workforce with specialist skills and experience, often working alongside the core service teams. They should be commissioned and funded by ICSs.

Appendix 2: Categories for palliative and end of life care: children and young people, and perinatal

Child and young person care

Category 1	**Life-threatening conditions for which curative treatment may be feasible but can fail**, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.
Category 2	**Conditions where premature death is inevitable**, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health. Examples: Duchenne muscular dystrophy.
Category 3	**Progressive conditions without curative treatment options**, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.
Category 4	**Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.** Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care. Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.

Together for Short Lives 2018. A guide to children’s palliative care, 4th edition

Categories for perinatal care

Category 1	An antenatal or postnatal diagnosis of a condition that is not compatible with long-term survival, eg bilateral renal agenesis, anencephaly.
Category 2	An antenatal or postnatal diagnosis of a condition that carries a high risk of significant morbidity or death, eg severe bilateral hydronephrosis and impaired renal function.
Category 3	Babies born at the margins of viability, where intensive care has been deemed inappropriate.
Category 4	Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, eg severe hypoxic ischaemic encephalopathy.
Category 5	Postnatal conditions that result in the baby experiencing 'unbearable suffering' in the course of their illness or treatment, eg severe necrotizing enterocolitis, where palliative care is in the baby's best interests.

BAPM 2010. Palliative care (supportive and end of life care) - A framework for clinical practice in perinatal medicine - Candidate conditions for perinatal palliative care

NHS England
Wellington House
133-155 Waterloo Road
London
SE1 8UG

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	01.
Service	Children's Emergency Respite Service
Commissioner Lead	NHS Cheshire and Merseyside
Provider Lead	Claire House Children's Hospice
Period	1 Year (1 April 2023 – 31 March 2024)
Date of Review	November 2023

1. Population Needs

1.1. National/local context and evidence base

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (Fraser et al, 2020). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030.

Palliative care is provided to infants, children and young people with a wide range of life-limiting or life-threatening conditions (in excess of 300). Some will have severe disabilities and multiple and particularly complex healthcare needs related to their condition, as well as palliative care needs. However, up to 15% of children and young people with palliative care needs do not have a definitive underlying diagnosis.

Access to palliative care should not depend on diagnosis or overall prognosis and can be provided at any stage of a child or young person's illness.

Services with the competencies to offer paediatric palliative care will support and care for children and young people and their families at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement.

The needs of children and young people living with more complex and/or long-term conditions that are life-limiting or life-threatening cannot be met by the capabilities of their core team alone. They need input from a workforce with specialist palliative care skills and experience.

(Taken from *Specialist palliative and end of life care services Children and young people service specification, 2023*; please refer to full document for further detail)

On average, people in their last year of life are admitted to hospital 2.28 times and have over 30 bed days in hospital – some have many more (The NHS Long Term Plan, 2019). Not only is this distressing for patients and their carers, but it also drives up costs for the NHS. Good end of life care is a high value intervention: it improves outcomes for patients and carers, at the same or lower overall cost to the NHS. The NHS Long Term Plan presents a crucial opportunity to address the unmet need of people approaching the end of life.

Community-based end of life care plays a critical role. Community end of life care is one of the few interventions shown to be effective in reducing reliance on emergency and acute care, largely through preventing avoidable emergency admissions. In England, there were over 1.5m Emergency Admissions for people in the last year of life in 2016, accounting for 9 million days spent in hospital at a cost of £2bn. Emergency admissions for people approaching the end of life are increasing. NHS costs are projected to double in the next 20 years. High quality palliative care could result in 60,000 fewer deaths in hospital, saving over £180 million each year (The NHS Long Term Plan, 2019).

Together for Short Lives Strategy 2018-2023

This strategy is the ambitious product of a range of answers from key stakeholders including families, children and young people, health and social care professionals, people who work in hospices and charitable agencies both in the UK and abroad. They were asked 'What does great palliative care look like?' The answers directly informed the strategy, resulting in an ambitious five year plan with children and families at the centre.

Recommendations:

1. To build a strong and sustainable children's palliative care sector.
2. Ensure that children, young people and families are better supported, connected and empowered.
3. Improve joined-up care and services.

To conclude, by 2023 we can deliver the change we know is right and necessary so that children's palliative care services are adequately funded, understood and supported, so that no child or family is denied the highest level of dignified and person-centred support.

Following this, Together for Short Lives recently released their new ten year strategy **"Making Every Moment Count" (2023).**

To steer work over the next decade, Together for Short Lives have set three strategic ambitions to make sure more children and families are able to get the support they need:

i. No family faces the journey alone – to increase reach so that more children and families can ACCESS 24/7 palliative care
ii. The best care and support – to improve the QUALITY of palliative care so families have the best support
iii. Support today, tomorrow and every day – to strengthen the SUSTAINABILITY of children's palliative care so families can rely on support.

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements, through to death and beyond. It focuses on enhancement of quality of life for the child/young person, and support for the family, and includes the management of distressing symptoms, provision of short breaks, and care through death and bereavement.

The Five Year Forward View, (NHS England, 2018) states that; "Support, aftercare and end of life care - which improves patient experience and patient reported outcomes, will all increasingly be provided in community settings". This continues to be a high priority for Cheshire and Merseyside ICB.

NICE Guidelines

In July 2019, NICE published new Guidance on the key Recommendations, they include:

- If possible, services should ensure that children and young people can be cared for at their preferred place of care and die at their preferred place of death
- Discuss with children and young people with life-limiting conditions and their parents or carers where they would prefer to be cared for and where they would prefer to die
- Provide children and young people and their parents and carers with the information they need on the care options available to them, including specific treatments and their preferred place of care and place of death
- Services should have agreed strategies and processes to support children and young people who are approaching the end of life and are being cared for at home. These services should be based on managed clinical networks and should collaborate on care planning and service delivery.

(End of life care for infants, children and young people with life-limiting conditions: planning and management, NICE, July 2019 [NG61])

NICE also provided a refreshed pathway in October 2019.

2. Outcomes

2.1. NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	1.6
Domain 2	**Enhancing quality of life for people with long-term conditions**	2.1, 2.4
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	
Domain 4	**Ensuring people have a positive experience of care**	4.6
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	

2.2. **National Outcomes:** Using the NICE quality standard (QS160) and the ambitions framework, commissioners and providers should agree and define the outcomes that demonstrate each of the following is met for their local areas:

• Each child and young person is seen as an individual:
– evidence of a personalised approach to care
– example: person-centred outcome and experience measures.

• Each child and young person gets fair access to care:
– evidence of steps to establish how equitable access to the service is and any measures to improve this.

• Maximising comfort and wellbeing:
– evidence of effective efforts to maximise the person’s comfort and wellbeing using established validated outcome measures.

• Care is co-ordinated:
– extent to which the service provider engages with local systems to share information that supports better co-ordination of care, e.g. through participation in electronic palliative care co-ordinating systems (EPaCCS) or equivalent as they are established.

• All staff are prepared to care:
– evidence from outcome measures, uptake of education and training, other staff support measures and appraisal systems for own staff, and contribution to the education and training of wider PEoLC teams in the locality.

• Each community is prepared to care:
– evidence of actions the service has taken, or plans to take, in relation to community engagement and understanding of PEoLC.

(Taken from *Specialist palliative and end of life care services Children and young people service specification, 2023*; please refer to full document for further detail)

2.3. Local defined outcomes

- All children and young people in Cheshire & Merseyside have consistent and equitable access to palliative care and end of life care at home.
- Increased number of children and young people dying in their preferred place, including their own home
- Increased number of children and young people receiving palliative and end of life care in their home

- Reduction in the number of hospital admissions and lengths of stay for children and young people receiving palliative care or end of life care
- Reduction in the number of children and young people with a life limiting illness dying in hospital
- Enhanced quality of care and dignity for all patients
- Improved patient experience
- Children and young people have their welfare or safeguarding needs identified early and support provided.

3. Scope

Emergency Respite Service: Specialist respite services [‘Specialist short breaks’ provide sometimes urgent extra care in an appropriate setting or programme for medically complex or technology dependent children who may otherwise be excluded from standard short breaks. This may include symptom management and assessment. Such breaks may take place in the child or young person's home or away from home in a setting such as a hospital, long-term care facility or hospice.

(Taken from *Specialist palliative and end of life care services Children and young people service specification, 2023*; please refer to full document for further detail)

Aims and objectives of service

- To provide unplanned/emergency respite for children, young people with a life limiting and life threatening conditions across Cheshire and Merseyside
- To improve outcomes and experiences for children, young people and their families living with life limiting and life threatening conditions; for families with children who have life limiting or life threatening conditions to have the support they need to live ordinary family lives as a matter of course.
- To work in partnership with the child, young person and family to provide the highest standards of care in a home from home environment and to support all family members
- To ensure an effective integrated model of care is developed that is safe, and provides a quality and cost effective service that supports the end of life needs of children, young people and their families.
- To support the development of effective partnership arrangements between health providers that enables advanced planning and co-ordination of integrated care.
- To provide advice, review and feedback for health professionals and families.
- To utilise the project in conjunction with existing services to support the development of comprehensive children’s community nursing; which meet the varied needs of children and young people and move care closer to home where clinically safe and appropriate to do so.

Service description/care pathway

The service will:

- Deliver an emergency/unplanned respite service for a total of 443 nights per year shared across all Places within the ICS footprint. The contribution of nights into that total from Places is outlined in the contract.
- Activity reporting will be at both ICS and Place level.
- Other nights over and above this threshold are subject to individual approval between commissioner and provider and costs will be shared between Places who have gone over their original contribution of nights into the pot of 443 nights. Ongoing evaluation of nights used per year will allow reassessment of proportional contributions from respective Places.
- Be person centred with the ability to respond rapidly but safely to facilitate choice in place of care.
- Referral for emergency respite can be made by the family or health and social care professionals.
- Reasons for emergency respite will include both health and social care reasons including end of life, symptom management, step down from hospital, serious parent/carer illness, parent/carer exhaustion, unexpected family crisis, care package breakdown.
- Each referral for emergency respite will be triaged by CH with referrals for end of life and symptom management identified as priority.
- Emergency respite provision for care package breakdown may be an option, but will be considered in partnership with existing care providers and may not always be possible and will certainly not be a long-term solution.

- Emergency respite will be provided by practitioners with appropriate qualifications, skill sets and expertise.
- Work collaboratively with statutory services, maximising the services the child and family receives. Work duplication will be reduced and therefore resource waste will be eliminated.
- Take into account safety issues in order to reduce any potential harm for the child, family or the staff providing the service.
- Implement and monitor policies in order to reduce risks associated with all aspects of clinical governance. This will include completing all relevant risk assessments for each child’s care.
- Establish and agree an individualised care plan for each child with their family/main carers.
- Claire House is responsible for all of the governance and monitoring with regards to Non-Medical Prescribers
- Costs per night are a contribution to full cost recovery rather than the full cost and are detailed in the contract. Costs will be reviewed on an annual basis in terms of activity, cost per night and proportional contributions per Place.

- **Population covered**

All children and young people within Cheshire and Merseyside aged 0-25 years inclusive with an identified need registered with a Cheshire and Merseyside GP or who reside in Cheshire or Merseyside.

- **Any acceptance and exclusion criteria and thresholds**

Referrals for emergency respite can be made by both families and health or social care professionals.

The reasons for the referral for emergency respite may include:

1) Health, including:
   a) End of Life Care
   b) Symptom management
   c) Step down from hospital after a prolonged stay or major surgery
   d) Step down from hospital after a prolonged admission

2) Social, including:
   - Close family bereavement
   - Parent/carer exhaustion
   - Parent/carer illness/hospital admission/death
   - Breakdown of care package (short term only)
   - Significant building work at home
   - Significant change in family circumstances (e.g. birth of new child)
   - Unexpected family events impacting ability to care for child

Claire House will endeavour to meet the requests for emergency respite but will always prioritise referrals for end of life care.

Interdependence with other services/providers

Claire House will work in partnership with Commissioners, existing children’s community nursing, Continuing Care and Complex Care Teams, Alder Hey specialist palliative care team and tertiary and secondary care providers.

Child Protection and safeguarding Children

Safeguarding and promoting the welfare of children and protecting them from harm is everyone’s responsibility, with everyone coming into contact with children and families having a role to play. (Working_Together_to_Safeguard-Children.pdf, July 2018)

Safeguarding children and adults will underpin all practice and the Provider will be expected to adhere to the relevant statutory guidance and implement wherever necessary. This includes all duties placed on the NHS organisation as detailed in chapter 2 of Working Together to Safeguard Children, 2018.

The provider will provide evidence of compliance with Cheshire and Merseyside's Commissioned Service Standards for Safeguarding Children and Adults at risks annually.

In particular the Provider will ensure:

- There are robust safeguarding children policies and procedures in place, ensuring that all Staff are aware of their individual responsibilities.
- All staff receive training to ensure they have knowledge about safeguarding and child protection and the knowledge and skills to intervene to protect children. Competencies need to be in line with Intercollegiate Document requirements.
- The Service must have the following in place:
- Safeguarding policies and procedures that comply with the Local Safeguarding Children Board policies and procedures;
- Arrangements in place to communicate effectively with other agencies including contributing to the Team Around the Family assessment framework process and the completion of the relevant LSCB multi-agency assessment tools to support work with the family.
- Arrangements in place to communicate effectively with other agencies including contributing to initial and review case conferences and other safeguarding meetings as appropriate to the needs of the children;
- Arrangements for the management of escalating risk
- An information sharing and confidentiality policy that is clear regarding when legally information can be shared without consent and explains service users' rights and responsibilities;
- Clear whistleblowing procedures
- Safer recruitment practice
- Appropriate supervision and support for staff
- Clear policies in line with those of the LSCB for dealing with allegations against people who work with children.

Transition

For many young people with life-limiting conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death. CH currently provides a service for children and young people 0-25 years. As such, they have specific health needs which differ from both younger children and older adults who need palliative care. These include advance care planning (ACP) and end of life planning. Young people should have parallel plans in place where it is unclear whether their condition will stabilise, deteriorate or enter the end of life phase. Young people with life-limiting conditions require holistic support from a range of providers spanning health, social care, education, and leisure and housing services. Claire House has a dedicated Transition Coordinator who will actively participate in multi-agency work to ensure person centred plans are developed for each young adult and delivered using a Team Around the Child model. The provider will work in collaboration with other key agencies to develop an integrated transition plan for any young person moving from children to adult services.

Discharge

The provider will take this into consideration as part of parallel planning. Any discharge from the Respite service will include ongoing post discharge support from the provider to the child and their family for as long as it is needed.

4. Applicable Service Standards

4.1. Applicable national standards (eg NICE)

- NICE Guideline (NG61), End of life care for infants, children and young people with life-limiting conditions: planning and management. (July 2019)
- NHS Long Term Plan (2019)
- Together for Short Lives Strategy (2018-2023)
- Together for Short Lives Ten Year Strategy (2023)
- Ambitions for palliative and end of life care, NHS England (2021)

4.2 Applicable standards set out in Guidance and/or issued by a competent body (eg Royal Colleges)

- Together for Short Lives (TFSL) (2018) Together for the 49000+ (Together for Short Lives Strategy 2018-2023)
- Specialist palliative and end of life care services Children and young people service specification (2023)
- NHS England Palliative and End of Life Care. Statutory Guidance for Integrated Care Boards (2022)
- NHS England Palliative and End of Life Care. Handbook for Integrated Care Boards (2022)
- HM Government (2018) Working together to safeguard children, DFE publications
- Royal College Paediatrics and Child Health et al (2014) Safeguarding Children and Young people: Roles and Competencies for Health Care Staff. Intercollegiate Document supported by the Department of Health
- Royal College Paediatrics and Child Health et al (2018) Looked After Children: Knowledge, skills and competences of health care staff. Intercollegiate Role Framework

4.3 Applicable local standards

- Cheshire and Merseyside Local Safeguarding Children's Boards Policies and Procedures
- NHS Cheshire and Merseyside ICB, Commissioning Standards to safeguard children and adults

5 Applicable quality requirements and CQUIN goals

Applicable Quality Requirements (See Schedule 4)

CQUIN goals - not applicable

6 Location of Provider Premises

The Provider's Premises are located at:

Claire House Children's Hospice
Clatterbridge Road
Wirral
CH63 4JD

Claire House CQC Provider Number: 1-101635394

7 Contract Monitoring

The service will collect activity and performance information as specified below and a report will be sent to the commissioner for each Place by the mid working day of the following month:

• Q1: Apr-Jun reported by mid of July	• Q2: Jul-Sep reported by mid October
• Q3: Oct-Dec reported by mid January	• Q4: Jan-Mar reported by mid April

Measure/Outcome	**Additional information/Target**	**Reporting mechanism and frequency**
Activity		
Total number of children on Claire House emergency respite service records		Quarterly report
No. of children with an individualised care plan	100% have a recognised individual care plan	Quarterly report
No. of new referrals		Quarterly report

No. of re-referrals		Quarterly report
Referrals by source	Alder Hey, GP, Children's Community Nursing Service etc and place of care at point of referral	Quarterly report
Gender and ages of all referrals	Breakdown by age bracket (0-3, 4-7, 8-10, 11-15, 16 plus)	Quarterly report
Reason for referral for emergency respite	Breakdown by close family bereavement, parent/ carer exhaustion, parent/carer illness/hospital admission, step down from hospital after a prolonged stay or major surgery, breakdown of care package (short term only), significant building work at home etc	Quarterly report
Outcome		
Nature of support required	Breakdown oncology, non-oncology etc	Quarterly report
No of children provided with emergency respite care		Quarterly report
Length of stay	For each referral	Quarterly report
No. of commissioned emergency respite nights used	For each referral	Quarterly report
Outcome	Breakdown deceased, step down etc	Quarterly report
Total onward referrals	No. and destination	Quarterly report
Benefit analysis		
No. of unplanned hospital admissions avoided	For each referral	Quarterly report
Cost savings per child	Breakdown HDU, oncology, no. nights on call etc.	Quarterly report
Patient experience/satisfaction		
Choice in preferred place of care	Evaluation of preferred and actual place of care	Quarterly report
Family survey – numbers of parent/carer feedback	Number and qualitative – comments	Annual Report

In addition, Claire House will provide quarterly quality reporting at ICS level as agreed at Joint Contract Meetings.

Claire House will also provide a detailed end of year report at ICS level including analysis of trends and review of service and activity.

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	02.
Service	Claire House Rapid Response Service
Commissioner Lead	NHS Cheshire and Merseyside ICB
Provider Lead	Claire House Children's Hospice
Period	1 Year (1 April 2023 – 31 March 2024)
Date of Review	November 2023

1. Population Needs

1.1. Context from national service specification

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (Fraser et al, 2020). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030.

Palliative care is provided to infants, children and young people with a wide range of life-limiting or life-threatening conditions (in excess of 300). Some will have severe disabilities and multiple and particularly complex healthcare needs related to their condition, as well as palliative care needs. However, up to 15% of children and young people with palliative care needs do not have a definitive underlying diagnosis.

Access to palliative care should not depend on diagnosis or overall prognosis and can be provided at any stage of a child or young person's illness.

Services with the competencies to offer paediatric palliative care will support and care for children and young people and their families at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement.

The needs of children and young people living with more complex and/or long-term conditions that are life-limiting or life-threatening cannot be met by the capabilities of their core team alone. They need input from a workforce with specialist palliative care skills and experience.

(Taken from *Specialist palliative and end of life care services Children and young people service specification, 2023*; please refer to full document for further detail)

1.2. National/local context and evidence base

Evidence Base
The Rapid Response (RR) Service aims to develop robust systems to support 24/7 palliative and end of life care for children and young people in their preferred place of care; through an effective integrated delivery of care by local and specialist services.

Claire House RR service is a 24 hour rapid response service which enables a step up, step down approach to care at home which provides specialist end of life care or enhanced nursing support to prevent unnecessary hospital admissions for those children with palliative and complex health care needs.

The RR team works in partnership with children/young people and their families as well as statutory services from health including primary, secondary and tertiary providers. This service specifically addresses the need for children who increasingly have very complex health care needs, to have increased access to high quality care and meets the recommendations of national strategy for EOLC.

Without the RR service, existing children's community nursing services are not currently commissioned to provide the 'step up' support for end of life care at home, including the availably of 24/7 CCN support, which would limit realistic choice of place for EOLC. In addition such professionals find it a challenge to maintain their skills and competence in end of life care due to the small number of cases and consequently lack of clinical exposure.

Specifically for Wirral Place, as there are no community children's nursing teams that will collaborate to ensure the safe delivery of end of life care at home, Claire House is commissioned to fulfil this role. In all other Places, Claire House will work in partnership with existing children's community nursing teams.

2. Outcomes

2.1. NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	1.6
Domain 2	**Enhancing quality of life for people with long-term conditions**	2.1, 2.4
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	
Domain 4	**Ensuring people have a positive experience of care**	4.6
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	

2.2. **National Outcomes:** Using the NICE quality standard (QS160) and the ambitions framework, commissioners and providers should agree and define the outcomes that demonstrate each of the following is met for their local areas:

• Each child and young person is seen as an individual:
– evidence of a personalised approach to care
– example: person-centred outcome and experience measures.

• Each child and young person gets fair access to care:
– evidence of steps to establish how equitable access to the service is and any measures to improve this.

• Maximising comfort and wellbeing:
– evidence of effective efforts to maximise the person's comfort and wellbeing using established validated outcome measures.

• Care is co-ordinated:
– extent to which the service provider engages with local systems to share information that supports better co-ordination of care, e.g. through participation in electronic palliative care co-ordinating systems (EPaCCS) or equivalent as they are established.

• All staff are prepared to care:
– evidence from outcome measures, uptake of education and training, other staff support measures and appraisal systems for own staff, and contribution to the education and training of wider PEoLC teams in the locality.

• Each community is prepared to care:
– evidence of actions the service has taken, or plans to take, in relation to community engagement and understanding of PEoLC.

(Taken from *Specialist palliative and end of life care services Children and young people service specification, 2023*; please refer to full document for further detail)

2.3. Local defined outcomes

- Increased number of children dying and being cared for in their preferred place of care.
- Reduced hospital spells or episodes for children.
- Facilitated real choice for end of life care at home.
- Improved quality of life for family
- Lessen the likelihood of family breakdown and the child/young person needing to be accommodated by the Local Authority.
- Choice for child/young person/family in venue for care provision
- Increase in numbers of children/young discharged from acute settings to domiciliary care

Care provision moves seamlessly between secondary/tertiary care, hospice in patient, and home according to family needs and preferences at any stage.

3. Scope

3.1. Aims and objectives of service

National context for Specialist palliative and end of life care to children and young people:

'Specialist services' support children and young people with a range of life-limiting or life-threatening conditions. They are experts in their field with knowledge and experience about the conditions and the issues they present.

A specialist children and young people palliative care team is defined as one that is supported by a doctor with specialty training (a consultant) in paediatric palliative medicine. They are supported in providing expert care and support to children, young people and families by specialist level professionals such as specialist nurses, pharmacists and psychologists where this is needed.

The provider must ensure the delivery of the components of a specialist palliative care team, which include:

- advanced symptom management:
  – complex symptom management skills
  – knowledge of the dying process
  – understanding of rare disorders and their pathways

- parallel planning and enhanced supportive care
- support for advance care planning, including emergency care planning and accessing children's continuing care
- support for end of life decision-making, including preferred place of care
- rapid discharge for end of life care, including fast track to hospice or home
- specialist medical and nursing support, available 24/7, for hospices, acute trusts, community palliative care teams and tertiary centres
- specialist equipment in the home (where not included in children's continuing care arrangements) may be commissioned on a case-by-case basis where unique needs are identified
- input into MDTs, 'team around the child' (TAC), pre- and debriefs relating to a child or young person's death, and other professional meetings, at hospitals, hospices and in the community
- identification of those with complex grief and at 'high risk', and their signposting/referral to appropriate local and/or specialist bereavement services
- education and training programmes across care settings, including bespoke patient-specific training of professionals in the use of specialist paediatric palliative care equipment, e.g. community patient-controlled analgesia and drug infusion devices.

(Refer to *Specialist palliative and end of life care services Children and young people service specification, 2023* for further detail)

Aims

The aim of this service is to provide high quality specialist palliative and end of life care to children/young people and their families in their home environment as agreed by the commissioner.

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Care of the dying

End of life care is provided for children and their families in the last hours and days of life. It incorporates four key domains of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

Objectives

- To ensure an effective integrated model of care that is safe and provides a quality and cost effective service that supports the end of life needs of children, young people and their families.
- To engage both strategically with emerging commissioning structures as well as build critical operational relationships locally to ensure plans are supported and meet the EOLC needs of children and young people.
- To support the development of effective partnership arrangements between health providers that enables advanced planning and co-ordination of integrated care.
- To provide critical review and feedback for health professionals and families.
- To work closely across Cheshire and Merseyside ICB Place areas.
- To ensure that continuous and clinically led reviews of the service are undertaken to review benefits of this model of care

3.2. Service description/care pathway

The service will:

- Deliver an equitable, rapid response EOLC service to be available 24/7 365 days per year.
- Be person centred with the ability to respond rapidly but safely to facilitate choice in place of care.
- Be provided by practitioners with appropriate qualifications, skills set and expertise.
- Work collaboratively with statutory services, maximising the services the child and family receives. Work duplication will be reduced and therefore resource waste will be eliminated.
- Take into account safety issues in order to reduce any potential harm for the child, family or the staff providing the service.
- Implement and monitor policies in order to reduce risks associated with all aspects of clinical governance.
- Establish and agree an individualised care plan with each family.

3.3. General Overview

The Rapid Response service consists of appropriate nursing and medical support, to provide core and specialist palliative and end of life care for children and young people.

The Rapid Response team works in partnership with parents and families and provides specialist nursing care, on a 24-hour basis, along with other elements of palliative care.

Service Description

The RR team will provide the following service provisions to children/young people with palliative and EoLC needs and their families:-

- End of Life Care – This will include 24 hour on call nursing service for advice and care.
- Symptom Assessment and Management
- Specialist Palliative Nursing Care
- Emotional and Psychological Support
- Bereavement Care and Support

In addition to the commissioned services above Claire House will provide access to counselling, psychology, play, music and complementary therapies as a charitable offer which enhances the holistic care the child and family receives.

Each child/young person will be allocated a key worker who will work with the family to assess their individual needs and plan their care.

The clinical team consists of two FTE nurse consultants, a medical consultant (5 PAs), three Band 7 palliative care nurse specialists, four Band 6 associate nurse specialists, one Band 4 nursing associate, and one trainee nursing associate. The senior team have undertaken palliative care, advanced clinical skills and non-medical prescribing qualifications.

Claire House is responsible for all of the governance and monitoring with regards to Non-Medical Prescribers.

Referral Standard Operating Procedures
Please see **Appendix 1** – End of Life Care Policy

Accessibility / Acceptability
This service is to be open 24 hours a day, 365 days a year including bank holidays and is available to children/young people aged 0-25 years inclusive, resident in Cheshire and Merseyside and who are assessed as requiring specialist palliative and end of life nursing care.

In order to ensure that parents/carers understand that this service is available for them to utilize, the Provider is to conduct an Equality Impact Assessment to ensure an action plan is produced to improve the accessibility of the service for the key groups that have been identified as hard to reach or vulnerable.

Referral Source
Children/young person or parents/carers/guardians may self-refer or be referred by professional agencies.

- Self-Referral
- Secondary Care
- Tertiary Care
- Primary Care

3.4. Population covered

The service will be available to the patients registered with a GP associated within Cheshire and Merseyside, plus those who are resident within its geographical boundary but are unregistered.

3.5. Any acceptance and exclusion criteria and thresholds

Families who live in Cheshire and Merseyside and have a child/young person (0-25 inclusive) where medical confirmation is given that the child/young person is suffering from a life threatening or life limiting condition.

3.6. Interdependence with other services/providers

The service cannot work in isolation and must work collaboratively with partners to deliver safe, effective care.

Partners will include:

- Specialist palliative care teams
- Hospital Children & Young People’s Departments
- Health Visitors
- School Nurses
- Secondary care
- Alder Hey and other specialist tertiary care providers
- GPs
- Community paediatricians and AHPs
- CAMHS
- Adult Mental Health Services
- Safeguarding services

- Third Sector Organisations
- Other services as appropriate

Stakeholders and interdependencies will vary as identified above and the need for interface with other service providers cannot be overstated. Access to and support from services should always be accessible as circumstances allow.

This service will be reviewed collaboratively with AHCH SPCT with a view to developing a more integrated model of specialist palliative care for Cheshire and Merseyside.

4. Applicable Service Standards

4.1. Applicable national standards (eg NICE)

- DH (2008) Better Care Better Lives. Improving Outcomes and experiences for CYP and their families living with life-limiting and life –threatening conditions. DH London
- NHS England (2013). E03/S/h - 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A - service specifications.
- Children and Young People's Health Outcomes Forum - Report of the Long-term Conditions, Disability and Palliative Care Subgroup (2012).
- Together for Short Lives Strategy (2018-2023)
- Together for Short Lives Ten Year Strategy (2023)
- Ambitions for palliative and end of life care, NHS England (2021)

4.2. Applicable standards set out in Guidance and/or issued by a competent body (eg Royal Colleges)

- Together for Short Lives (TFSL) (2013) Commissioning children's palliative care: A guide for Clinical Commissioning Groups (CCGs)
- Together for Short Lives (2013). A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions
- Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives.
- Noyes J, Tudor Edwards R, Hastings RP, Hain R, Totsika V, Bennett V, Hobson L, Davies G, Humphreys C, Devins M, Haf Spencer L, Lewis M (2013). Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. BMC Palliative Care 2013, 12:18.
- Specialist palliative and end of life care services Children and young people service specification (2023)
- NHS England Palliative and End of Life Care. Statutory Guidance for Integrated Care Boards (2022)
- NHS England Palliative and End of Life Care. Handbook for Integrated Care Boards (2022)

5. Applicable quality requirements and CQUIN goals

5.1. Applicable Quality Requirements (See Schedule 4)

CQUIN not applicable

6. Location of Provider Premises

The Provider's Premises are located at:

The Provider's Premises are located at Clatterbridge Road, Bebington, Wirral, CH63 4JD.

Claire House CQC Provider Number: 1-101635394

7. Contract Monitoring

Not applicable.

The service will collect activity and performance information as specified below and a report will be sent to the commissioner for each Place by the mid working day of the following month:

• Q1: Apr-Jun reported by mid of July	• Q2: Jul-Sep reported by mid October
• Q3: Oct-Dec reported by mid January	• Q4: Jan-Mar reported by mid April

Claire House will provide quarterly quality reporting at Place and ICS level as agreed at Joint Contract Meetings.

Claire House will also provide a detailed end of year report at ICS level including analysis of trends and review of service and activity.

Appendix 1

Provider’s End of Life Care Policy

End of Life Care Policy.pdf