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# Specialist palliative and end of life care services

## Children and young people service specification

18 January 2023

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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 PEO LC 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 PEO LC.]

## 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

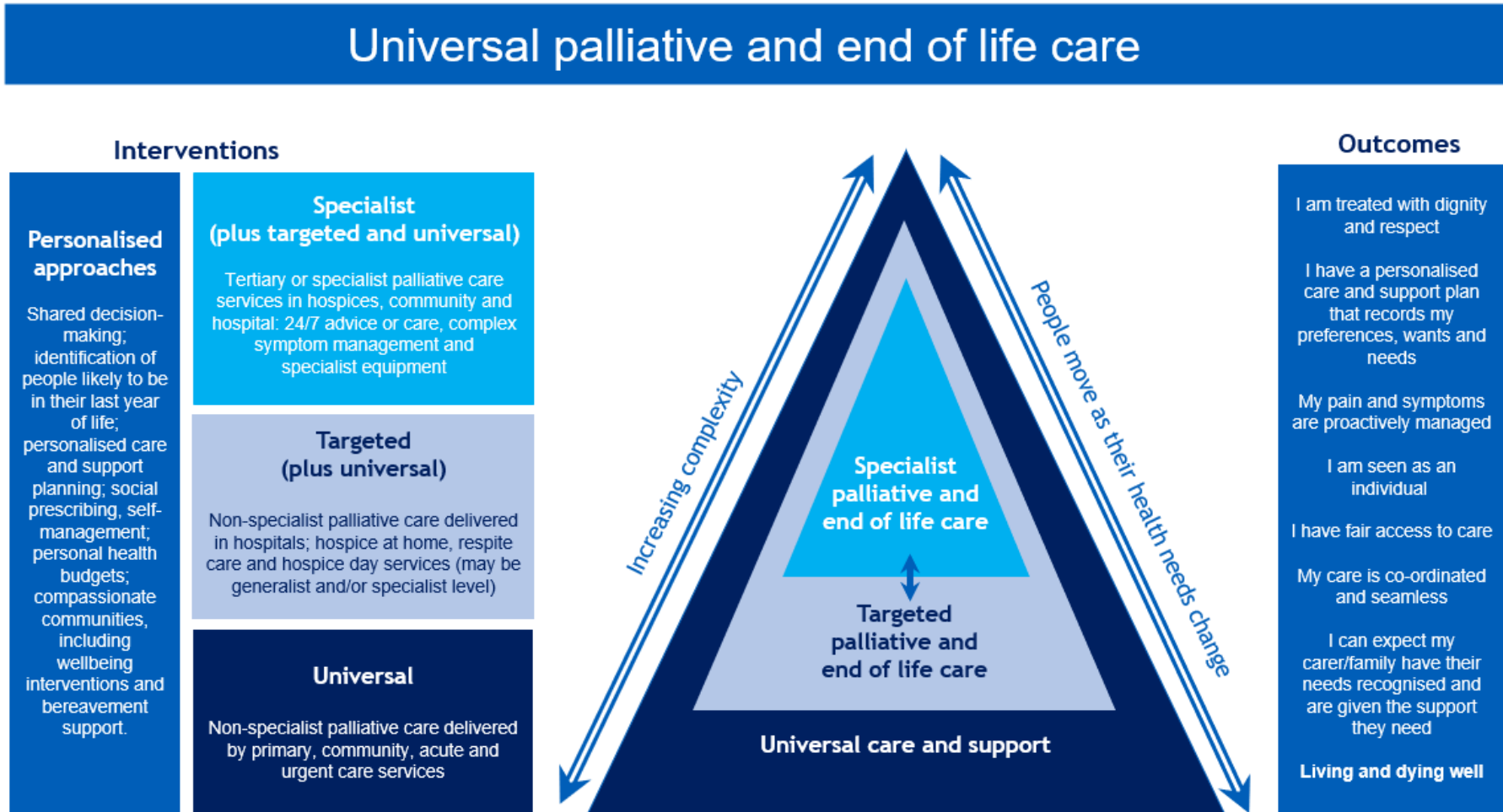
opportunities for support missed and specialist provision targeted where it is needed most.

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



## 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 PEO LC 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 PEO LC 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
<b>Referral</b>	
1. Have defined referral criteria that include specialist level palliative care (SLPC) for: <ul style="list-style-type: none"> <li>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</li> <li>b. the child or young person with unresolved needs that cannot be met by the current team. These needs may be physical,</li> </ul>	Ambition 2

Service characteristic	Link to ambitions framework
<p>psychological, social and/or spiritual, eg complex symptoms, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions</p> <p>c. the specialist service can be offered alongside the active treatment of an underlying condition.</p>	
<p>2. Have a referral process that includes an auditable system for prioritisation linked to patient outcomes.</p>	<p>Ambitions 2 and 4</p>
<p>3. Accept referrals based on need rather than diagnosis.</p>	<p>Ambition 2</p>
<p><b>Assessment and care</b></p>	
<p>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.</p>	<p>Ambitions 2, 3 and 4</p>
<p>5. Have timely access to the medication and equipment needed for specialist-level inpatient or home-based care.</p> <p>[Commissioner to include specific parameters.]</p>	<p>Ambitions 2, 3 and 4</p>
<p>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.</p>	<p>Ambitions 1 and 4</p>
<p>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.</p>	<p>Ambitions 1, 3 and 6</p>
<p>8. Respond to those with protected characteristics in a sensitive and inclusive way, including by providing access to advocacy, translation and interpretation services.</p>	<p>Ambitions 1 and 2</p>

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
<b>Co-ordination and partnership working</b>	
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
<b>Leadership and governance</b>	
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: <ul style="list-style-type: none"> <li>• audit and quality improvement methodology</li> <li>• patient-centred outcome and experience measures and user feedback (in keeping with the requirements of the <a href="#">Accessible Information Standard</a>)</li> <li>• data collection and sharing to aid service improvement at local and national level</li> <li>• adequate access to electronic clinical information, including pathology and imaging</li> <li>• arrangements for engagement in research in line with the service's objectives</li> </ul>	Ambitions 1, 2, 4, 5 and 6



Service characteristic	Link to ambitions framework
<ul style="list-style-type: none"> <li>• arrangements for all staff and volunteers to be appropriately trained and supported to give competent, reliable, confident and compassionate care.</li> </ul>	
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 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 PEO LC 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 users 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.

<b>‘Core’ services</b>	Key palliative and end of life activities that are commissioned and funded by integrated care systems (ICSs) or local authorities. These are essential services.
<b>‘Enhanced’ services</b>	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.
<b>‘Specialist’ services</b>	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](#)

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