SCHEDULE 2 – THE SERVICES

A. Service Specifications

<table>
<thead>
<tr>
<th>Service Specification No.</th>
<th>Service</th>
<th>Commissioner Lead</th>
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<tbody>
<tr>
<td></td>
<td>Children’s and Young People’s Palliative and End of Life Care: Service model for a comprehensive approach to delivering palliative care from identification of need through to end of life</td>
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Red text are notes to the commissioner and should be removed from the final specification.

This specification sets out an integrated approach and can be used in entirety with a multi-provider contract arrangement or similar. Where commissioned from a number of providers then the specification needs to be amended accordingly and included in the relevant contracts.

1. Population Needs

1.1 National/local context and evidence base

In England, prevalence of children with life-limiting conditions has risen 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 LLC in England by 2030.

Palliative care for children is provided to infants, children, and young people with life-limiting or life-threatening conditions representing an extremely wide range of diagnoses (in excess of 300) and there is an overlap with those with severe disabilities and complex needs. However, a significant proportion of children and young people with palliative care needs (up to 15%) do not have a definitive underlying diagnosis. Children and young people with life-limiting or life-threatening conditions often have multiple complex healthcare needs, including needs related to their underlying condition, as well as palliative care needs. Services that embrace the philosophy of paediatric palliative care, and have the competencies to do so, will offer support and care for children and young people at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement.
Palliative care should not be dependent on diagnosis or overall prognosis and can be provided at any stage of a child or young person’s illness. Not all children and young people will have active palliative care needs at any one time. It is therefore not always possible to identify provision of paediatric palliative care for CYP by diagnosis alone.

Specialist Palliative Care services are required for children and young people living with more complex and/or long-term conditions which 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.

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

1.2 Local Context

Local strategies, responses to national guidance, data (including patient experience or surveys) and narrative to be inserted here.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

<table>
<thead>
<tr>
<th>Domain</th>
<th>Preventing people from dying prematurely</th>
<th>Enhancing quality of life for people with long-term conditions</th>
<th>Helping people to recover from episodes of ill-health or following injury</th>
<th>Ensuring people have a positive experience of care</th>
<th>Treating and caring for people in safe environment and protecting them from avoidable harm</th>
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<tbody>
<tr>
<td>Domain 1</td>
<td>Preventing people from dying prematurely</td>
<td>Enhancing quality of life for people with long-term conditions</td>
<td>Helping people to recover from episodes of ill-health or following injury</td>
<td>Ensuring people have a positive experience of care</td>
<td>Treating and caring for people in safe environment and protecting them from avoidable harm</td>
</tr>
<tr>
<td>Domain 2</td>
<td>Enhancing quality of life for people with long-term conditions</td>
<td>Yes</td>
<td></td>
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<tr>
<td>Domain 3</td>
<td>Helping people to recover from episodes of ill-health or following injury</td>
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<tr>
<td>Domain 4</td>
<td>Ensuring people have a positive experience of care</td>
<td>Yes</td>
<td></td>
<td></td>
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<tr>
<td>Domain 5</td>
<td>Treating and caring for people in safe environment and protecting them from avoidable harm</td>
<td>Yes</td>
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2.2 Local defined outcomes

Using the NICE Quality Standards (QS160) and the Ambitions Framework, commissioners and providers should work collaboratively to achieve the following outcomes and define them for their local areas:

- **Each CYP is seen as an individual**
  Evidence of a personalised approach to care, e.g. as measured through using person-centred outcome and experience measures.

- **Each CYP gets fair access to care**
  Evidence of steps taken to establish the extent to which the service provides fair access, and any measures taken to improve this.

- **Maximising comfort and wellbeing**
  Evidence of effective efforts on maximising the person’s comfort and wellbeing using established validated outcome measures

- **Care is coordinated**
  Extent to which the service provider engages with local systems to share information that supports better coordination of care, e.g. through
participation in Electronic Palliative Care Coordinating Systems (EPaCCS) or equivalent as they are established.

- **All staff are prepared to care**
  Evidence, using outcome measures, of education and training, other staff support measures and appraisal systems for own staff, and contribution to the education and training of wider palliative and end of life care teams in the locality.

- **Each Community is prepared to care.**
  Evidence of actions that the service has taken, or plans to take, in relation to community engagement and understanding of palliative and end of life care.

A series of ‘I Can’ statements have been developed to capture key outcomes for the children, young people and their carers. These are included in Appendix 2 and they can be used to expand the recommended outcomes listed in this section.

In addition to the above, local commissioners and providers should agree specific, measurable quality indicators to be used locally. These will be included in section 5.2.

### 3. Scope

#### 3.1 Aims and objectives of service

**Commissioner to include relevant key aims and objectives of the service provider(s):**

This may include:

- A list of the key services to be provided
- A list of key workforce with specific characteristics i.e. level of skill and training
- An integrated approach to palliative and end of life services with structures and systems which improve communication and coordination between service providers including seamless transitions of care
- An MDT model of delivery
- A model of delivery 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 and families, clear referral pathways to other services such as CAMHs
- Use of IT systems such as EPaCCS (or equivalent)
- Participation in a Managed Clinical Network approach
- A local training offer which targets specific groups including those across health, social care, education, and the voluntary sector.
3.2 The Service Model

The service framework consists of a whole system approach. Commissioners should aim to ensure that appropriate services are available to children and young people through from universal services, core services and to specialist provision. This tiered view of the framework does not seek to compartmentalise but to join the provision into a seamless pathway. Care and support should be provided by the right professional, at the right time and in the right place. This will ensure opportunities for support are not missed and specialist provision is targeted where needed most. See Figure 1.

These tiers are clarified as such to aid commissioners in planning development and should not be a barrier to integrated working. In fact, close liaison between teams will be vital to ensure that the child or young person’s story is told as few times as appropriate; 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.

Figure 1

The level of involvement from each service area will fluctuate throughout the child or young person’s journey. This is not a stepped approach but flexible model that responds to need. Each level of provision is dependent upon the others to ensure a holistic approach to health, wellbeing, emotional, social and spiritual needs of the child or young person and their families and carers. No single area of provision can provide for all the needs.

3.3 Delivering the Integrated Model

The following sets out the integrated service model as per figure 1. The tiers of universal and core are included for completeness, but the majority of this specification focus on the requirements for specialist palliative and end of life care provision.
Commissioners may wish to highlight the sections relevant to their provider and/or add details of how each tier will be achieved locally.

### 3.3.1 Universal Services

‘Universal services’ is the term applied to services to which all children, young people and their families have access. The key services within this category include primary care, health visitors, social care, and education services. This category also includes wider community groups. These services are embedded in the communities that 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 there are key duties they will offer in support of the child or young person and their families.

These include:

- **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 will be able to share information with and receive information from the MDT. They should be in close communication with core teams. Especially with those delivering care at home.
- **Health Visiting / School Health Nursing**: These professionals will play a leading role in ensuring the child or young person can access the local offer for the Healthy Child Programme (HCP).
- **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, local authority often work with ICSs to deliver safeguarding services and coordinate care for Looked After Children.
- **Education**: Education should remain accessible to all children and young people where appropriate with learning and physical need adaptations made. An Education and Health Care Plan (EHCP) is an important requirement for the child or young person. A SENCO will lead on ensuring the EHCP is completed by, and is made known to, the relevant people around the child or young person. School nursing services will 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, 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.

### 3.3.2 Enhanced Services

‘Enhanced’ services will be predominantly be provided and funded by children’s hospices and other charitable organisations. This arrangement may include a range of activities such as:

- Bereavement support for non-complex grief
- Emotional and practical support, including advocacy
- Parent/ Carer support and groups
These services will not be routinely funded by NHS commissioners but may form part of a wider commissioned offer.

### 3.3.3 Core Services

**Core services** provide targeted and skilled support in a range of settings. The majority of children and young people’s palliative care will be provided at this level. They can be provided by a range of organisations including community services, acute hospital services or hospices.

**Core Palliative Care Multi-Disciplinary Team (MDT)**

For children and young people with a diagnosis of life-limiting or life-threatening illness, core services will be delivered around an MDT model.

The team should ensure liaison between services to achieve seamless care that works to the agreed personalised care and support plan. The key objectives of the Core PEOtLC MDT are:

- Ensure a personalised care and support plan, and where applicable an Advance Care Plan is offered and agreed and is actively used by all services in regard to care and support
- Plan and deliver symptom control
- To identify a care coordinator or key worker who is responsible for coordinating their care All relevant services to meet the needs of the child or young person are engaged and are available for access as appropriate. This includes physical, emotional, and psychological services
- Equipment and resources required 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 specialiist support as required
- All transfers of care are planned for with good communication e.g. discharge planning
- Short Breaks or respite is offered within age appropriate settings
- Professionals (universal and core) have the relevant training and skills and know when to seek specialist advice.

**Core Respite Services**

The provision of short breaks is a key part of service provision (NICE NG61) and there are a variety of models for providing this. ‘Standard Short Breaks’ services are a way of giving parents/carers a much-needed break from their caring responsibilities and a way of improving outcomes for the children and young people, e.g. to support independence and socialising with their peers. This can be with the day-to-day looking after of their child or young person, either in their own home or in specially equipped respite facilities such as a hospice. Short breaks can range from a few hours in the home to longer stays away from the family home in a special unit.

Short breaks can also offer a break for children themselves, and in some instances the respite care means the families are able to spend quality time together that isn’t
dominated by caring duties (as these are taken care of by staff) rather than time apart.

**Core MDT staffing models**

NICE provides guidance on what constitutes this team of professionals. This is given below as:

- 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. Where available it may also include hospice professionals or members of palliative care charities.
- Social care practitioners
- Education professionals
- Family representatives
- Spiritual advisors
- Allied health professionals (for example 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

Members of the team should be adjusted accordingly in response to the changing needs of the child or young person.

**3.3.5 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 a range of knowledge and experience about the conditions and issues it presents. A specialist CYP palliative care team is defined as one which is supported by a doctor with specialty training (a consultant) in paediatric palliative medicine. They are supported by specialist level professionals such as specialist nurses, pharmacists, and psychologists providing expert care and support to children, young people, and families where it is needed.

The key delivery components of a specialist palliative care team include:

- Advanced symptom management:
  - Complex symptom management skills
  - Knowledge of the death and 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 identified**

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• 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
• Identifies complex grief and those at ‘high risk’ with 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 PPC equipment e.g. community PCA and drug infusion devices.

Specialist Respite Services
‘Specialist Short Breaks’ care provides sometimes urgent additional 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.

Specialist short break care may take place in the child or young person’s home or in a setting outside of the home such as a hospital, long-term care facility or hospice.

Specialist Service Model
The model of specialist service delivery will vary from place to place and is often dependant on the maturity of the local system and wider offer of core care. The following can be considered by the commissioner and provider(s):

Specialist Palliative Care Multi-Disciplinary Team (MDT). Specialist level palliative care can be delivered by a multidisciplinary team (MDT) of staff 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 comorbidities. The specialist team should be involved in the early stages of planning palliative care but then may be involved in different stages of the child or young person’s journey as required.

The specialist children and young people’s palliative care team should have the ability to provide workforce and support to children and young people on a 24/7 basis (this may be remote support or part of a wider regional offer). The workforce will 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 who have expertise in providing psychosocial support in the context of palliative, end of life care and bereavement (for example in providing social, practical, emotional, psychological, and spiritual support).

Specialist outreach teams provide disease-specific or palliative care outreach to children and young people at home. These teams are usually multi-disciplinary. In addition to providing home care, the outreach palliative care teams usually play an important role in consultation, liaison, and provision of direct care. The team provides advice to health professionals, promotes the care in symptom management, provides counselling and
education to the child or young person and family, participates in discharge planning, liaises with community services, and support family through to bereavement.

**Nurses Specialising in Palliative Care.** Where a nurse is leading a service or has a role with a significant autonomous advisory component, such as in a community or hospital liaison settings or nurse-led outpatient clinics, it is expected that the nurse would be at the level of Clinical Nurse Specialist (CNS) in palliative care or consultant nurse in palliative care. These nurses may have lower grade nurses responsible to, or supervised by them, to support the delivery of services or, there may be delegation from registered to non-registered staff as part of a skill mix. In other settings such as in-patient units, nurses who have received specialist level palliative care training will be part of the SPC MDT.

### 3.4 Key Care Components

All providers of care, from all tiers of provision will align with key care principles. These are the enablers to improve experience for children and young people and their families and are crucial to ensuring choice, personalisation and supporting self-management.

The service characteristics are structured below to make the links to ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 more explicit.

*These should be worked through and adapted to available or planned local services because they may result in additional resource and cost pressures.*

The service will:

<table>
<thead>
<tr>
<th>Service Characteristic</th>
<th>Link to Ambitions Framework</th>
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<tbody>
<tr>
<td>REFERRAL</td>
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<tr>
<td>1. Have defined referral criteria which include specialist level palliative care for:</td>
<td>Ambition 2</td>
</tr>
<tr>
<td>a. the CYP with progressive life-limiting illness, with or without comorbidities, where the focus of care is on quality of life, including complex symptom control;</td>
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<tr>
<td>b. the CYP with unresolved complex needs that cannot be met by the capability of the current team. These needs may be physical, psychological, social and/or spiritual. Examples include complex symptom, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions;</td>
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<td><strong>c.</strong> The specialist service can be offered alongside active treatment of an underlying condition.</td>
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<tr>
<td><strong>2.</strong> Have a referral process which includes a system for prioritisation that is auditable and linked to patient outcomes.</td>
<td>Ambitions 2 and 4</td>
</tr>
<tr>
<td><strong>3.</strong> Accept referrals based on need rather than disease label.</td>
<td>Ambition 2</td>
</tr>
<tr>
<td><strong>ASSESSMENT &amp; CARE</strong></td>
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<td><strong>4.</strong> 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 specialist level palliative care advice from a consultant in palliative medicine, including face to face assessment where this is necessary.</td>
<td>Ambitions 2, 3 and 4</td>
</tr>
<tr>
<td><strong>5.</strong> Have timely access to medication and equipment, for specialist-level in-patient or home-based care, to meet the needs of the CYP. <em>CCG to include specific parameters.</em></td>
<td>Ambitions 2, 3 and 4</td>
</tr>
<tr>
<td><strong>6.</strong> Work in partnership with CYP, 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 that that is needed.</td>
<td>Ambitions 1 and 4</td>
</tr>
<tr>
<td><strong>7.</strong> Identify and assess the needs of the family and those important to the CYP, including psychological and social needs, and provide support, preparation for the caring role at whatever level is required to be undertaken, and facilitate access and signposting to other services, including pre-bereavement and bereavement.</td>
<td>Ambitions 1, 3 and 6</td>
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<tr>
<td><strong>8.</strong> Be responsive to age, culture, faith and ideology, disability, sexuality, and gender issues in relation to palliative care, dealing with them in a sensitive and inclusive way, including access to advocacy, translation, and interpretation services.</td>
<td>Ambitions 1 and 2</td>
</tr>
<tr>
<td><strong>9.</strong> Use a multi-disciplinary approach to care, with a competent workforce with recognised expertise in specialist level palliative care that uses evidence based best practice. People must be reviewed, and discussed by the multidisciplinary team regularly, as defined by local operational policy.</td>
<td>Ambitions 3 and 5</td>
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</table>

**COORDINATION & PARTNERSHIP WORKING**
10. Work in partnership with other services to meet the CYP’s needs, ensuring that assessments and personalised care planning are reliably communicated and coordinated with other services involved with the CYP’s family in a timely fashion.

11. Ambitions 1 and 4

12. Access and use an electronic palliative care coordination system to facilitate this coordination, as such systems become available locally, and where the individual agrees to its use.

Ambitions 1 and 4

13. Have a defined operational policy for multi-disciplinary and partnership working to include arrangements for multidisciplinary team meetings, and communication across care settings and organisational boundaries within a quality and governance framework.

Ambition 4

**LEADERSHIP & GOVERNANCE**

14. Have specialist level palliative care clinical leadership at senior strategic level within the organisation (e.g. Senior Management Team level).

Ambition 5

15. Have a suitably resourced quality, IT and governance framework, which should include:
   a. audit and Quality Improvement methodology;
   b. patient centred outcome and experience measures and user feedback;
   c. data collection and sharing to aid service; improvement at local and national level;
   d. adequate access to electronic clinical information, including pathology and imaging;
   e. arrangements for engagement in research in line with the service’s objectives; and
   f. arrangements for all staff and volunteers to be appropriately trained and supported to give competent, reliable, confident, and compassionate care.

Ambitions 1, 2, 4, 5 and 6

16. Be configured and established to lead and/or contribute to the delivery of education, training and continuing professional development (CPD) to the wider workforce regarding best practice in palliative and end of life care.

Ambition 5

17. Use the growing evidence base to enable the development of innovative practice.

Ambition 3 and 5

18. Contribute to, and encourage, public understanding, involvement, and engagement in developing compassionate communities, including local awareness, practical support, and planning for future care.

Ambition 6
All providers of care, from all tiers of provision will align with the key care principles. These are the enablers to improve experience for people with PEoLC needs and their families and are crucial to ensuring choice, personalisation and supporting self-management.

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) are a series of facilitated conversations in which children and young people, or those who know them well, actively participate to explore the management of their health and well-being 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 the most to them. It addresses issues and identifies outcomes and actions to resolve these.

Personalised care and support planning should be key for CYP receiving palliative and end of life services. It is an essential tool to integrate the child or young person’s experience of all the services they access so they have one joined-up plan that covers their health and wellbeing needs.

There is no set template for what a personalised care and support plan should look like, but it should reflect the following:

- A way of capturing and recording conversations, decisions and agreed outcomes in a way that makes sense to the child or young person and their family.
- Should be proportionate, flexible, coordinated, and adaptable to a child or young person’s health condition, situation and care and support needs.
- Should include a description of the child or young person, what matters to them and all the necessary elements that would make the plan achievable and effective.

More information on personalised care and support planning can be found on the NHS England website:

**Advance Care Planning (ACP)** is recommended by NICE (NG61 and QS160) to be considered for each child or 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 will apply but with additions that are pertinent to supporting a child/young person and family in palliative care. The guidance sets out the key components in detail but in summary the plan could include:

- 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 and
  - the key professionals involved in care
- A statement about who has responsibility for giving consent and evidence of parental responsibility
• A summary of the life-limiting condition
• An agreed approach to communicating with and providing information to the child or young person and their parents or carers
• An outline of the child or young person’s life ambitions and wishes, for example on:
  o family and other relationships
  o social activities and participation
• Education
• How to incorporate their religious, spiritual, and cultural beliefs and values into their care
• A record of significant discussions with the child or young person and their parents or carers
• Agreed treatment and prescribing plans and objectives
• Education, Health and Care plans, if relevant
• A record of any discussions and decisions that have taken place on:
  o preferred place of care and place of death
  o organ and tissue donation
  o management of life-threatening events, including plans for resuscitation or life support
  o specific wishes, for example on funeral arrangements and care of the body
• Details of any systems in place to get early help to avoid a crisis or handle an emergency
• A distribution list for the Advance Care Plan
• A record of Parallel Planning (where applicable)
• Discharge planning agreements from acute hospital to community.

**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 that includes specific guidance on decision-making for children and young people. Furthermore, specialist teams can support families and clinical teams in decision-making processes.

The GMC guidance can be accessed at: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

### 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 have” a personal health budget (PHB). For continuing care this is often a process to implement single teams of carers to build relationships and trust with the family.

Opportunities for a PHB are not limited to continuing care activities only, numerous 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.

**Further information on PHBs and children’s continuing care can be found at:**

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<tr>
<th>3.4.3 Family Needs</th>
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<tr>
<td>Quality palliative and end of life care includes giving care and support to families, friends, carers, and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people. The needs of the family (including siblings) need to be assessed and where possible addressed. Ensuring the carers are adequately supported is important to enable management in a home environment where desired. Where there are opportunities to do so, the family should be offered training to enable self-management within the family.</td>
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<tr>
<th>3.4.4 Care of Team Around Child/Young Person</th>
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<tr>
<td>Everyone who is called upon to support the child or young person and their wider family will at times find it emotionally challenging. Every member of the team around the child and family should receive support and an opportunity to feedback and discuss what is happening. For example, access to professional psychological support for staff and standards for debriefs. Professionals as well as volunteers should have access to ongoing support and supervision.</td>
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<th>3.4.5 Transition</th>
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<td>It is important for teams at all levels, universal, core, enhanced and specialist, to be aware of transition needs of children and young people. Transition points can be identified for health, education, or any other large-scale stage of change where a child or young person may need support. 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. Guidelines for transition are included in section 4.2 and are a recommendation in NICE NG43.</td>
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**There is a separate Palliative Care specification concerned with providing palliative care to adults aged 18 years and older. It is important that young people at a transitional age are catered for within either of these specifications.** |

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<th>3.4.6 Communication</th>
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<td>Good communication is vital to ensure that the child or young person and their family understand their condition, their plan, their key points of contact and what they may expect in their journey.</td>
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Good principles include:

- 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 told once to each service and not multiple times. Professionals communicate well with each other and work as a team
- The child or young person and their family are listened to about what works for them and what is important
- Next steps in treatment and care are always well communicated in advance.

### 3.4.7 Information and Data Sharing

Underpinning choice and decision making is good information. This is important for both the child or young person and their family to have and to be supported to use it. Information can support self-management if provided in the right way and at the right time. Information should be shared appropriately by professionals, but children or young people should be directed to support organisations that can provide other relevant information and support.

To ensure any agreed plan can guide a person-centred approach, it has to be available to that person, so that they can review, change, and update it themselves. Subject to that 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 encompass the recording and sharing of preferences at the end of life. There should be ambitious local targets for the rollout of systems for sharing digital records.

Electronic Patient Care Coordination Systems (EPaCCs) should be implemented to support quality information sharing.

### 3.4.8 Complex Decision Making

There are rare events of contentious cases within paediatric palliative care. This may include issues pertaining to 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.

In cases regarding funding, the relevant commissioner will support families and providers in reaching a consensus. This may be via Individual Funding Request processes.

### 3.5 Population covered

Paediatric Palliative Care is concerned with providing palliative care to children and young people (and their families) with either life-limiting or life-threatening conditions who are considered unlikely to reach their 18th birthday.
'Infants, Children and young people' refer to everyone up to their 18th birthday as specified by NICE Guidance (NG6). This includes the antenatal period up to young adults. There is acknowledgement that different services will have different acceptance criteria for age. The recommendation is that all services use the definition of age as set in this specification as a minimum standard but where appropriate they work towards implementing services available for those up to the age of 25. This is especially important when considering service users with learning disabilities and transition requirements.

Commissioner to include any relevant local criteria.

Commissioner may wish to consider additional population requirements that will support the reduction of health inequalities.

3.6 Any acceptance and exclusion criteria and thresholds

Paediatric Palliative Care services should be accessible to babies, children, and young people with life-limiting conditions.

There are no nationally agreed criteria for accessing specialist palliative care, but a common theme is that of complexity. Complexity is not only about the child or young person’s level of need, but also social complexity 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 described in broad groups (see tables in Appendix 3 for children’s and perinatal categories). These groups are illustrative of the wide range of conditions likely to benefit from a palliative care approach and/or support from children and young people’s palliative care services. These examples are neither exclusive nor fixed; children may move between the groups or be in more than one group at any time.

Palliative care can be seen as a thread that runs throughout the lives of children and young people, often alongside other treatments. This is why the concept of parallel planning is important, where palliative care is offered in parallel with and alongside curative treatment, or treatment aimed at significantly prolonging life. The palliative care approach should be present 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. The providers of specialist level palliative care services will often have clear acceptance criteria that need to be shared with potential referrers.

Commissioners may wish to consider:
- What happens to those instances where people are not eligible for referral;
- What information is needed locally on services available and how they are accessed;
- Discharge criteria;
- Support for integrated cross sector/agency working.
3.7 **Interdependence with other services/providers**

There is a need for close working between services and liaison between all tiers of the model should be developed and maintained as appropriate. It is important for all levels of all service providers from the statutory and voluntary sector, work collaboratively to deliver to a truly integrated service model.

The following should represent local services covering the geographic area. In the delivery of this integrated service, key interdependencies are for example:

- Primary and Community Providers – GPs, district nurses, and out of hours services
- Other multi-disciplinary specialist teams
- Rapid Response Team
- Social Care services – both in hours and out of hours
- Other providers of CYP Palliative and End of Life Care services: statutory and voluntary
- Providers of Acute Care
- Urgent and Emergency Care services, including 111 and ambulance services
- Providers of Adult Palliative Care
- Providers of services for individuals with long-term conditions
- Local authority services and education.

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

3.8 **Managed Clinical Networks**

One effective way to achieve more integrated working is through networks, which have the potential to bring together different organisations to share best practice and provide a structure through which providers and commissioners can strategically plan for service development and plan services effectively. They also offer potential for hearing the voices of service users and benefitting from managed co-production.

Informal children and young people’s palliative care networks are currently established in almost all regions and countries of the UK and are to varying degrees achieving this potential. These networks will benefit from having clear linkages with the Strategic Clinical Network (SCN) for their region.

One of the key recommendations of the National Institute for Health and Care Excellence (NICE GC61) 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. Guidance on managed networks are listed in section 4.2.

*Commissioner to specify how the provider will contribute to the local arrangement for the managed network.*

4. **Applicable Service Standards**

4.1 **Applicable National Standards**

**NICE Guidance NG61**: End of life care for infants, children, and young people with life-limiting conditions: planning and management

**NICE guideline NG43**: 2016. Transition from children to adults’ services for young people using health or social care services

**NICE Quality standard QS140**: 2016. Transition from children to adults’ services


Child Death Review: Statutory and operational guidance

4.1.1 NHS Long Term Plan.

The NHS Long Term Plan sets out a commitment for the NHS to offer more joined-up coordinated care and to be more proactive in the services it provides specifically end of life care.

- 1.4: The NHS will increasingly be …more differentiated in its support offer to individuals… as, for example, with end of life choices….
- 1.41: We will expand our [Personal health budget] offer [to]… those receiving specialist end of life care.
- 1.42: With patients, families, local authorities, and our voluntary sector partners at both a national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care. By rolling out training to help staff identify and support relevant patients, we will introduce proactive and personalised care planning for everyone identified as being in their last year of life. A consequence of better-quality care will be a reduction in avoidable emergency admissions and more people being able to die in a place they have chosen.

4.1.2 Personalised Care

In addition, the NHS Long Term Plan (LTP) makes personalised care business as usual across the health and care system as one of the five major, practical changes needed to achieve the new NHS service model. Personalised care means people have more choice and control over the way their care is planned and that it is delivered based on ‘what matters to them’ and their individual diverse strengths, needs and preferences. This happens within a system that supports people to stay well for longer and makes the most of the expertise, capacity and potential of people, families, and communities in delivering better health and wellbeing outcomes.

4.2 Applicable standards set out in Guidance and/or issued by a competent body

- Together for Short Lives: [Setting up a Managed Clinical Network in Children’s Palliative Care](#).

- [Ambitions for Palliative and End of Life Care](#). 2021. National Palliative and End of Life Care Partnership

- Department for Education. 2011. [Short breaks for carers of disabled children](#): departmental advice for local authorities.

- Department for Education. 2014. [Special educational needs and disability code of practice](#): 0 to 25 years.


### 4.3 Applicable local standards

*Subject to agreement between Provider and Commissioner.*

### 5. Applicable quality requirements and CQUIN goals

#### 5.1 Applicable Quality Requirements (See Schedule 4A-C)

*Subject to agreement between Provider and Commissioner but should include a form of patient and family reported feedback as a minimum.*

Local outcomes for evidencing achievement of the Ambition Statements may include for example:

- Recurrent emergency admissions in last 90 days of life,
- Number of discussions where personalised care and support planning conversations has taken place (not absolute numbers of care plans which may vary depending on the individual),
- Patient reported outcomes
- Patient and carer reported experience.

#### 5.2 Applicable CQUIN goals (See Schedule 4D)

*Subject to national and local CQUIN requirements. Commissioner to insert as appropriate.*

### 6. Location of Provider Premises

The service should be commissioned to provide care for children and young people as close to home as possible. The place of care will depend on the clinical need and child or young person and family’s choice.

*Commissioner to specify as appropriate.*
### 7. Individual Service User Placement

Not applicable

### 8. Applicable Personalised Care Requirements

#### 8.1 Applicable requirements, by reference to Schedule 2M where appropriate

Commissioners to insert all applicable personalised care approaches which may include:
- Choice
- Personalised Care and Support Planning
- Supported Self-Management initiatives
- Personal Health Budgets
- Social prescribing pathways
- Applicable Shared Decision Making approaches.
**Appendix 1: Definitions of Terms**

### Infants, Children and Young People

‘Infants, children and young people’ refer to everyone up to their 18th birthday as specified by NICE Guidance (NG61, NG43) and the Children’s and Families Act (2014). This includes the antenatal period up to young adults. There is acknowledgement that different services will have different acceptance criteria for age. The recommendation is that all services use the definition of age as set in this specification as a minimum standard but where appropriate they work towards implementing services available for those up to the age of 25. This is especially important when considering service users with learning disabilities and transition requirements.

The term children and young people will be used within this specification to refer to infants, children, and young people.

### Palliative Care

Children’s and young people’s palliative care is an active and total approach to care, from the point of diagnosis or recognition throughout the child or young person’s life, death and beyond. 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 and the child’s 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 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)s or Local Authorities. These are essential services.

### ‘Enhanced’ services

These are services which provide an important contribution to the health and well-being of children 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 which are life-limiting or life-threatening. The needs of this group of people 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: I Can Statements

The ‘I Can’ statements form the basis of an outcome driven service model. The statements reflect best practice and will be aspirational in many areas as they work with partners towards a new model of care. They are not intended to be measurable, but a tool which commissioners and providers may use to ensure the ethos of their services is fit for purpose.

These statements are intended to be used generically and for a child or young person of any age including babies. The statements should be applied from the point of view of the child or young person, or in the case of those of a very young age from the perspective of the family. It is important to acknowledge capacity and consent when applying the decision-making frameworks.

NOTE: Some statements will be aspirational as services develop.

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<td><strong>My Services &amp; Professionals</strong></td>
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| 16  | I can access a named GP/primary care team who understands me and can be responsive to my needs. This will include:  
   - Prescribing  
   - Home visits  
   - Out of hours support  
   - Referral to appropriate services  
   - Support to my wider family  
   - Feeds information into MDT and receives feedback from MDT. |
| 17  | I can have access to 24/7 skilled nursing support services in all settings who have the right expertise and values. |
| 18  | I can expect a local core paediatric MDT comprising of, or with access to, healthcare professionals from primary, secondary, or tertiary services, including specialists in my underlying condition, hospice professionals and other members of the MDT team. |
| 19  | I can expect a specialist paediatric MDT team which will include:  
   - a paediatric palliative care consultant  
   - a nurse with expertise in paediatric palliative care  
   - a pharmacist with expertise in specialist paediatric palliative care  
   - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological, and spiritual support).  
   (NICE guidance NG61) |
| 20  | I can expect 24/7 access to specialist paediatric palliative care advice which will be available for me, my carers and the other professionals supporting me. |
| 21  | I can access appropriate medication, consumables, and equipment in all care settings with timely provision – e.g. wheelchairs, mobility aids and hoists including safe and prompt repair, replacement and servicing. |
| 22  | I can expect integrated comprehensive discharge plans to meet my needs in a timely and appropriate way which includes appropriate equipment. |
| 23  | I can expect access to short breaks in setting which meets my needs and wishes, enables me to feel safe and which is suitable to my age and my developmental stage. |
Appendix 3: Categories for Palliative and End of Life Care for Children, Young People and Perinatal

**Categories for children and young people care**

| Category One | 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 Two** | 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 Three** | 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 Four** | 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.* |


**The categories for Perinatal Care**

*Category 1.* An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis, or anencephaly.

*Category 2.* An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. 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, e.g. severe hypoxic ischemic encephalopathy.

*Category 5.* Postnatal conditions which result in the baby experiencing “unbearable suffering” in the course of their illness or treatment, e.g. severe necrotizing enterocolitis, where palliative care is in the baby’s best interests.