What is children’s palliative care (CPC)?

Palliative care for children with a life-limiting or life-threatening condition is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancing quality of life for the child/young person and supporting the family. It includes managing distressing symptoms, providing short breaks and care through death and bereavement. Life-limiting conditions are those for which there is no reasonable hope of cure and from which children are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail.

CPC differs greatly from adult’s palliative care. Whereas the majority of adults only need palliative care at the end of their lives, children with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which results in children requiring CPC is more diverse.

CPC is an approach to care which can be used exclusively or in conjunction with curative treatments. It can be defined by the following four categories:

1. Life-threatening conditions for which curative treatment may be feasible but can fail – such as cancer or congenital heart disease.

2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well – such as Duchenne muscular dystrophy.

3. Progressive conditions without curative treatment options, such as Batten disease.

4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

A comprehensive local CPC service spans health, social care and education. It is a whole-family approach and has the following characteristics:

- It is flexible and focused on children, their parents and their siblings.
- It is accessible 24 hours a day, seven days a week, 365 days a year – from diagnosis or recognition to bereavement.
- Supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind.
- It is not age, time or diagnosis specific – 15% of children who need CPC have no definitive underlying diagnosis.
- It is multi-disciplinary and multi-agency.
- It is accessible to people of different faiths, culture, ethnicity and locations.
- It includes pre and post-bereavement support for families.
- It is able to manage symptoms.
- It supports parents in caring for their children according to their needs and wishes.
- It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children’s to adult’s services.
This resource is designed to support Clinical Commissioning Groups (CCGs) to effectively commission palliative care for children and young people. It covers the following:

- What is children’s palliative care?
- Who needs children’s palliative care?
- Who provides children’s palliative care?
- How should children’s palliative care be commissioned?

Please note that this guide refers to general healthcare aspects of CPC only, which are the responsibility of CCGs. Specialised CPC is commissioned by NHS England.

Who needs CPC?

It is estimated that more than 40,000 children (0–19 years) in England in 2009/2010 were living with a life-limiting or life-threatening condition. This represents a very small population in healthcare commissioning terms; evidence shows that these small populations make commissioning appropriate services difficult. As well as often being inefficient, it can also prevent effective strategic care planning. Fraser et al. show the prevalence of life-limiting conditions in children and young people for every local authority district in England. A recent study has found that, among a local population in North Wales of 2,271 children with a life-limiting condition, 501 children per year needed ongoing CPC in contact with hospital services; 24 children required end-of-life care every year.

The overall prevalence in England increased from 25 per 10,000 population in 1999/2000 to 32 per 10,000 population in 2009/10. This is due to increasing life expectancy and improving quality of life resulting from advances in treatment and support. Children living with a life-limiting or life-threatening condition may survive to an age where they will need to transition to adult services.

Who provides CPC?

Universal, targeted and specialist CPC is delivered by a web of providers; general CPC services may be commissioned from the statutory and voluntary sectors using collaborative commissioning arrangements. A significant proportion of CPC is delivered by the voluntary sector. Voluntary sector providers, including children’s hospices, bring social value to communities: when the NHS remunerates these organisations for the CPC they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide CPC services which are part-funded from statutory sources, further adding value. Commissioning a comprehensive CPC service will help CCGs to meet their duties under the Public Services (Social Value) Act 2012.

Commissioners should ensure sustained and effective delivery of CPC. At all times, locally available and community-led CPC should be at the heart of provision to children. This should be supported by:

- Specialist medical input (e.g. medical consultants with expertise in the child’s condition)
- Sustainable community children’s nursing teams
- Children’s hospice services
- Specialist palliative care providers
- Access to secondary and tertiary care
- Emotional and psychological support
- Local authority children’s services – social care (including services providing equipment to disabled children), education, housing and leisure
- Community paediatrics
- Primary care

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How should CPC be commissioned?

Actions for CCGs

The NHS Institute for Improvement and Innovation identifies a number of key actions to be followed as part of the commissioning process\(^6\). On this basis, CCGs should consider taking the following action immediately:

Build partnerships

Children who need CPC require holistic support which is currently arranged through health, social care and education. CCGs should consider commissioning CPC in partnership with local authorities using agreements under section 75 of the National Health Services Act 2006\(^7\) to ensure an integrated service for children with life-limiting and life-threatening conditions. CCGs also need to be aware of their duties under the Children and Families Act 2014. From September 2014, this will require CCGs to jointly commission services for children with special educational needs and disabilities (SEND) with local authorities. CCGs will also need to co-operate with local authorities in ensuring that single assessments and Education, Health and Care Plans (EHCP) are put in place. EHCPs will be for children who have learning difficulties and disabilities which result in special educational needs — therefore including some children who need CPC. The Government’s Draft SEND code of practice\(^8\) specifies that Health and Wellbeing Boards should consider the needs of children and young people who need palliative care. GPs should consider using their knowledge of children with life-threatening and life-limiting conditions who are registered with their practice to inform their CCG’s CPC commissioning.

Analyze and plan

A report from the York Health Economics Consortium to inform the Craft-Killen review of CPC\(^9\) concluded that “the relatively small numbers of children and the specialist nature of the services points to the advisability of planning these services for a larger population of at least one million”. A CCG should therefore consider approaching its neighbouring CCG(s) with a view to working at a sub-regional level to assess local demand for CPC and to create the economies of scale necessary to commission services effectively. CCGs should also consider including local populations of children with life-limiting and life-threatening conditions within Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies. The Government’s Draft SEND code of practice\(^8\) specifies that Health and Wellbeing Boards should consider the needs of children and young people who need palliative care. GPs should consider using their knowledge of children with life-threatening and life-limiting conditions who are registered with their practice to inform their CCG’s CPC commissioning.

Design pathways

Commissioners should refer to the Together for Short Lives Core Care Pathway for Children with Life-limiting and Life-threatening Conditions\(^2\). This is a critical tool for linking children and their families to community services, hospital-based services, social services, education, children’s hospices and other voluntary providers in one, joined-up planning process. There are three stages to CPC as highlighted in the pathway: diagnosis or recognition that a child’s care is going to be

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palliative rather than curative; ongoing care; and end of life and bereavement care. CCGs should recognise the difference, and the need for phased and timely transitions, between children’s and adult’s palliative care pathways. CPC pathways should integrate with pathways for disabled children to ensure a whole service approach.

Specify and procure
CCGs should take care to ensure that their own specifications for local, general CPC services closely correlate with the specialised CPC service specification E03/S/h13, which is the responsibility of NHS England. The latter focuses on a multi-professional specialist palliative care team, led by a medical consultant working at Paediatric Palliative Care Competency Level 4. It encompasses functions including complex symptom management and prescribing unlicensed medicines. In contrast, for example, a CCG’s responsibilities include commissioning community children’s nursing teams, many of which provide the bulk of general CPC within their local areas. A Government-commissioned review of funding arrangements for palliative care has recommended that an NHS tariff for palliative care should be introduced11. This is currently being developed and is due to be implemented in 2015. It will specify the NHS-commissioned elements of CPC in more detail and should inform CCG procurement. CCGs should not wait for this process to complete, however, and should immediately consider commissioning a comprehensive local CPC service where they have not done so already.

Deliver and improve
CCGs should support CPC services in collecting and measuring data on the outcomes they are achieving; continually evaluating their performance; and innovating to improve provision.

The cost-effectiveness of CPC
Effectively commissioned and delivered CPC can play a cost-effective role in supporting early discharge for children from acute care settings through step-down care. It can also help to reduce unplanned admissions among children to acute care settings. The Government-commissioned funding review10 highlights that hospital admissions in the last year of life for children who need CPC cost an estimated £18.2m. This far outweighs the cost of providing CPC outside of the hospital setting. Research has also shown that short breaks provided by children’s hospices – which may include healthcare interventions – help to reduce stress on families and demand on public services12. Bereavement services for parents and siblings before and following the death of a child can help to mitigate the need for other service interventions later in their lives.

Outcomes
A comprehensive local CPC service can contribute to improving the following indicators set out in the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS):

Domain one:
Preventing people from dying prematurely

C1.1: Combined indicator on potential years of life lost (PYLL) from causes considered amenable to healthcare adults and children and young people (NHS OF 1a i & ii)

Domain two:
Enhancing quality of life for people with long term conditions

C2.1 Health-related quality of life for people with long term conditions (NHS OF 2)
C2.2 People feeling supported to manage their condition (NHS OF 2.1)

Domain three:
Helping people to recover from episodes of ill health or following injury


C3.4 Emergency admissions for children with lower respiratory tract infections (NHS OF 3.2)

Domain four: Ensuring that people have a positive experience of care

- Improving the experience of care for people at the end of their lives.
- Improving children and young people’s experience of healthcare.
- Improving people’s experience of integrated care.

A comprehensive local CPC service can also deliver improvements against indicators suggested for inclusion in the NHS Outcomes Framework and the CCG OIS by the Children and Young People’s Health Outcomes Forum Long-term Conditions, Disability and Palliative Care Subgroup:

- Getting a quality multi-disciplinary assessment that reflects all the child’s or young person’s needs, in addition to those of their family.
- Getting a quality package of care (including a health care plan for emergency situations or an end of life care plan where appropriate) fully integrated across health, education and social care with access to key working support, information to enable the child or young person and family to manage the condition and ensure timely provision of equipment to support maximum participation.

Who should be involved in commissioning general CPC?

- The child or young person who needs palliative care
- Their family
- Professionals providing children’s palliative care
- The regional children’s palliative care network – CCGs should consider developing formal partnerships with existing local networks
- Delivery organisations, including children’s hospices and other voluntary providers
- The local CCG(s) – specifically leads for children’s and end of life care services
- Local parent-carer forums

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