



Paediatric Palliative Care



There are a rapidly growing number of children living with life-limiting and life-threatening conditions across the UK.

Research suggests that such children and their families would benefit from some elements of the palliative care approach and from knowing about the support that is available from children's palliative care services



What is Paediatric Palliative Care?

What?

- An active and total approach to care
- It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support



When?

- From the point of diagnosis, throughout the child's life, death and beyond



How?

- It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family



Who may receive Paediatric Palliative Care?

Category 1

Life-threatening conditions for which curative treatment may be feasible but can fail

- Children with Cancer
- Some Cardiac Conditions

Category 2

Conditions where premature death is inevitable

- Cystic Fibrosis
- Neurodegenerative Conditions
- Duchene's Muscular Dystrophy

Who may receive Paediatric Palliative Care?

Category 3

Progressive conditions without curative treatment options

- Batten's Disease
- Neurodegenerative Disease

Category 4

Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health

- Severe cerebral palsy
- Multiple disabilities, such as following brain or spinal cord injury

When might palliative care be right?

Palliative care can be introduced at any point throughout a child's life; it is completely individual.

Some children may require palliative care from birth or diagnosis; others only as their condition deteriorates.

Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life. Intent to cure should not mean that palliative care input is not offered when appropriate.

In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not an option. However, each situation is different and care should be tailored to the child

Paediatric Palliative Care





What is a Children's Hospice?



Services Offered at Derian House



Perinatal Service

Derian @ Home

DAHRT

Day care

Respite and End of Life Care

Services Offered at Derian House

Counselling

Sibling support

Respite Care- 0-26
years old

Family Flats

End of Life Care

Sunflower rooms

Bereavement Support

Youth Services

Transition

Facilities offered at Derian House



Hydrotherapy Pool

Private Cinema

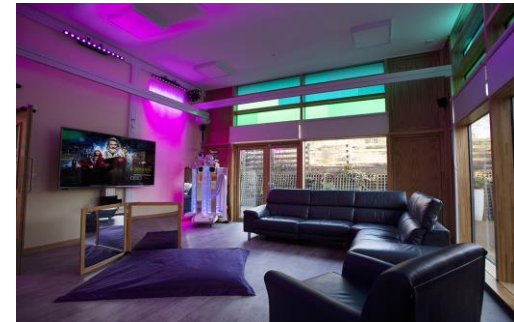
Accessible Park

Messy play & Crafts

Sensory Room

Days out

Holiday Lodges



Sensory Room


Advance Care Planning

- The CYPACP is a document designed to capture advance care planning discussions between professionals, patients and their families.
- It aims to aid these discussions giving prompts of important issues to consider and also to give space and structure to enable documentation of




Child and
Young Person's
Advance Care Plan
Collaborative


Name:	DOB:	NHS No:
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Child and
Young Person's
Advance Care Plan



ID photo



QR code

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES
Plans can begin **antenatally** and are suitable for infants, children and young people

Name (baby, infant, child or young person):	EDD (if relevant):
Known as (if different):	DOB:
Address including postcode:	
NHS no:	Gender (optional):

If ANTENATAL this document is filed in mother's notes (with relevant birthing plan):

Mother's name:	Mother's NHS no:	Mother's DOB:
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ALLERGIES:

For Child/Young Person or Carers' Use – Who to call in emergency (eg 999 or 111, or Hospice, etc)

In emergency call:
Other situations:

See also Emergency Contacts on last page


This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

Not every page/section needs to be completed.

Date of Plan/Last review

Irrespective of the 'Date of plan' it is good practice to check this still reflects current decisions / views, and to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see <http://cypacp.uk/>



<http://cypacp.uk/>
<https://www.respectprocess.org.uk/>

Version 5
Incorporating ReSPECt

Page 1 of 10 Out of hours support and emergency contacts can be found on the last page

Perinatal Palliative Care



Perinatal palliative care is defined as the planning and provision of supportive care during life and end-of-life care for a fetus, newborn infant or infant and their family in the management of an appropriate candidate condition.

Advances in ultrasound and fetal medicine in recent decades have improved prenatal diagnosis, including fetal conditions where the efficacy of interventions carried out at birth are ineffective, questionable or harmful to the neonate

Palliative care focuses on making a person's quality of life as good as possible by relieving discomfort or distress. A person can receive palliative care for any length of time, from a few days to several years. Some babies will still receive active treatment until that treatment is considered no longer viable or in the best interest of the baby.

Professionals can struggle with the difference between end of life and palliative care and sometimes this can prevent early help to support a family throughout their antenatal or neonatal diagnosis.

Symptom Management Planning

- The APPM was established in November 2009 after the merger of Children's Hospice UK doctors' group and the British Society of Palliative Medicine
- Joining forces provided a platform to better promote and support practice and reflects the work of paediatric palliative medicine practice across the sector and develop tailored resources and educational opportunities to our members

Download the APPM Master Formulary (5th edition, 2020) - PDF

APPM CLINICAL GUIDELINES- now available

Transition

Whilst NICE (2016) recommends that “health and social care service managers in children’s and adult services should work together in an integrated way to ensure a smooth and gradual transition for young people,” research evidence suggests that many staff feel ill equipped and often lack confidence to provide this care. The Care Quality Commission (2014) emphasised that “everyone seems to want to do the right thing but there seems to be a missing link and no one seems to work together.”



“Transition is a time in which we need to empower young people. But it is also a time to let them explore and explain their own destiny and help them achieve that. Not everyone’s ambitions look the same, not everyone wants to be fully in, or out, of control.” Hannah Hodgson

Paediatric Palliative & End of life Care Education Project

Elearning & Face to Face sessions

Compassionate Communication

Grief and Bereavement Care

When a Child is Dying

When a Child Has died

Advance care planning level 1 &2

Symptom Management Planning Level 1 &2

Advanced Communication Skills Training

