



Paediatric Palliative Care Guidelines

September 2022



CHILDREN'S HOLISTIC, INTEGRATED,
PALLIATIVE CARE SERVICE

Overview

This document offers practical guidance to professionals who are caring for a child or young person who has been identified as requiring 'palliative care' or who may be approaching the end of their life and so likely to require end of life (EOL) care in the near future.

What is paediatric palliative care?

Paediatric palliative care (ACT/RCPCH definition):

- Is an active and total approach to care from the point of diagnosis through child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life and support for the family.
- Includes management of distressing symptoms, provision of short breaks and care through death and bereavement.
- Addresses the whole experience and is not about cessation of treatment and is often integrated alongside active interventions and treatment.

What is end of life care?

End of life care is the care a child and family receive in the last few days or weeks leading up to the child's death. Medication and interventions are reviewed in relation to their appropriateness throughout this time.

When should paediatric palliative care be introduced?

Evidence has shown that families with a child with a life-limiting or life-threatening condition value the ongoing support from professionals experienced in palliative care, including psychological and spiritual support along with symptom management, from the point of diagnosis. However, palliative care is often only considered right at the end of child's life. There are often times during the child's illness that families need to be supported to make difficult decisions, for example about review of treatment goals. Professionals may be better able to support this process if they have already had the opportunity to build a relationship with the child and family allowing sensitive discussions to take place. Involvement of professionals with an interest in palliative care can be made at any point from the diagnosis of a life-limiting or life-threatening illness to support these discussions or for further advice.

Palliative care services provided by Newcastle Upon Tyne Hospitals

<http://nuth-intranet/cms/GeneralInformation/CoronavirusInformation/Clinicalguidance/EndofLife.aspx>

<http://nuth-intranet/cms/Portals/0/End%20of%20Life%20Care/Palliative%20and%20End%20of%20Life%20Care%20Guidelines%202021-DOWNLOAD.pdf>

CYPOONS

Based in Great North Children's Hospital, the CYPOONS team (Children and Young People's Oncology Outreach Nurse Specialists) provide specialist palliative and end of life care to patients across the North East and Cumbria with a cancer diagnosis.

North East and North Cumbria Paediatric Palliative Care Collaborative

(previously named 'network')

This group supports educational events and clinical case discussions and brings together individuals interested in paediatric palliative care from across the region. The Regional SCN leads (Dr Helen Aspey and Suzanne Garbarino) represent the paediatric population within the all age network.

CHIPS

Children's Holistic Integrated Palliative Care Service (CHIPS) has been in place since October 2020, based in Newcastle Upon Tyne Hospitals and providing regional specialist paediatric palliative care across North East and North Cumbria.

CHIPS supports families and children with life limiting and shortening conditions, and the professionals caring for them, throughout a child's life. Families living with an oncology diagnosis will continue to be supported by the CYPOONS team.

The service works alongside existing teams caring for children with life limiting and shortening conditions. The team consists of four doctors and three nurses from a range of backgrounds, but all with a special interest and experience in palliative care. The team is supported by an admin assistant.

The CHIPS team



Dr Helen Aspey (Head of Department)
TEL: 0191 9177572



Dr Ellie Bond
TEL: 0191 9177572



Dr Jo Elverson
TEL: 0191 9177572



Dr Jane Boyle
TEL: 0191 9177572



Clinical Nurse Specialist Rebekah Hoskins
TEL: 0191 9177570



Clinical Nurse Specialist Christine Mackerness
TEL: 0191 9177570



Clinical Nurse Specialist Allison Shiel
TEL: 0191 9177570



Administrator Alison Kinsey
TEL: 0191 9177570

The Service

The team offers specialist palliative care management and advice to patients, families and professionals. We provide inpatient support for the Great North Children's Hospital for Children and outreach for children being cared for across the region at home, local hospital or hospice.

The services offered by the team include:

- Introducing palliative care support to families at diagnosis
- General advice and support for teams working with families and children with life limiting conditions
- Support with anticipatory and emergency healthcare planning
- Complex symptom management
- Coordinating and supporting end of life care, at preferred place of death. Planned on an individual basis and in collaboration with local teams
- Supporting decision making; particularly in the context of complex ethical decision making or decision making around life sustaining therapy
- Signposting to local bereavement support services

- Staff support: Pre- and debriefs relating to a patient's death, and other professional meetings, at Great North Children's Hospital, other local hospitals, hospices and in the community.

Referrals and Contact Information

CHIPS provides a 7 day/week service, operating within office hours, for the whole of the region.

Referrals can be made by any healthcare professional. If a patient needs to be assessed by a member of the team the named consultant for the child must give approval.

The team will ask you to complete a referral form to ensure they have all the relevant information about the child and their family (see below).

Tel: 0191 9177570

Monday – Friday 8 am – 6 pm

Saturday – Sunday 9 am- 5 pm

Referral Line (24 hour)

NECTAR 0191 2826699 option 5

(Response next day from 9 a.m.)

General email:

nuth.chipsdoctors@nhs.net

nuth.chipsnurses@nhs.net

Living with a life limiting condition

How can CHIPS help?

- Coordinating/supporting local MDT support
- Signposting to other organisations - Rainbow Trust, Local Offer, charities
- Making decisions/plans – support writing Emergency Healthcare Plans
- Supporting difficult discussions

When is the 'right time' to refer?

- From diagnosis if appropriate, or at times of deterioration or change
- Phone for advice if unsure

End of Life Care

How can CHIPS help?

- Symptom management
- Place of care and exploring wishes
- Support writing Emergency Health Care Plans
- Supporting discharge to preferred place of care
- Supporting discussions and decisions around DNACPR

Rapid Transfer Home

- CHIPS can support professionals to arrange rapid discharges home or to an alternative place of care (for example local hospice) accommodating children/young people and families wishes where possible
- See Appendix B for Rapid discharge checklist

After Death

Please consider the following:

- Medical certification of death
- CDOP process
 - Link to Trust guidelines on child death [Intranet > Support Services > Safeguarding Children and Adults > Child Death > Policies and procedures](#)
 - <https://www.ecdop.co.uk/NorthandSouthTyne/Live/public>
- Post Mortem and Coroner
 - Chaplaincy 48129
 - Mortuary 24421
 - Coroner checklist See Appendix C
 - Coroners referralportal [Referrer Details \(icasework.com\)](#)
- Organ donation – contact Specialist Nurses Organ Donation 03000203040
- Bereavement support
 - The Chaplaincy team are trained to provide mental health first aid and to refer to other agencies as appropriate
 - Discuss with Hospital bereavement officers (2231146 (FRH) 2824348 (RVI)
 - For Local Authority bereavement referrals email bereavementreferrals@newcastle.gov.uk
- CHIPS are happy to facilitate staff debriefs for teams
- It is good practice to offer a follow up meeting with families after death.

Useful Resources

- NICE Guidelines “End of life care for infants, children and young people with life-limiting conditions: planning and management”
<https://www.nice.org.uk/guidance/ng61>
- <https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>
- ReSPECT document (link)
[CYPACP – Child & Young Persons Advance Care Plan](#)
- Emergency Health Care Plan [EHCP-Doc-Final-Version-May-2021-E-Fillable.docx \(live.com\)](#)
- DNACPR [DNACPR-NHS-Print-form-v17a-2018.pdf \(northerncanceralliance.nhs.uk\)](#)
- Local offer link for information on local services
<https://www.newcastlesupportdirectory.org.uk/getting-started-newcastle-local-offer>

Appendix A

Referral Form

REFERRAL FORM

Please send to: nuth.chipsnurses@nhs.net

For Urgent Referrals please contact CHIPS Nursing Team: 0191 9177570 (Monday-Friday 0800-1800, Saturday-Sunday 0900-1700)

Patient Details				
NAME:		DATE OF BIRTH:		
ADDRESS:		GENDER:		
		NHS NUMBER:		
		PREVIOUS NAMES?		
ETHNIC GROUP:		INTERPRETER REQ:	Y	N
RELIGION:		LANGUAGE:		

In the event of only one Parent/Carer please provide details of a 2nd Emergency Contact in the Parent/Carer Detail No.2 Box

PARENT / CARER NO.1 DETAILS			PARENT / CARER NO.2 DETAILS		
NAME:			NAME:		
Relationship to Child:			Relationship to Child:		
Telephone No:			Telephone No:		
Address:			Address:		
Email Address:			Email Address:		
Does this Person have Parental Responsibility?	YES	NO	Does this Person have Parental Responsibility?	YES	NO
If <u>NO</u> please state who holds parental responsibility in the boxes below					
Name:			Name:		
Relationship to Child:			Relationship to Child:		
Address:			Address:		
Telephone No:			Telephone No:		

SIBLINGS: Yes/No			
Names(s)		Age and DOB:	

Diagnosis	
Reason for referral <i>(Examples of reason for referral include Symptom Control, Advance Care Planning, Support around coordinating care at the end of life)</i>	
Medications	
Allergies	
Any other important information: <i>(Any other medical history or social history which is important for the team to be aware of)</i>	

Key Agencies involved:			
	Name	Postal Address & Email Address	Tel No.
GP Name & Practice			
Lead Consultant			
Community Paediatrician			
Community Nurse			
Health Visitor			
Social Worker			

Hospital Agencies involved:	Name	Postal Address & Email Address	Tel No.
Other Consultants			
Specialist Nurse(s) e.g. Epilepsy Gastro Cardiac Continuing Care			

Community Agencies involved:	Name	Postal Address & Email Address	Tel No.
School Nurse			
School/Nursery			
Physiotherapist			
OT			
SALT			
Dietician			
Short Break provision			
Other			

Paediatric Palliative Care Guidelines

REFERRER DETAILS	
Name:	
Address and contact number:	
Parental consent to referral?	
DATE OF REFERRAL:	

URGENCY:	Immediate (Please phone to discuss)	
	Urgent- within 24hrs (Please phone to discuss)	
	Soon- Within 1 week	
	Planned routine review	

Appendix B

Rapid Discharge checklist

Rapid Discharge Checklist

Date of Discharge:

Documentation and Communication

Planning MDT Attendance

CHIPS CYPOONS PICU (FRH/GNCH) NECTAR Parent team Local Team Hospice

Transport

Outcome Transport plan summary

Where:	by Whom:
---------------	-----------------

Family transport: safety assessed Decision re family member in NECTAR Ambulance

DEATH IN TRANSPORT DISCUSSED WITH FAMILY destination if dies enroute:

DNACPR

Completed stored in patient notes hardcopies to family reviewed by teams

EmHCP

Updated stored in patient notes hardcopies to family reviewed by teams

Symptom management plan

Completed stored in patient notes hardcopies to family reviewed by teams

Other

GP updated CCN team updated

NEAS special patient note Completed and emailed

Local Coroner informed of expected death

Specialist teams involved updated:
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Home assessment

Access to home for patient/ trolley

Steps
Road
Rear Access
Internal logistics
Patient Mobility

Power points available / extension cable

Syringe drivers provision

Professional Support

Plan re community team

Plan Re CHIPS / NECTAR

Family Communication Assessment

Procedures at the Time of Death

Family provided with written and verbal information on procedures at the time of death

Issue	Discussed	Outcome
What to do / who to contact when child dies	✓	
Medical certification of death		
Requirements for cremation		
Likely changes to the child's body following death		
Organ / tissue donation requirements		
Registering the death		
Organising a funeral		

CLINICAL STATUS

PICU Patient: Ventilation settings: P rate Fio2 itime
 Infusions:
 Observations: HR BP SpO2 Co2 Access
 Misc: Access Drains Other:

All Patients Assessment:
 Symptoms:

Surprise question time:

Airway

Suction machine Y/N Family training Tracheostomy training NA / Y / N

Breathing

Breathing changes discussed with family Y/N

Oxygen requirement Y/N Supply organised by:

Drugs

Just in Case box stocked:

IV Locked Box Stock:

Drug	Expiry	No. supplied

Drug	Expiry	No. supplied

Elimination

Plan discussed with family to monitor urine and bowel function

Feeding & Fluid

Feed plan family informed & recorded in Symptom management plan Stop feeds 2 hours before transfer

Hygiene and Skin integrity

Assessment of palliative care needs: Pressure relief mattress /bed Continence aids

Infection

Plan for infection agreed Community Antibiotic Treatment provided in Just in Case box

Consumables

ITEM	✓	ITEM	✓	ITEM	✓
Gloves		Medicinal feed		Clinical waste bags	
Syringes		Giving sets		Sharps Bin	
SC cannula: Gauge		Ph Paper			
Needles: Gauge		Suction catheters			
Extensions lines		Trache box			

Bereavement Support

Provision of books / media / support organisation information on Bereavement

Provision of Memories box / CHIPS advice leaflet Provision of sibling bereavement media

Follow up contact offered to family

Date Followed up / signed:

Additional Notes

(Please include further information on home assessment, professional support, communications assessment – interpreter requirements, learning disability, vision/hearing impairment, plan on arrival home)

HOSPICE Information for Professionals

To be completed after NECTAR visits to Hospices

Butterwick

Jigsaw

St. Oswalds

Zoe's Place