

C&YP Palliative Care North Lincolnshire



Information Leaflet

What is Palliative care?

Palliative Care for Children and Young Person is an active total approach to care from the point of diagnosis of a life limiting, life threatening condition or recognition of deterioration, embracing, physical, emotional, social and spiritual elements. It focuses on an enhancement of quality of life for the child, support for the family and includes the management of distressing symptoms, through death and bereavement.

What are the benefits of an early referral to palliative care?

It is often difficult to predict the progression of many childhood conditions even when medical treatment is provided as life prolonging or in the hope of cure. An early referral allows more time to establish a trusting relationship with families to ensure that care planning is guided by each family's individualised thoughts and wishes.

A referral does not mean giving up hope. In fact, it allows for more time to plan care and provide the best possible support for a child, their family and other involved in a proactive holistic manner.



Triggers for referral to palliative care

Diagnosis of life limiting, life threatening condition or recognition of deterioration

Four groups of life-limiting and life-threatening conditions

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail.</p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
Category 2	<p>Conditions where premature death is inevitable.</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy.</i></p>
Category 3	<p>Progressive conditions without curative treatment options.</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>

Togetherforshorterlives.org.uk

- Uncertain prognosis
- Difficult symptom management
- Family in need of support to manage on-going complex care needs
- Support for difficult discussions
- Support for advanced care plan/ReSPECT
- Advice and support for professionals



How can the Palliative care nurse support patients and families?

- Assessment and management of pain and other Difficult symptoms experienced during the course Of a child or young person's illness
- Enhance communication to coordinate and link Families with available home care, hospital and Community services
- Information around respite options
- Facilitate discussions for goals of care and end Of life care planning including resuscitation orders
- Provide care and support during different stages Of a child's illness
- Bereavement support for parents, siblings and other extended family member.

Palliative care services will not replace the medical teams who care for a child at hospital or in the community. The goal is to work with you and other health services to enhance the care and quality of life for children/young person and their families.



What is a Child & Young Person's advanced care plan?

A CYPACP is document that is done in collaboration between child, young person, families and professionals involved. It sets out agreed thoughts and wishes of care during deterioration or emergency care. CYPACP documents have to be right for you and discussions may span over periods. It doesn't mean treatments are being limited or withdrawn but that plans, thoughts and wishes ahead for deteriorations or emergencies as have been made as it can be difficult to make rational informed decisions during emergency situations. Decisions can always still be changed, including in an emergency situation and the plan can be reviewed whenever you wish, and you don't have to wait for a review date.

What Is ReSPECT?

Recommended Summary plan for Emergency Care and Treatment is one part of the CYPACP we use. We understand and appreciate talking about death can be extremely difficult and you may not be ready to discuss CPR and this is ok, the team will continue to provide CPR based on your child/young person's best interest, however if you feel that you want to discuss CPR staff will support you through this decision, continuing to provide your child/young person with the best possible care to keep your child/young person comfortable and as pain free as possible.



Palliative Care Lead Nurse

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Andy's Hospice

https://www.standrewshospice.com/about_us/andys-childrens-services/

Tel: 01472 350908

Together for shorter lives

Supporting them to make sure they get the vital care and help that they need.

www.togetherforshorterlives.org.uk

Call the Helpline
0808 8088 100

Child and Young Person's Advanced Care Plan

Support information for advanced care plans

<http://cypacp.uk>

Family Fund

The Family Fund helps families with severely disabled children to have choices and the opportunity to enjoy everyday life.

They give grants for things such as washing machines, hospital visiting costs, computers and holidays.

www.familyfund.org.uk

Tel: 01904 550055



When You Wish Upon a Star

A national organisation set up to grant wishes for seriously ill children between the ages of 2 and 16.

www.whenyowishuponastar.org.uk

Tel: 0115 979 1720

Jens Special Place

Child bereavement support group based in Scunthorpe, The group ultimately aims to support children in expressing their grief.

<https://www.jensspecialplace.co.uk/>

Child Bereavement UK

www.childbereavement.org.uk

Bereavement Services

Telephone: 01494 568900

