

# Children's palliative care

**This leaflet gives you information about the children's (paediatric) palliative care service at Evelina London. Our service aims to improve quality of life for children with a serious illness and their families.**

You have been given this leaflet because your child has been referred to our palliative care team. We recognise that this can be a very worrying time for you. We hope that the leaflet helps to:

- reassure you
- answer some of the common questions that families have
- give you details of our service

## Why your child has been referred to us

Palliative care for children is different from adult palliative care, which focuses on individuals near the end of their life. Children's palliative care teams support babies, children and young people up to their 18<sup>th</sup> birthdays, who have life-threatening or life-limiting conditions.

### Life-threatening conditions

If a child has a life-threatening condition, medical treatments might be successful. However, we recognise that the child is fragile and there is a high risk of death in childhood.

### Life-limiting conditions

If a child has a life-limiting condition, there is currently no cure available. Sadly, it is likely that a baby or child may die before becoming an adult.

## Our palliative care team for children

The children's palliative care team is based at Evelina London Children's Hospital. It is made up of:

- consultant doctors, who specialise in children's palliative medicine
- clinical nurse specialists, who specialise in children's palliative care
- junior doctors
- administrators
- a specialist pharmacist

Any child who is referred to us has a named consultant and nurse, who can build up a relationship with your family. They oversee your child's care and are your points of contact. However, you may not always see the named consultant or nurse if they are away or unavailable. Our whole team helps to look after your child.

We may see children at various places, including:

- Evelina London
- other hospitals
- hospices

- at home
- in school

We work alongside community and hospital teams, and in partnership with families.

## The aims of our service

Our palliative care team works together with the other medical teams that already look after your child. We care for your child as a whole person or holistically. This means that we consider their physical, emotional and spiritual needs, within the context of your family. We also support you to make decisions in your child's best interest.

## How the palliative care team can help

Our palliative care team can help with:

- advance care planning
- symptom management
- end of life care

### Advance care planning

We can work with you to make an advance care plan. This is a document that records your wishes for your child if their health gradually or suddenly gets worse.

It may feel very emotional to make an advance care plan. However, most of our families have a sense of relief afterwards for various reasons. For example:

- the process allows families to think in advance about the different options if their child suddenly becomes very unwell or deteriorates
- families report that knowing what they would like to happen in different situations gives them a sense of control
- making an advance care plan can help families to worry less about future uncertainty

An advance care plan is not legally binding. It is best practice to review the document every 6 to 12 months or when there are any changes in your child's condition.

Children who are referred to our palliative care team do not always have an advance care plan in place. We often talk to families about making an advance care plan and guide them through the process. This can help us to:

- prepare families for what may happen if their child becomes more unwell
- explain what choices families may have about their child's treatment at that time

### Symptom management

We support and manage a variety of symptoms that a child may have due to their condition, alongside our specialist colleagues. Our aim is to take a holistic approach to you and your child, which means dealing with all aspects of wellbeing. The symptoms that we manage include but are not limited to:

- breathing problems
- seizures or fits (sudden bursts of electrical activity in the brain that temporarily affect how it works)

- agitation (being anxious or restless)
- pain
- vomiting (being sick)
- constipation
- feeding issues

Together with an advance care plan, we can give you a symptom management plan if needed. This is a step-by-step guide to help you manage your child's symptoms using medicines at home or in a community setting.

The symptom management plan is personalised to your child. The complexity of the plan depends on where you want your child to be cared for and their specific treatment. We review the plan regularly and make sure that it reflects your child's present state of health.

### End of life care

Our team supports babies and children who are sadly at the end of their lives. We aim to review children who are felt to be at the end stage of their illness regularly. However, this depends on:

- the family's wishes
- what symptoms the child has and how serious they are

We can also support you with some of the practical and legal processes that you may face after a bereavement.

### Next steps

Our goal is to support you and your child in a flexible way. We decide how to help in partnership with you and this is likely to change throughout your child's treatment.

The palliative care team liaises with you and the main professionals looking after your child. We arrange to meet you and answer any questions that you may have.

We hope that this leaflet has explained who we are, and how we might be able to help you and your child. It can take time to process all of this information. If you think of any questions not covered here, we will be happy to answer them.

### Contact us

If you have any questions or concerns about children's palliative care, you can contact our team from Monday to Friday, 9am to 5pm.

**Palliative care team** duty **mobile:** 07747 267 799

**Hospital switchboard,** **phone:** 020 7188 7188 extension 53823

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)



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