

Where can I get further help or information?



Together for Short Lives:

www.togetherforshortlives.org.uk

Child Bereavement Charity:

www.childbereavement.org.uk



A book that has been reproduced on line; it is written by a mother who could not find the information that she needed when she needed it. It can be found at:

www.specialchild.co.uk

You can talk with other parents who are in a similar position through the contact a family scheme :

 0808 808 3555 www.cafamily.org.uk



Each hospital has a Patient Advice and Liaison Service (PALS)

Local Contacts:



Child and
Young Person's
Advance Care Plan
Collaborative

Information for Parents



www.cypacp.nhs.uk

Sometimes families worry about what might happen if their child suddenly or unexpectedly becomes unwell. Talking through what might happen can help reduce some of these worries and concerns.

Who is this leaflet for?

This leaflet is for families who have a child or young person with a life-limiting condition. It provides information about our Child & Young Person's Advance Care Plan (CYPACP): what it is, how it is created and what it means for the child. There is a separate leaflet for your child/ young person to read.

What is a Child & Young Person's Advance Care Plan?

A CYPACP is a document that sets out an agreed plan of care to be followed if/ when your child's condition deteriorates. It is very difficult to make rational and informed decisions during a crisis, so the benefit of a CYPACP is that a plan of action can be made before the situation occurs. You are still free to change your mind at any time, including when an emergency occurs.

How does it work?

Everyone who plays an important role in the life and health care of your child and, if appropriate, your child themselves, can be involved in the advance planning. The plan covers a variety of different circumstances including slow deterioration and sudden emergencies, but is specific to the needs of your child and your family.

A key feature of an Advance Care Plan is that it is shared with all professionals involved in the routine care of your child as well as those who might be called in an emergency. This means that everyone has clear information about the wishes and needs of your child and your family, so that they can provide that care.

What does the process involve?

The first step in the process is deciding whether the time is right to make a CYPACP. You and your family are likely to have questions about this. We will try to answer your queries and concerns as realistically and sympathetically as possible. You may also want to talk through the issues with friends or family, or your religious advisor, or have any of these people with you when you next talk to your child's doctors.

You may have very clear thoughts about some aspects of care, whereas other aspects may be less clear to you. A member of your child's team can show you a CYPACP and discuss the various options that might be suitable for your child. We will work together with you at your pace to put together a plan for your child/ young person.

What happens when the plan is agreed?

Once a CYPACP plan is agreed it will be signed by you and the senior doctor or clinician looking after your child. Copies of the CYPACP are given to you and to each of the health care professionals who are routinely involved in your child's care, as well as those who might be contacted in an emergency.

Advance Care Plans are reviewed regularly to ensure that the plan of care is still appropriate and that everyone remains in agreement. The team caring for your child will discuss with you how often these reviews will take place.

What if I want to change an aspect of the Advance Care Plan once it has been agreed?

If you want the Advance Care Plan to be changed or reviewed you do not have to wait for the next review date. Just talk to one of your child's care team, and the care plan can be reconsidered.