

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

Your parents 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 Young People



www.cypacp.nhs.uk

Sometimes you might worry about what might happen if you suddenly or unexpectedly become unwell. Your family probably worries about this too. Talking through what might happen with all your carers can help reduce some of these worries and concerns.

Who is this leaflet for?

This leaflet is for young people who have a life-limiting condition. It provides information about a Child & Young Person's Advance Care Plan (CYPACP): what it is, how it is created and what it means for you.

What is an Advance Care Plan?

A CYPACP is a document where your wishes are written down so that they can be followed if your condition deteriorates. It is very difficult to think about this when you are very unwell, so the benefit of an Advance Care Plan is that a plan can be made before this happens.

How does it work?

Everyone who plays an important role in your life and health care can be involved in the advance planning. The plan covers a variety of different circumstances, including a gradual decline in your condition and sudden emergencies. It will record what you and your family want to happen.

Your CYPACP will be shared with all the people involved in your care as well as those who might be called in an emergency. This means that everyone has clear information about your wishes and needs so that they can look after you according to your wishes.

What does the process involve?

The first thing to think about is whether the time is right to make a CYPACP. You are likely to have questions about this. Your health care team will try to answer all of your questions 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. You might also want to have some of these people with you when you next talk to your doctors.

You may have very clear ideas and feelings about some of this, but others parts may be less clear to you. A member of your team can show you a CYPACP and discuss how it might work for you. We will work with you, at your pace, to put together a plan which suits you best.

What happens when the plan is agreed?

Once a CYPACP is agreed it will be signed by you and your doctor and, if appropriate, by your parent(s). Copies of the CYPACP will be given to you and to each of the health care professionals who are regularly involved in your care, as well as those who might be contacted in an emergency.

CYPACPs are reviewed regularly, to ensure that the plan is still right for you and that everyone remains in agreement. The team caring for you 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 CYPACP to be changed or reviewed you do not have to wait for the next review date. Just talk to one of your care team, and the care plan can be looked at with you and altered if needed.