



Child and
Young Person's
Advance Care Plan
Collaborative
www.cypacp.uk

Advance care planning for your child

This leaflet provides information about Child & Young Person's Advance Care Plan for families who have a child or young person with complex medical needs.

What is a CYPACP?



An Advance Care Plan is a document that sets out what matters the most to you and your child, your hopes and wishes for current and future care.

It helps your family, and the whole team of professionals looking after your child, discuss options and prepare for when your child becomes very unwell, either gradually or in an emergency.

Talking through what might happen in these cases when your child is doing well can help navigate these worries by giving you a sense of control.

How does it work?

A key feature of an Advance Care Plan is that it is shared with all professionals involved in the ongoing care of your child as well as those who might be called in an emergency. This means that everyone who plays an important role in the life and healthcare of your child and, if appropriate, your child themselves, can be involved in the advance planning.



The plan covers a variety of different circumstances for when your child's health worsens, and explains exactly what you and your child's priorities would be in each situation.

What does the process involve?

The first step to think about is when you would like to start to develop the advance care plan. It is easier to make plans whilst your child is well. You don't have to complete it all in one go.



You and your family are likely to have questions about this. Your healthcare team is there to listen and try to answer all of your queries and concerns as fully as possible.

You may also want to talk things through with family, friends or your religious advisor. You can also ask to have some of these people with you when you next talk to your child's medical team about the plan.

You may have very clear thoughts about some aspects of care, whereas others may be less

certain. A member of your child's team will work with you to discuss options and create a plan that feels right for your child at that time.

What happens when the plan is agreed?

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



You can ask for your plan to be reviewed at any time and your child's team will do this with you as regularly as you agree. This is to ensure that the plan of care still meets your evolving hopes and needs, and everyone is on the same page about the best plan of action. If these things change over time, you can always talk to one of your child's care team, and the plan can be reconsidered at any point.

Where you can find further help and information

Together for Short Lives
www.togetherforshortlives.org.uk

Child Bereavement UK
www.childbereavementuk.org

Special child
www.specialchild.co.uk

An online book written by a mother who could not find the information that she needed when she needed it.

Contact
www.contact.org.uk

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

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