

what happens if...?

ADVANCE CARE PLANS

Planning ahead for the needs of children and young people with life-limiting or life-threatening conditions



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 an Advance Care Plan: what it is, how it is created and what it means for the child. There is a separate leaflet for young people to read.

What is an Advance Care Plan?

An Advance Care Plan 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 an Advance Care Plan is that a plan of action can be made before the situation occurs.

How does it work?

Everyone who plays an important role in the life and health care of your child or a young person, and if appropriate your child/ young person 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 individual 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 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 an Advance Care Plan, and you are likely to have questions about this. Your child's health care team 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 an Advance Care Plan 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 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 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.

Where can I get further help or information?

ACT – The Association of Children with Life-threatening and Terminal Conditions and their families www.act.org.uk

Child Bereavement Charity
– www.childbereavement.org.uk

www.specialchild.co.uk is 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. Through the contact a family scheme you can talk with other families or young people who are in a similar position:

www.cafamily.org.uk, or telephone 0808 808 3555. Each hospital has a Patient Advice and Liaison Service (PALS)

Local Contacts: