



Advance Care Planning Clinic

This leaflet is for children and young people who are invited to attend a Paediatric Advance Care Planning Clinic. It explains what will happen in the clinic and what you might like to do to prepare for the clinic.

Introduction

Some children and young people will have episodes of illness that may result in hospitalisation or unexpected deterioration.

In line with national guidance, we believe that planning for these episodes in advance can:

- Help ensure that you feel confident in managing your child's care.
- Help you feel in control of difficult situations as much as possible.
- Allow your child to have the best chances at remaining well and being cared for where they and you feel most comfortable, with the expertise they need.
- Allow the emergency services to support you in the plans that are being made for your child.
- To reduce some of the questions you may be asked when you bring your child to hospital, by documenting the decisions we have reached together.

How do I get an appointment?

The team of doctors and nurses looking after your child may suggest that this would be helpful and arrange an appointment.

OR, you may have heard of Advance Care Planning and have asked your child's health care team for more information.

If this would be helpful for your child/young person, then an appointment will be offered to meet up and start putting a plan together.

Sometimes, if a child is very unwell in hospital, we might do this on the ward instead.

Who will be at the appointment?

A number of people will be there, such as:

- Your child's main consultant.
- Your child's community nurse (CCN).
- An intensive care doctor – so you can ask questions about paediatric intensive care (also known as PICU).
- A palliative care doctor – some, but not all, of the children who come to this clinic might have a shortened life expectancy. Palliative care doctors can be helpful in thinking about preventing distressing symptoms and keeping children as healthy as possible.

- Interpreter – please inform us if you need an interpreter; if English is not your first language or you need British Sign Language support. Some of the information can be complicated and we find that a professional interpreter can be very helpful in ensuring you get all the information you need, even if you normally can manage quite well without one.

What will be discussed?

We aim to discuss topics relevant to your child's care over time. If there are things that you really do not want to discuss, please let us know in advance or during the clinic.

Any of the following topics may be helpful for your child, depending upon their health, including:

- Current overview of health – what are the main risks to their health and any concerns you or the medical team have?
- What are the things that are important to your child and family?
- What has happened before – for example trips to PICU or the high dependency unit (HDU)?
- Develop a plan for what happens if...
 - They get a chest infection.
 - They have a big seizure.
 - They become extremely unwell.
- For some families, we may discuss matters relating to the end of their life, but this might not be relevant to your child.

How is this discussion documented?

No one will make decisions about your child/young person without you being involved in the decision.

After the appointment, a standardised document (advance care plan – ACP) is drawn up. Your CCN will share this with you.

If you are happy that it reflects the conversation we have had, it will then be signed and circulated to an agreed list of people. We will send you a copy of this document.

Is this a legal document?

The ACP is a record of the decisions we have made up to the point it was signed.

As we cannot predict every eventuality, circumstances may mean that you or the doctors involved in your child's care can over-ride it. However, they will not do this without discussing it with you first.

Can my child take part in these discussions?

If your child cannot make sense of these discussions, then they would not usually be involved, as you can make decisions on their behalf.

However, there are situations where a young person may choose to take part in some or all of these discussions, and they would be welcome to do so.

If this is the case for your child, please discuss with your CCN or doctor how this might be best done, so that you and your child get the right information.

Further information about Advance Care Planning

<https://www.nice.org.uk/guidance/ng61/informationforpublic>

<http://cypacp.uk/>

Please ask your medical team for more information as you or your child/young person needs it.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Dr S Hughes, RBFT Paediatrics

Reviewed by E Ambrose (Alexander Devine Hospice), E Flannery (Palliative Care) and P Somwanshi (Paeds): November 2023

Next review due: November 2025