

AT A GLANCE How to complete an advance care plan



Clear, honest communication between families and the wider multi-disciplinary team involved in their care is key to successful advance care planning, where there is collaboration around decision-making, informed by both the family wishes and professional expertise.



Allow enough time

Time spent in preparation and writing it well will enable children and families to effectively communicate difficult decisions and important information with their medical teams. Completing it may require several consultations and discussions, which may take place over several days or weeks.



Complete the plan electronically

Ideally it should be completed online and then printed out for signing and circulation, ensuring all care settings have a copy. The original copy should stay with the child.

What is in an advance care plan

No sections within the core document should be deleted, except the neonatal sections, if not appropriate.

Basic demographic information

Address, emergency contacts, NHS number, allergies, date of plan, decision making, interpreter, communication and mental capacity

Summary diagnosis, background information and personal background information

Wishes around end of life

Organ donation, Coroner / post-mortem/ medical examiner referrals

Neonatal section

Plan for delivery and plans for after delivery/birth, management of baby at birth

Management of anticipated complications / deteriorating health

Management of an acute significant deterioration / emergency

ReSPECT form

The ReSPECT/DNACPR section needs to be signed by an appropriate clinician, usually, the child's lead consultant.

There is no date for review recorded on the plan, it depends on the child's individual circumstances and at the discretion of the lead clinician



Child and
Young Person's
Advance Care Plan

The process of thinking things through - a parent's perspective



In hindsight it almost felt like a birth plan. A chance to think through all the options...and also accept that you don't have control over it. But if you have not thought it through then they you are much less likely to end up in a situation that feels right.

It is crucial to address sensitive topics instead of avoiding them - a doctor's perspective



Throughout it is important to get the family's language and context. It's also really important not to dodge some of the sections that may feel sensitive. Prepare a family before a meeting by providing an information sheet or indeed a blank plan so the family feels able to consider and think about what will be discussed.