

Advance care planning

Planning for how you would like things to be at the end of your child's life is never easy. Some people find it easier to begin thinking about what they do NOT want to happen. For example, "I don't want my child to be in pain" or "I don't want our family to be separated". We can help you create a plan to avoid circumstances like these, where possible.

- The [Child and Young Person Advance Care Plan \(CYACP\)](#) and [ReSPECT](#) documents are used throughout the UK.
- These documents are recognised wherever your child is being cared for.
- This is a plan generated from open and honest discussions with you and your child, if possible, so that personal preferences can be written down to help guide care and support throughout your child's life.
- It can take into account things you feel are important to your child, as well as cultural or religious needs.
- This is a working document and you do not have to complete all sections in one conversation. It may be added to over time.
- Some families like to make these plans long before their child is in an end of life phase, others prefer to think about such matters as the moment arrives.
- In our experience, having a plan in place often helps families have more control in a highly emotive situation.
- Developing these plans helps to consider decisions about care and treatment for your child, such as: admission to hospital for managing health needs with intravenous fluids or antibiotics, admissions to the paediatric intensive care unit or whether you wish for emergency resuscitation measures.
- The process for a child looked after by the local authority (LAC) may differ. As part of these discussions, we will ask you about a preferred place of care for your child during end of life care, so we can do our best to support your choices.





Call 0808 196 9495 anytime (freephone)

- During office hours your call will be answered by the SMNS administrator who will direct your call to a nurse, or please leave a message and one of the team will contact you as soon as possible.
- Outside of office times, when you have access to the on-call service, telephone calls are answered by a call handling service:
 - Please ask to speak to the on-call Symptom Management Clinical Nurse Specialist.
 - You will be asked for basic information about your child, including name, date of birth and a brief reason for calling.
 - This information will be given to the SMNS Clinical Nurse Specialist who will return your call as soon as possible.
- In the unlikely event you are unable to reach us via this number, please call the EACH central number 01223 800 800 (calls charged at local rate).
- If you need urgent attention, please call 999.