



TIPS E Advance Care N Planning

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1 Advance Care Planning is a dynamic and ongoing process, for which the child / young person and their family should be actively involved.

- An Advance Care Plan may evolve over a number of years.

2 It is important to understand the child's / young person's and their parent's preferred role and approach to decision making.

- What matters most to them about current and future care.
- How do they want to engage in shared decision making, families might not want to make the final decision.

3 Advance Care Plans help future discussions and decision making.

- They help families discuss their hopes, values and goals.
- It is not always possible to make final decisions in advance. However, Advance Care Plans help all those involved to support appropriate ongoing joint decision.

4 Advance Care Planning is about life, end of life and beyond.

- It aims to maximise life but also enables families and professionals to consider death and beyond.
- It is NOT just a resuscitation document.

5 The existence of an Advance Care Plan does NOT mean a limitation of treatment.

- Palliative care incorporates 'active management'.

6 It is important to develop and record discussions of Advance Care Planning with the child / young person where they are able and their parents /carers.

- It requires sensitive and skilled communication.

7 The Advance Care Plan can be shared across all environments that the child encounters: home, hospital, school, hospice and respite care, and remains valid when parent(s) or next of kin cannot be contacted.

- Everyone coming into contact with children with medical complexity should be aware of Advance Care Planning.

8 The child / young person and their parents can change their minds and revise their Advance Care Plan.

- Advance Care Planning can highlight potential difficulties and help find solutions.
- It is important to communicate to families that professionals cannot act in ways which they feel are unethical or inappropriate.

9 When writing Advance Care Plans consider users.

- Avoid ambiguity where possible e.g. Clear and concise information is more appropriate in emergencies.
- Background and context help with future discussions and joint decision making.

10 Some parents may not wish to have an Advance Care Plan or sign any documents. They are communication tools not legal documents.