

# AT A GLANCE How to talk about advance care planning



**Advance care planning needs sensitive and skilled communication. This is best done in a series of conversations, as part of a compassionate and caring approach that promotes choice and shared decision-making.**

Conversations may include talking to the affected child, siblings, parents, and friends. Discussions will cover complex and difficult issues around options for treatment and care, as well as values and beliefs, hopes and fears.

## Some of the key principles to consider

- Be adequately prepared and use an appropriate safe space
- Consider who else should be present. Both parents should be present with a trusted advocate alongside the family
- Consider the level at which a child or young person may wish to be involved
- Be honest and transparent, use clear, non-medical language, ask open questions and use prompts
- Listen and acknowledge the sadness and distress
- Don't be afraid of silence, give families space and time to gather their thoughts and process information
- Manage expectations, use open directive questions – ‘*what is most important to you now?*’
- Reflect and clarify what you have understood
- Summarise what you have heard and if you have missed anything, ask families how they want to move on
- Record and share appropriately, ask for guidance if you need more help



Child and  
Young Person's  
Advance Care Plan

## Putting our child at the heart of all decisions - a parent's perspective



*Advance care planning made it feel like it was actually a wide holistic view of our daughter and how we could support her on her journey, looking at all of her and what mattered to her.*

## Enabling choices - a doctor's perspective



*The really important element is about enabling choices and that choice is about a place that means something to a child and family as well as treatments that would be important to consider.*