

AT A GLANCE What matters most to parents and families



No one wants to think about their child being in pain or dying. However, families in this situation want experienced professionals to provide the best experience of advance care planning, comfort and support.

Parents, like everyone else, want to feel heard, held and prepared. Advance care planning enables them to communicate their needs and hopes for their child's care



Recognising the importance of each family's values, culture and beliefs

Parents do not want professionals to avoid conversations with them and want to talk about their thoughts, hopes and fears. They want professionals to understand the day-to-day demands of family life and to recognise the importance of their family values, culture and beliefs. They may wish to discuss options of care, as well as end of life choices, including, care after death, funeral planning and bereavement support.



The highest quality of life for their child

Parents want professionals to share information about options for treatment and care. They look to balance the management of symptoms with not wanting their child to suffer.



A non-judgemental and caring approach

Sensitive communication and relationships with professionals who have the skills and knowledge to guide parents is central to supporting them to make the 'right' decisions. Understanding that each child and family is different and that they will need time and space to adjust to the changing situation is essential in planning when to talk.



Child and
Young Person's
Advance Care Plan

Gaining clarity before acute situations - a parent's perspective



When we knew that we were having a meeting with our daughter's doctor to discuss the ACP, we would then have a look at it for ourselves at home. Often we realised we might not be fully on the same page and that one of us understood something like this or somebody else understood that. Then we were able to go to our meetings and say how does this work? And I remember every time the doctor would explain it to us and it would provide such clarity...the differences between myself and my daughter's dad we could iron out before we were in an acute situation having to make a decision.

Understanding a family's hopes and fears - a doctor's perspective



It's about understanding what the family most hope for and most fear still in their palliative journey. And to be able to offer realistic, meaningful and practical achievable choices