

AT A GLANCE Starting discussions: who and when?



When to start advance care planning discussions is unique to every child or young person and their family.

The process of advance care planning can begin soon after diagnosis or recognition of a life-limiting condition. Some children will have an advance care plan for many years before they reach the end of their life and it can be applicable as part of parallel planning.

When?

Important considerations

- ✓ Readiness of parents to talk
- 📍 In a place of family's choice
- 🕒 As soon as an opportunity arises following diagnosis
- ✗ Avoid moments of crisis
- 💬 Understanding of triggers and prompts that would lead to a conversation

Who?

Where possible is initiated by someone who:

- Knows the family and has time to lead on ACP
- Understands the emotional impact of conversations and has the ability to provide support.
- Is able to consider all possible treatment and care options and addresses them in terms of the benefit for the child.
- Understands the process may involve several different discussions over a period of time
- Is able to include members of the family and key members of the multi-disciplinary team



Child and
Young Person's
Advance Care Plan

Changes in our child's condition led to initial discussions

- a parent's perspective

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It was when we started having more contact with the team at my daughter's children's hospice that we started to think about it and have more conversations about it.

Finding the right time to initiate discussions

- a doctor's perspective

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An advance care plan tends to happen either at a crossroads that happens because of an acute event that would then prompt a conversation or otherwise we would see the introduction to a palliative care team as another opportunity.