

Advance Care Planning

Advance care planning is a process to discuss the child's and their family's values, goals and hopes and identify their future healthcare preferences. Advance care planning often takes place through a number of conversations and can be documented on specific forms but isn't necessarily legally binding. As the child or family's situation changes their preferences may also change so it is important to maintain an open dialogue with the child and their family.

What is advance care planning?

Advance care planning is a process in which:

- › the clinical team shares with the family knowledge about the child's condition, prognosis and the potential effectiveness and benefit of treatments versus the burden of various interventions
- › the child and family shares with the clinical team their values, goals and hopes, and what they think the child might experience as a benefit or a burden.

The objective of advance care planning is to determine the overall goal of medical care and the interventions that should and should not be provided. This will guide current treatment, as well as future treatment in the event of a deterioration in the child's condition.

The most important element of advance care planning is the process of reflection and information sharing. This will help families and clinicians to make the best possible decisions if a medical crisis occurs.

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Some guiding principles for advance care planning

Advance care planning is a process, not an event

Advance care planning is a dynamic and ongoing process, not an event. Parents and, where appropriate, children need time to observe, reflect, think and talk. Some need more time than others, and many need to see tangible signs of deterioration or treatment failure (e.g. physical changes, imaging or test results). It is also important to remember that preferences and opinions may change over time.

Take medical responsibility where appropriate

It is important not to present unrealistic or inappropriate interventions as a choice for the family to make. For example, if cardiopulmonary resuscitation would be ineffective at this point in the illness, this should be gently explained to the family, not framed as a decision for them to make.

Explore the parents and child's preferred role in decision making

Parents and children vary in how and when they wish to contribute to decision making. At one end of the spectrum are those who wish to take most of the responsibility; at the other end are those parents who prefer the treating team to take the lead role.

In most cases decision making is shared. It is helpful to explore what role individual parents would like to play. In most cases it is important to explicitly state that parents should not feel alone in this process.

It is OK for a child to die without an advance care plan

Some parents do not wish to make decisions ahead of time, but the opportunity should be offered if circumstances allow.

Parents do not need to sign any documents

These documents are communication tools rather than legal documents and do not need to be signed by parents.

How to talk to the child and family about advance care planning

Always start a conversation by exploring the child's and parents' understanding of the child's condition

Talk about the 'big picture' before discussing specific interventions

Explore hopes, fears and goals. Who is this child? What do they enjoy? What do they find hard? How do they experience their illness and treatment? Where do they want to be as they deteriorate?

Explore what it means for that parent to be a 'good parent'

Much of the struggle for parents centres on their wish to be a 'good parent'. They are often caught in a dilemma: should they leave no stone unturned in the search for a cure (or prolonging life) or should they focus on the child's comfort? Provide frequent reassurance that you want to provide the best care for the child and support for the family.

Consider the rational and emotional elements

Health professionals are trained to approach clinical decision making in a very rational way. Parents often approach it from a more emotional perspective.

This is not to say that clinicians don't experience emotions or that parents cannot be rational. When eliciting, understanding and responding to parents emotions is important to show compassion. Acknowledging emotions also helps parents because it's difficult for them to do any cognitive processing when they are feeling emotionally overwhelmed.

Carefully consider and define the goals of care which may change over time

The most crucial step is to establish and agree upon the overall goal of care at a given point in time. This usually falls into one of the following categories:

- › focus on sustaining life
- › primary goal is to sustain life but with some limits
- › primary goal is comfort but some interventions to sustain life are considered appropriate
- › exclusive focus on comfort.

It is advisable to share the advance care planning documents with other healthcare providers, this may include by uploading the documents to a person's My Health Record.

Advance Care Directives

An Advance Care Directive is a legal document that allows a person to make their future healthcare preferences known if they were to lose their capacity to make decisions. It will only operate when a person no longer has decision-making capacity. The law and forms for Advance Care Directives are different in each state and territory and the terminology used may vary as well (e.g. Advance Directives, Advance Health Directives). Whilst people under the age of 18 years may consent to medical treatment, in some jurisdictions they cannot complete an Advance Care Directive.

Advance Care Directives can be used to communicate **specific instructions** about particular types of medical treatment such as:

- › blood transfusions
- › artificial hydration and nutrition
- › cardio-pulmonary resuscitation
- › assisted ventilation

Advance Care Directives, as with broader advance care planning, are able to be updated if a person's preferences change at a later date.

Acknowledgement: 'Thinking Ahead. Planning care for children with life-limiting conditions'. The Royal Children's Hospital and Department of Health and Human Services Victoria. 2017. 'Advance Directives'. QUT End of Life Law in Australia. end-of-life.qut.edu.au/advance-directives