

Advance Care Planning in the Paediatric Setting: 'Thinking Ahead'

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Differences in paediatrics

- Not every child patient needs an ACP
- The decision-makers (parents) are generally present to make decisions in real time
- Children can contribute to ACP but cannot legally refuse treatment
- The needs of the parent and the needs of the child may be different
- Any ACP is a communication tool, not a legal document

- In one study, nearly half of parents had thought about withdrawal of treatment before the option was raised by the paediatrician.

Barriers to ACP in paediatrics

- Prognostic uncertainty
- High expectations in terms of 'saving children' and 'not giving up'
- Emotional response of paediatricians
 - Guilt, grief, sense of failure
- It is difficult to develop and maintain skills because (happily) child death is relatively uncommon

Current status

- ACP tends to occur very late or not at all (despite presence of life-limiting illness)
- Tick box document driving tick box conversations
 - Unable to capture discussions in evolution
- Form misconstrued as a legal document
- Conversations focus on interventions rather than values

'Thinking Ahead'

- Triggers for ACP in paediatrics
- Framework
 - Series of conversations
 - Goals of Patient Care document
- Discussion guide for paediatricians
- Companion policy document
- 'Caring Decisions' booklet/website

Clinical triggers

- Illnesses
- Illnesses+
- 'Surprise question'

'Thinking Ahead'

Step 1

- Living with a life-limiting illness

Step 2

- Current or potential future deterioration

Step 3

- Goals of Care Document

Step 4

- End-of-life care

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Step 1: Living with illness

- What do you (child)/does your child enjoy?
- What do you (child)/does your child find most difficult about their illness/treatment?
- As you think of the future:
 - What is most important?
 - What are your hopes?
 - What are your fears? What are the things that keep you awake at night?
 - What are your goals?

Step 2: Deterioration

- Describe the possible scenarios.
- Based on those scenarios, explore values, hopes and fears
- Example phrase, 'If time were shorter than we all hope ...'
 - What would be most important to your family?
 - Have you had any thoughts about where you would like to be (home, hospital, VSK)?
 - Is there anything you particularly wish to avoid?
 - Is there anything you want to do?

Step 3: Goals of Care

Step 3: Goals of Care Document*

***Must be completed by senior medical staff*:** Name _____ Date: _____

Resuscitation status has not been discussed – attempt full resuscitation
 Resuscitation status has been discussed but not completed - see notes
 Resuscitation status has been discussed and the following has been agreed

NO LIMITATION OF MEDICAL INTERVENTIONS

A LIFE SUSTAINING TREATMENT	
<input type="checkbox"/>	The primary goal of care is to assist the patient to fully recover from an acute and potentially reversible deterioration. For full resuscitation and all appropriate life-sustaining treatments → For MET calls For ICU admission

LIMITATION OF MEDICAL INTERVENTIONS

B LIFE SUSTAINING INTERVENTIONS WITH SOME LIMITATIONS	C PRIMARILY SYMPTOM MANAGEMENT & NON-BURDENSOME INTERVENTIONS
<input type="checkbox"/>	The primary goal of care is to assist the patient to fully recover from an acute and potentially reversible deterioration but with the limits defined below:
<input type="checkbox"/>	The primary goal of care is to optimise the patient's comfort, but some less burdensome life-sustaining measures may be appropriate, as defined below:

	YES	NO	NOT DISCUSSED Default to "YES"
Comfort management and symptom control (this would always be provided)			
Blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NGT insertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oral / PEG antibiotics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IV antibiotics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IV fluids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood products	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Airway suction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oxygen (via nasal prongs / mask)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non invasive ventilation (HFNP / CPAP / BiPAP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MET calls	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ICU admission	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intubation and mechanical ventilation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cardiac compressions *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inotropes *	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Central venous access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

* If patient is not for intubation and mechanical ventilation, it is not usually appropriate to offer cardiac support

D END OF LIFE CARE: MAINTAINING COMFORT & DIGNITY - See "Palliative Care Symptom Management Plan"	
<input type="checkbox"/>	The goal of care is to optimise the patient's comfort and dignity → MET calls for symptoms only <u>Not</u> for ICU admission

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*Adapted from Thomas RL, Zubair MY, Hayes B, Ashby M. Goals of care: a clinical framework for limitation of medical treatment. Med J Aust 2014; 201: 452-455

Step 4: End-of-Life Care

- Where would you hope to be at this time (e.g. home, hospital, hospice)?
- Are there any spiritual/cultural needs you would like us to know about?
- Are there any other special wishes you would like us to know about?