Advance Care Planning in the Paediatric Setting: ‘Thinking Ahead’
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
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

**A Life Sustaining Treatment**

- 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

**B Life Sustaining Interventions with Some Limitations**

- 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:

<table>
<thead>
<tr>
<th>Comfort management and symptom control (this would always be provided)</th>
<th>YES</th>
<th>NO</th>
<th>NOT DISCUSSED: Default to &quot;YES&quot;</th>
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</thead>
<tbody>
<tr>
<td>Blood tests</td>
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<tr>
<td>NGT Insertion</td>
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<td>Oral / PEG antibiotics</td>
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<td>IV Antibiotics</td>
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<td>IV fluids</td>
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<td>Blood products</td>
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<td>Airway suction</td>
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<td>Oxygen (via nasal prongs / mask)</td>
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<tr>
<td>Non invasive ventilation (NIVP) / CPAP / BIPAP</td>
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<td>MET calls</td>
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<td>ICU admission</td>
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<tr>
<td>Intubation and mechanical ventilation</td>
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<td>Cardiac compressions*</td>
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<tr>
<td>Intravenous access</td>
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<td>Central venous access</td>
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* If patient is not for intubation and mechanical ventilation, it is not usually appropriate to offer cardiac support

**C Primarily Symptom Management & Non-Burdenome Interventions**

- 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:

**D End of Life Care: Maintaining Comfort & Dignity**

- The goal of care is to optimise the patient’s comfort and dignity — MET calls for symptoms only. Not for ICU admission

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?