

Thinking ahead framework

Planning care for children with life-limiting conditions



The Royal **Children's**
Hospital Melbourne



VICTORIA
State
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Health
and Human
Services

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Introduction

Each year, hundreds of children in the state of Victoria live with or die from life-limiting conditions (Consultative Council on Obstetric and Paediatric Mortality and Morbidity 2014).

It is possible to plan ahead for interventions that reflect the preferences of the child and their family and the recommendations of the treating team in the event of an acute deterioration. This helps to ensure these children are not subjected to burdensome medical treatments that do not offer substantial benefit. It also helps families to prepare for the future, consider priorities and plan where they would hope to be (home, hospital, hospice) when their child reaches the end of their life (Wolff, Browne and Whitehouse 2011).

Although many children with life-limiting conditions die in circumstances where their death is anticipated well in advance, conversations about what treatments the child and their family would prefer and the treating team recommend, tend to occur late in the illness course, often in the last few hours or days of the child's life (Feudtner et al. 2011; Heckford and Beringer 2014; Stark, Hynson and Forrester 2008). This can lead to unnecessary suffering for the child and distress for the parents and siblings, and may deny families choices regarding place of care (Stark, Hynson and Forrester 2008).

Advance care planning is 'a process of discussions between families and health care providers about preferences for care, treatments and goals in the context of the patient's current and anticipated future health' (Spicer et al. 2015).

It is a process in which:

- the clinical team shares with the family knowledge about the child's condition, prognosis and the potential efficacy and benefit versus the burden of various interventions
- the child and family shares with the clinical team their values, goals and hopes, and what they believe 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.

This framework is intended to assist paediatricians and other health professionals approach advance care planning. It offers:

- principles upon which to base practice
- a progressive approach to discussions
- tools to capture key information and decisions that have been made and communicate these to other healthcare providers.

It also provides case examples.

Resources for advance care planning in the paediatric setting

This document is part of a suite of resources. It is intended for use in conjunction with:

Thinking ahead policy: Planning care for children with life-limiting conditions

This is a companion document for the Victorian Government policy, *Advance care planning: have the conversation; A strategy for Victorian health services 2014–2018*.

It discusses the ethical and practical aspects of advance care planning in the paediatric setting and provides an approach to decision making.

Thinking ahead discussion guide: Planning care for children with life-limiting conditions

This guide is intended to help paediatricians and other clinicians approach advance care planning by offering ways of framing the discussion and examples of phrases that can be used.



Principles

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. While they currently don't have the force of a legally executed instrument in Victoria, a doctor is less vulnerable from a legal perspective if they can document they have considered the values and preferences of the child and their family when making medical treatment decisions. If the Victorian Government's Medical Treatment Planning and Decisions Bill 2016 is passed, it will take effect after March 2018 and will clarify this matter significantly by giving legal effect to advance care plans.

Normalise advance care planning as part of the care of children with life-limiting conditions

Take medical responsibility where appropriate

- It is important not to present unrealistic or inappropriate interventions as a choice for the family to make. If for example, 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 child/parents' preferred role in decision making

- Parents and children vary in the extent to which 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, and in most cases it is important to explicitly state that parents should not feel alone in this process.

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, and some need more time than others. Many need to see tangible signs of deterioration or treatment failure (for example, physical changes, imaging or test results). Preferences and opinions may change over time.

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

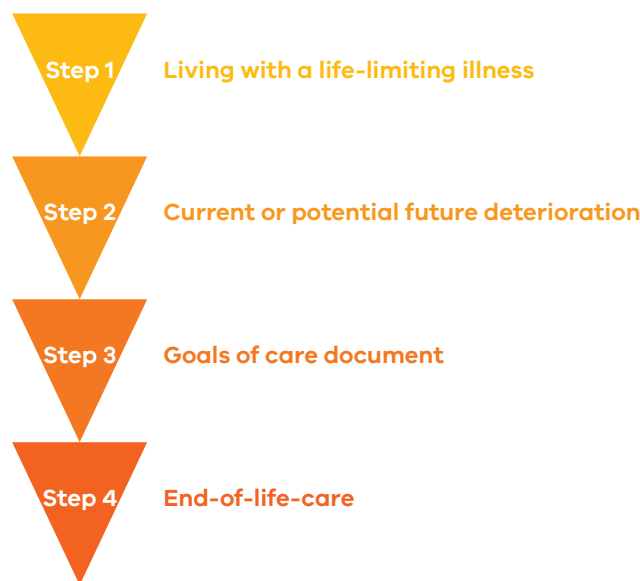
- Health professionals are trained to approach clinical decision making in a very rational way. Parents often approach it from a more emotional perspective. This is not to say that clinicians don't experience emotions or that parents cannot be rational. Eliciting, understanding and responding to parents' 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 (these 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.

Thinking ahead – an approach

Advance care planning unfolds over time. Even in the most acute situations, the conversation should not begin with a discussion about specific interventions. It should begin by talking about what the family understands about the situation, what is important to them, what their hopes and goals are, and what their fears are. The *Thinking ahead framework* provides a four step approach to conversations.



Each party brings their own expertise. The child and parent bring particular knowledge of their values and priorities, and the treating team brings knowledge about the diagnosis, prognosis and possible treatments. The treating team should then provide guidance based on the clinical situation and the child's and family's values and goals.

The goals of care document is one component of the advance care planning discussion. It is not a statutory legal document and it does not need to be signed by parents. It is a communication tool that captures any decisions that have been made regarding medical treatments that should or should not be provided.

It is the discussion with family members, clinicians and significant others that is the important element. People may choose not to complete a document, however, putting decisions in writing strengthens the process.

It is important not to treat advance care planning as a form-filling exercise with parents. Rather, explain that decisions will be documented based on the discussion so that other staff can find critical information quickly in the event of an acute deterioration.

Some parents may wish to see and keep a copy of the goals of care document, others will not.

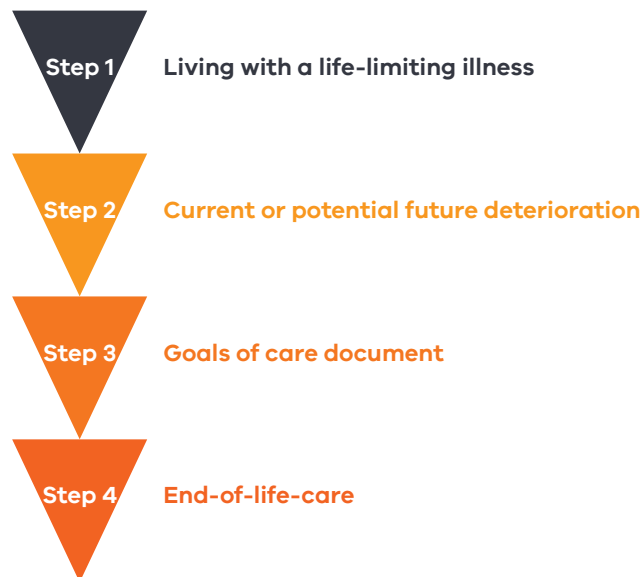


Medical, nursing and allied health staff can discuss and document Steps 1, 2 and 4. Step 3 should only be completed by senior medical staff.

The suggested prompts are just a guide. You don't have to ask all the questions. They are designed to include parents and children where appropriate. Even young children can provide insights into their goals for their care, their hopes and fears as well as things they find hard and things they enjoy. These insights can help the adults in their lives make the best possible decisions.

It may not always be possible to complete a goals of care document before an acute deterioration occurs. Information gathered from discussions based on the *Thinking ahead framework* Steps 1 and 2 will still be helpful to staff dealing with such an event.

First discussion: living with a life-limiting illness



Discuss values and goals

When: After diagnosis of a life-limiting illness or during a stable phase (see Appendix 2).

Who: Doctors, nursing or allied health staff with the child (where appropriate) and the family.

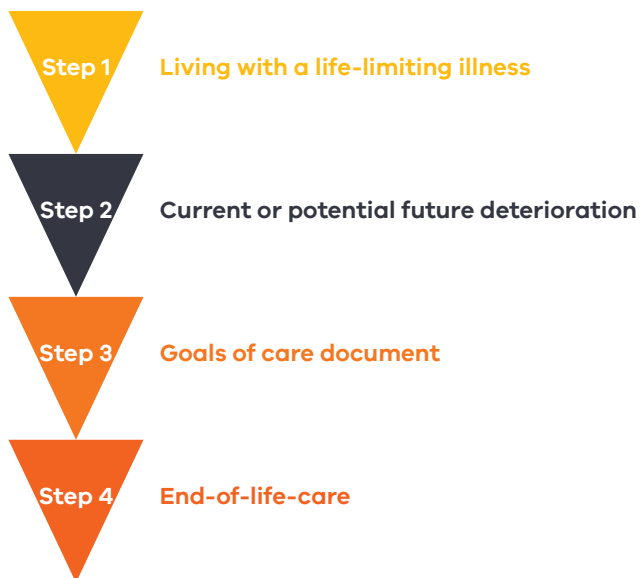
Use the discussion tool to clarify your understanding of the values and goals of the child (where possible and appropriate) and the family.

The purpose of this step is to build a solid foundation for future decision making and to assist the family in their own thinking about what is important to them. (Appendix 1 contains a tool for recording this conversation.)

The questions you may wish to ask are:

- What do you (or does your child) enjoy?
- What do you (or does your child) find most difficult about their illness and 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?

Second discussion: current or potential future deterioration



Discuss possible scenarios, hopes and fears

When: Where there is a risk of sudden, acute deterioration (see Appendix 3).

Who: Doctors should describe potential clinical scenarios to the family. Doctors, nursing or allied health staff can help explore the child's and family's values, priorities, hopes and fears.

This discussion uses your understanding of the values and goals of the child and the family to explore their hopes and fears as they apply in possible future scenarios.

The purpose of this step is to start the family and the child, where appropriate, thinking about future decisions. (Appendix 1 contains a tool for recording this conversation.)

Describe the possible scenarios. Based on those scenarios, explore values, hopes and fears.

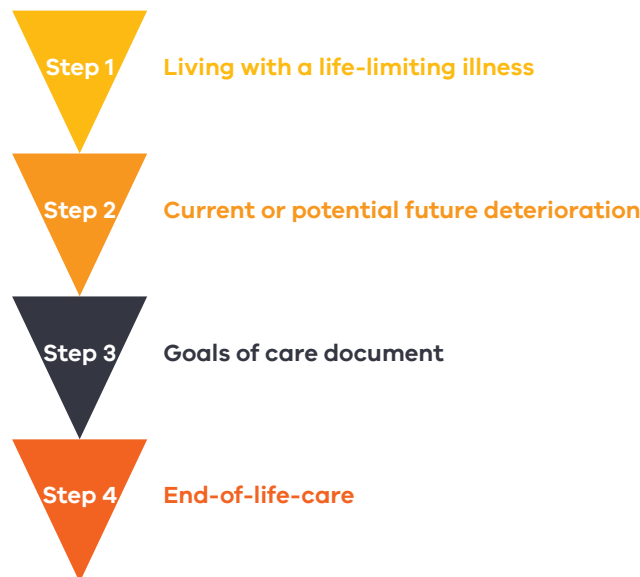
Example phrases:

'If time were shorter than we all hope ...' or 'if it looked like (child) was approaching the end of their life ...'

- What would be most important to you and (child)?
- Have you had any thoughts about where you would like to be — home, hospital, hospice?
- Is there anything you particularly wish to avoid?
- Is there anything you would want to do?

Depending on how the conversation progresses, you may or may not feel it appropriate to progress straight to step 3.

Third discussion: goals of care



Discuss, decide upon and document goals of care¹

When: If there is current or potential for acute deterioration, or if the child is actively dying (see Appendix 3).

Who: Senior medical staff with the child, where appropriate, and family.

This discussion builds on the understanding of the values and goals of the child and the family discovered in steps 1 and 2.

The purpose is to document agreed goals of care and decisions made about specific interventions. (A tool for recording this conversation can be found in Appendix 1.)

Define the overall goal of care with the family. 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 (complete step 4).

Considering the family's values and goals, decide with key members of the treating team what recommendations will be provided to the family about specific interventions.

¹ Adapted from Thomas RL, Zubair MY, Hayes B and Ashby M 2014, 'Goals of care: a clinical framework for limitation of medical treatment', *Med J Aust*, vol. 201, pp. 452–55



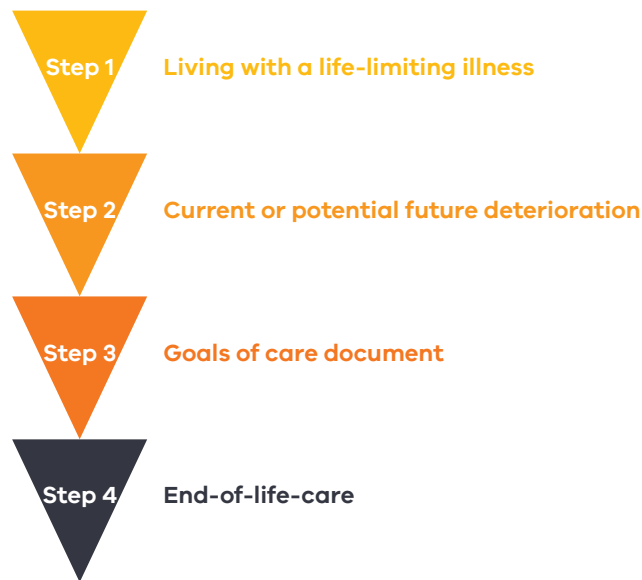
The goals of care is not a statutory legal document and it does not need to be signed by parents. It is a communication tool that captures any decisions that have been made regarding medical treatments that should or should not be provided.

It is important not to treat this process as a form-filling exercise with parents. Rather, explain that decisions will be documented based on this discussion so that other staff can find critical information quickly in the event of an acute deterioration.

Some parents may wish to see and keep a copy of the goals of care document. Others will not.

The goals of care document may need to be updated over time as the clinical situation changes and the child's and family's goals and views change in response.

Fourth discussion: end-of-life care



Discuss end-of-life care

When: If a child is actively dying and the primary goal of care is to optimise comfort.

Who: Doctors, nursing or allied health staff with the child, where appropriate, and the family.

The purpose of this step is to understand how to prepare for the final stage of the child's care. (Appendix 1 contains a tool for recording this conversation.)

Questions you may wish to ask are:

- Where would you hope to be at this time? (For example, 'Some families have a very strong wish to be at home. Others think they would feel safest in a hospital or hospice'.)
- Is there anywhere that you would hope not to be? (For example, 'Some parents worry that it might happen in an ambulance, emergency department, intensive care unit'.)
- Are there any spiritual or cultural needs you would like us to know about?
- Are there any other special wishes you would like us to know about?

Timing of steps

Advance care planning unfolds over time.

Even in the most acute situations, the conversation should not begin with a discussion about specific interventions.

Step 1: Living with a life-limiting illness

These discussions should occur soon after diagnosis of a life-limiting condition, or during a stable phase (see Appendix 2 for a list of life-limiting conditions where at least step 1 of advance care planning is recommended).

Step 2: Current or potential future deterioration

This builds on step 1. It should occur where there is deterioration or risk of sudden, acute deterioration (see Appendix 3 for recommended triggers).

Step 3: The goals of care document

This builds on steps 1 and 2. It should be completed if there is a significant risk of sudden, acute deterioration (see Appendix 3 for recommended triggers).

Step 4: End-of-life care

This should occur if the child is clearly dying and the primary goal of care is comfort.



Appropriate levels of advance care planning

The level of advance care planning required will depend on the extent to which a child's illness has progressed and are outlined in Table 1 below.

Some children/parents may wish to complete all steps, even at an early stage in their illness (see case example 2). Others may not wish to complete any steps.

Table 1: Advance care planning stages and illness trajectory.

Stage of life-limiting illness	Minimum level to be offered	Goals of care discussion (step 3) offered
Early stage of illness/diagnosis of life-limiting condition	Step 1	Optional
Stable phase	Step 1	Optional
Slow deterioration, some risk of sudden deterioration	Steps 1+2	Recommended
Significant risk of sudden, acute deterioration	Steps 1+2+3	Essential
Acutely unwell	Steps 1+2+3	Essential
Dying	Steps 1+2+3+4	Essential

Case examples

Example 1: Life-limiting illness unfolds over months to years

This example illustrates how advance care planning can unfold over time.

Step 1: Goals and values, hopes and fears: living with a life-limiting condition

Rose is nine years old and has the most severe form of cerebral palsy.

She requires a wheelchair for mobility, a gastrostomy for feeding and is dependent on others for all her care. She is not able to communicate verbally but can express joy and pain. Rose suffers severe seizures from time to time despite anticonvulsant medication. She attends a special development school. She has an evolving scoliosis.

Rose's paediatrician has the following discussion with the parents.

- What does Rose enjoy?
- What does she find difficult?
- As they think of the future:
 - What is most important?
 - What are their hopes?
 - What are their fears?
 - What are their goals?

She records this discussion in the document provided.

Step 2: Goals and values, hopes and fears – potential future deterioration

Rose has required a couple of admissions recently for pneumonia. She was quite unwell during the last admission and needed non-invasive ventilation. She found this distressing and it took her a few weeks to recover. She now requires suction at home to manage oral secretions.

Rose's paediatrician reflects on recent events with the family. She tells them she is worried that Rose is becoming increasingly vulnerable to respiratory tract infections and that children at this stage of their illness are at risk of becoming seriously unwell. She says that she noticed how difficult the last admission was and tells them it is important they think together about how to best care for Rose through a similar illness in the future.

She says,

'I know these are hard things to think about but if Rose was to become very unwell again ...

- What would be most important to you and Rose?
- Have you had any thoughts about where you would want to be (home, hospital, hospice) if it looked like time were short?
- Is there anything in particular you wish to avoid?

Rose's parents say that they are aware of her deterioration and when it is clear she is dying, they don't want to 'prolong the inevitable'. They hope to care for her at home at the end of her life. However, they feel that overall, her quality of life is currently good and, for now, they want to provide her with a reasonable opportunity to recover from this acute illness.

There is a discussion about levels of ventilatory support and the parents say they don't want Rose to be intubated but are unsure about BiPAP (a form of non-invasive ventilation) and will need guidance about that at the time.

This discussion is documented and the paediatrician explains that she will also complete a 'Goals of patient care form'.

She tells them this is simply to let colleagues know where she and the family are up to in their thinking, and that it is not a legally binding document.

She also makes a referral to palliative care, explaining that this team can provide important supports and that they often help with care for patients where the future is uncertain.

Step 3: Goals of care document.

The goal of care decided on is indicated as 'B: Life-sustaining interventions but with some limitations'. Rose is not to be intubated and she should not receive cardiac compression or inotropes.

Rose struggles at home for two months with increasing suction requirements. She is tired and shows little interest in things that normally bring her pleasure. She has not been back to school. She presents to the emergency department with probable aspiration pneumonia and is in significant respiratory distress.

The emergency department physician talks to the family about Rose's condition and tells them he understands from the documents he has read that they are eager to give Rose an opportunity to recover, but they don't want to burden her too much with interventions that might cause her distress. They confirm this and tell him the last two months have been very difficult for Rose.

The emergency department physician, the admitting unit and the family agree they will trial BiPAP and intravenous antibiotics for 48 hours. If Rose finds BiPAP distressing or is not showing signs of recovery after this period, the parents want to discuss the possibility of taking her home.

Step 4: Values and goals: end-of-life care

Two days after admission it is clear Rose is deteriorating and that she is really struggling with BiPAP.

The parents say they don't know what to do. Rose's paediatrician reviews with the parents the conversations they have had over time: how Rose loved school but can no longer attend, how they wanted to avoid unnecessary suffering at the end of her life, and how they hoped to be at home.

She says that based on this, it is her opinion that BiPAP should be stopped and the focus should now be exclusively on comfort. The parents agree and the goals of care document is changed to reflect the new goal. Arrangements are made for Rose to be cared for at home.

Example 2: Life-limiting illness unfolds over weeks to months

This example illustrates how all steps may be completed together if the clinical situation dictates or the opportunity arises (for example, the conversation progresses quickly).

Step 1: Goals and values, hopes and fears – living with a life-limiting condition

Charlie is four months old and has spinal muscular atrophy type 1. He is already very weak and struggling to feed. It is thought that he only has a few months to live. The neuromuscular treating team talk to the parents and explain Charlie's illness and prognosis and the different approaches to managing his condition.

At an outpatient appointment a couple of weeks after the diagnosis, the nurse coordinator asks the family if they have had a chance to reflect on their hopes and fears, and their overall goals for Charlie's care. The parents say they hope he will be comfortable as his condition unfolds. They are fearful of seeing him gasping for breath as he deteriorates.

The nurse asks if it would be OK to discuss how deteriorating respiratory function and distress would be managed. At their request, she briefs the neurologist and asks him to join them.

Step 2: Goals and values – future deterioration

There is a discussion about what is most important to the family, where they would want to care for Charlie and anything they especially want to avoid. The parents say that comfort is the most important thing and they want to avoid hospital as much as possible. They do not want Charlie to struggle for breath.

Step 3: Goals of care document

The neurologist explains that every effort will be made to ensure Charlie's comfort and that a goals of care document will be completed so that any health professional involved in care will know what the goal is and what interventions are appropriate and what interventions are not. Together they decide on care as indicated by 'C: Primarily symptom management with some non-burdensome interventions'. The paediatrician explains that he will communicate that cardiopulmonary resuscitation, ventilatory support and intravenous antibiotics are not consistent with Charlie's goals of care.

Given Charlie is alert and hungry, naso-gastric tube feeds are currently appropriate, although the rate may need adjusting according to the volume Charlie can tolerate.

Oxygen may or may not be helpful. If trialled, the goal will not be to achieve a particular oxygen saturation but to see if it eases Charlie's respiratory difficulty.

Step 4: Goals and values – end-of-life care

A referral is made to the palliative care team who visit at home later that week and work through step 4 with the family, just in case Charlie deteriorates very quickly.

Appendix 1: Tools for documenting discussions/decisions

Step 1: Living with life-limiting 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?
Any other important information from this discussion? For example, what role in decision making would the child or parent prefer to take?
Name of health professional documenting discussion:
Date:

Step 2: Current or potential future acute deterioration

Medical staff to describe to the family possible scenarios

Example phrase:

'If time were shorter than we all hope ...' or 'If it looked like (child) was approaching the end of his life...'

What would be most important to you and (child)?

Have you had any thoughts about where you would like to be (home, hospital, hospice)?

Is there anything you particularly wish to avoid?

Is there anything important you would want to do?

Any other important information from this discussion?

Name of health professional documenting discussion:

Date:

Step 3: Goals of patient care summary*

Must be completed by senior medical staff

Name	Date		
<input type="checkbox"/>	Resuscitation status has not been discussed with the family — attempt full resuscitation if appropriate		
<input type="checkbox"/>	Resuscitation status is currently being discussed — see notes		
<input type="checkbox"/>	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 and 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 are always to be provided	<input type="checkbox"/>	N/A	<input type="checkbox"/>
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"/>
Low-flow oxygen (via nasal prongs / mask)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
High-flow oxygen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bag and mask ventilation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-invasive ventilation (CPAP / BiPAP)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MET/Code Blue 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"/>
Intraosseous needle insertion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>*If patient is not for intubation and mechanical ventilation, it is not usually appropriate to offer cardiac support</i>			
D. End of life care: maintaining comfort and dignity			
<input type="checkbox"/>	<p>The goal of care is to optimise the patient's comfort and dignity.</p> <p>Consider referral to the palliative care team to obtain a symptom management plan.</p> <p>→ MET calls for uncontrolled symptoms/support for nursing staff only</p> <p>Not for ICU admission</p>		
This goals of care document has been rescinded on date		and no longer applies.	
Signed:		Name:	

Step 4: End-of-life care: discussion

Where would you hope to be when (child) reaches the end of his life?

For example:

'Some families have a very strong wish to be at home. Others feel safest in a hospital or hospice.'

Is there anywhere that you would hope not to be?

For example:

'Some parents worry that it might happen in an ambulance, emergency department or intensive care unit.'

Are there any spiritual/cultural needs you would like us to be aware of?

Are there any other special wishes you would like us to be aware of?

Any other important information from this discussion?

Name of health professional documenting discussion:

Date:

Appendix 2: Suggested triggers to commence Step 1 of ACP discussion

These are suggested conditions that should trigger the **commencement** of advance care planning with children and families (Step 1). Please see Appendix 3 for suggested triggers to **progress** the discussion to steps 2 and 3.

General

Any child or family who expresses a desire to discuss advance care planning.

Malignant

- Malignant disease with inevitable fatal outcome (for example diffuse intrinsic pontine glioma)
- Actively progressing metastatic disease
- Malignant disease with progression on best therapy
- Relapsed malignant disease
- Malignant disease with predicted outcome \leq 40 per cent survival with best treatment
- High-risk bone marrow transplant

Respiratory

Compromised respiratory status and:

- child with cystic fibrosis considering lung transplant/at the time of transplant
- child with cystic fibrosis with forced expiratory volume in 1 second (FEV1) <30 per cent predicted for age
- child with cystic fibrosis with ventilator dependence or those ineligible for lung transplant
- bronchiolitis obliterans
- central hypoventilation syndromes
- patients who are chronically ventilator dependent.

Genetic

- Trisomy 18, 13
- Potter syndrome
- Epidermolysis bullosa (junctional)
- Osteogenesis imperfecta type 3/4
- Other rare chromosomal anomalies with likely poor prognosis



Neurological / neurodegenerative / neuromuscular/ neurodevelopmental

- Progressive neurodegenerative conditions
- Duchenne muscular dystrophy
- Spinal muscular atrophy type 1
- Severe brain injury secondary to trauma, anoxia or infection
- Persistent vegetative state
- Batten disease
- Metachromatic leukodystrophy/adrenoleukodystrophy
- Brain malformations including anencephaly, hydranencephaly, lissencephaly and severe schizencephaly
- Static encephalopathies, including cerebral palsy, with progressive complications (for example, recurrent respiratory tract infections, scoliosis)
- Severe infantile encephalopathies
- Rett syndrome

Metabolic

- Krabbe disease
- Hunter syndrome
- Hurler syndrome
- Niemann-Pick disease
- Menkes syndrome
- Infantile Pompe disease
- Sanfilippo syndrome
- Tay-Sach disease
- Fabry disease
- Sandhoff disease
- Severe mitochondrial disorders
- Severe metabolic disorders for which bone marrow transplant is a therapeutic consideration

Renal

- Neonatal polycystic or severe structural renal disease
- Neonatal oligo/anuric renal failure
- Renal failure with complex comorbidities or other life-limiting conditions

Gastrointestinal

- Short gut syndrome without prospect of curative therapy
- Biliary atresia without prospect of curative therapy
- Multi-visceral organ failure
- Feeding tube under consideration for any progressive or severely disabling neurological condition with no expectation of improvement

Neonatal

- Extreme prematurity with concomitant severe complications such as bronchopulmonary dysplasia, grade IV intraventricular haemorrhage, periventricular leukomalacia.
- Hypoxic-ischemic encephalopathy (moderate to severe)
- Prematurity complicated by major congenital malformations

Antenatal

- Any antenatally diagnosed condition likely to be incompatible with life
- Any antenatally diagnosed condition likely to result in a significantly shortened lifespan

Cardiac

- Advanced heart failure symptoms attributable to congenital or acquired cardiac disease
- Cardiomyopathy (acquired, dilated, restrictive or hypertrophic)
- Failing single ventricle physiology:
 - hypoplastic pulmonary arteries
 - single ventricle failure
 - plastic bronchitis
 - protein-losing enteropathy
- Severe primary or idiopathic pulmonary hypertension
- Multiple or end-stage secondary organ failure following cardiac interventions
- Combination of cardiac diagnosis and underlying life-limiting neurologic/ chromosomal diagnosis

Appendix 3: Suggested triggers to progress to steps 2 and 3

Ask yourself, 'Would I be surprised if this child died within a year?' If the answer is 'no' [I would not be surprised], consider progressing to steps 2 and 3.

Child or parents wish to progress advance care planning discussions.

Life-limiting condition and any of the below:

- family or staff recognise deteriorating patient condition
- conflict between parents and clinical team regarding use of life-sustaining medical therapy
- three or more unplanned hospital admissions in the past 12 months
- prolonged unplanned hospital admission > 3 weeks
- intensive care unit stay \geq 1 week
- multi-organ failure
- severe infectious disease
- initiation of palliative therapy
- palliative therapy **and** new/progressing symptoms
- participation in phase 1 trial
- increasing difficulty controlling symptoms
- prolonged or failed attempts to wean off invasive ventilation
- escalating non-invasive ventilation requirements
- under consideration for transplant (solid organ or bone marrow).



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