



Thinking ahead policy

Planning care for children with life-limiting conditions

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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 in the paediatric setting has particular challenges (Horridge 2015; Lotz et al. 2015). It is obviously a highly emotive subject for both families and health professionals, as no one wants to contemplate or discuss the possible death of a child. Like any difficult task, those involved may find ways of delaying these conversations, or avoiding them altogether.

Unfortunately, avoidance is not without negative consequences. It denies children and families the opportunity to voice an opinion about the care they really want to receive and where they want that care provided, and it may mean they do not have the chance to say and do things that are important to them.

There is evidence that helping parents understand their child's prognosis and emotionally and practically prepare for their child's death reduces the likelihood of complicated grief (Lotz et al. 2015; Meert, Thurston and Thomas 2001).

This companion document for *Advance care planning: have the conversation – a strategy for Victorian health services 2014–2018* (Department of Health 2014) seeks to:

- define advance care planning as it applies in the paediatric setting (that is, for persons under the age of 18 years)
- outline how advance care planning is different in the paediatric setting, including the ethical and current legal considerations
- provide a framework for advance care planning in the paediatric setting (the *Thinking ahead framework*) including:
 - a set of triggers for advance care planning
 - a flowchart outlining a recommended approach
 - a series of documents to capture discussions and decisions
 - a discussion guide to assist paediatric health providers discuss advance care planning with families



- describe the use of advance care planning in clinical care
- outline a recommended approach to the implementation of advance care planning in tertiary paediatric centres.

The overall objectives of advance care planning in the paediatric setting are to:

- ensure the opportunity to think about and discuss goals of care is offered to the right children and their families at the right time
- provide health professionals with the skills and knowledge they need to ensure these discussions occur in a timely, effective and compassionate way
- ensure discussions and any decisions made are documented and communicated to relevant services and health professionals
- enable those who respond to any acute deterioration in the child's condition to manage the situation in a way that reflects the goals of care.

The primary audience for this companion document is:

- publicly funded paediatric health services
- rural, regional and metropolitan health services who provide care for children
- paediatricians
- paediatric nursing and allied health workers
- general practitioners
- children's hospices and respite facilities
- ambulance services.

As health services operate within the broader health and social service systems, the directions and actions outlined in this document are also relevant to a range of other service providers (for example, schools).

Policy context

United Nations Convention on the Rights of the Child (United Nations 1989)

Australia ratified the Convention in 1990 and therefore has a duty to ensure all children enjoy the rights set out within it. Of particular relevance to advance care planning are:

- Article 3, which states that 'in all actions concerning children ... their best interests shall be a primary consideration'
- Article 12, which states that 'a child who is capable of forming his/her view has the right to express those views freely on all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'
- Article 13, which states that the child should have the 'freedom to seek, receive and impart information and ideas of all kinds'.

Advance care planning: have the conversation; A strategy for Victorian health services 2014–2018 (Department of Health 2014)

Aims to ensure all Victorians accessing health services will have opportunities to express their preferences for future treatment and care through advance care planning. The strategy acknowledges but does not specifically address the issue of advance care planning in paediatrics.

National framework for advance care directives (Australian Health Ministers' Advisory Council 2011)

This framework does not make provision for children.

Medical Treatment Act 1988

This act does not make provision for children.

Guardianship and Administration Act 1986

This act does not make provision for children.

Medical Treatment Planning and Decisions Bill 2016

The Victorian Government introduced legislation to Parliament in September 2016, which if passed will take effect after March 2018. This will provide greater clarity regarding the legal status of advance care plans. Importantly, the Bill clarifies that a child who has decision-making capacity can make their own medical treatment decisions or execute an advance care directive which will apply as a legal document in the event they do not have capacity at a future time. It is already recognised that if a child has capacity they should be able to make some of their own medical treatment decisions. While the proposed Bill does not yet affect the current legal landscape regarding these issues, unless and until it commences, health professionals should make themselves aware of its proposed effect.



Strengthening care for children with a life-threatening condition 2008–2015

(Department of Health 2008)

This policy aims to ensure Victorian children with life-limiting conditions have access to high-quality palliative care. Principle 1, Information and Decision Making, highlights the importance of including children and families in decision making.

‘Children with a life-threatening condition and their families have information about options for their future care and are actively and appropriately involved in those decisions.’

The expected outcomes are:

- Children and their families are consulted about who is informed about their care and who makes decisions about their care.
- Children are informed about and involved in making decisions about their care as appropriate to their age and developmental stage.
- Families of children with a life-threatening condition are informed about and involved in decision making about their child’s care.
- The unique needs of a child with a life-threatening condition and their families are addressed through developing and implementing an agreed plan.’

Advance care planning in the paediatric setting

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.

Discussions are had with parents or legal guardians and the child to the extent that the child's developmental level, physical condition and willingness permits. The United Nations Convention on the Rights of the Child states that 'a child who is capable of forming his or her view has the right to express those views freely on all matters affecting the child' (United Nations 1989).

It is possible for even very young children to provide valuable insights into how they experience certain treatments. This can be very helpful in guiding the decision-making process, as parents and health professionals may not always be aware of how painful or frightening interventions can be for a particular child. It may be that something can be done to ease the burdens of treatment or it may be that the child's views sway the decision away from providing particular interventions.

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.

In most cases these are discussions that evolve and progress over time. It is always important to document the key points that have been covered in the discussions and sometimes it is possible to document decisions that have been made. Various forms of documentation are available. In the *Thinking ahead framework*, the document in which decisions are recorded is referred to as a '*Goals of patient care summary*'.

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

There is a delicate balance to be found however. Families need to be given the opportunity to participate in decision making, but these are difficult conversations and it is important that efforts to undertake advance care planning do not become intrusive and traumatic.

The importance of advance care planning in the paediatric setting

'In this extraordinary world of medical miracles, one thing has not changed; the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child?'

– Hilary Cass, President Royal College of Paediatrics and Child Health, United Kingdom (Larcher et al. 2014)

Research conducted in Victoria and internationally indicates that although children with life-limiting conditions often die in circumstances where their death can be anticipated well in advance, conversations about what treatments are and are not in their best interest tend to occur late in the illness course, often in the last few hours or days (Stark, Hynson and Forrester 2008).

This may lead to unnecessary suffering, and it potentially denies families choices regarding place of care. For example, when children die it tends to be in situations of high acuity, often in an intensive care unit (Ramnarayan et al. 2007).

Given that many of these children suffer from life-limiting conditions, it seems reasonable to expect there to be opportunities to consider the best approach to managing an acute deterioration ahead of time. Parents are troubled long into bereavement as a result of their child experiencing a 'difficult moment of death' (Kreicbergs et al. 2004; Surkan et al. 2006).

By preparing families and establishing clear goals of care, advance care planning can help to reduce distress for both the child and their family.

Advance care planning is becoming increasingly important as technological advances see more children survive with chronic and complex medical conditions. The lives of these children can be sustained at home with interventions such as non-invasive ventilation, and in hospital with more invasive treatments. The benefits and burdens of these interventions require careful consideration in light of the child's changing condition and the goals and values of the child and their family.

The Canadian Paediatric Society has published a position statement which asserts that 'advance care planning is part of the standard of care for paediatricians and other health care practitioners involved in the care of paediatric patients with chronic life-threatening conditions. It is our responsibility to initiate these discussions rather than wait for patients and family members to ask' (Canadian Paediatric Society 2008). The Royal College of Paediatrics and Child Health, the American Academy of Pediatrics, the British Medical Association and the Royal Australasian College of Paediatrics have all published position statements, policies and frameworks to guide practice in this area (Larcher et al. 2014; American Academy of Pediatrics Committee on Bioethics 1994; Royal Australasian College of Physicians 2008; British Medical Association 2007).

An essential element of paediatric advance care planning is consideration of the child's voice (Pousset et al. 2009). Children are often excluded from discussions about their illness and treatment in an effort to protect them from distressing information (Bluebond-Langner 1989; Hilden, Watterson and Chrastek 2000). In some cases this is entirely appropriate, in others it is not, and results in decisions being made without crucial information about how the child feels.



The parents' involvement is also crucial. In the same way that parents protect children from difficult conversations, paediatricians may protect parents. Up to half of all parents have considered the withdrawal of treatment before their child's paediatrician raises the possibility (Meyer et al. 2002). As difficult as it is, parents would like their child's medical team to enable them to make decisions about their child's care (Wharton et al. 1996; Sullivan, Monagle and Gillam 2014; Hammes et al. 2005).

From a policy perspective, advance care planning is a key element of the Victorian state government's policy, *Strengthening care for children with a life-threatening condition 2008–2015* (Department of Health 2008).

The aim of 'Principle 1: Information and decision-making', is that 'children with a life-threatening condition and their families have information about options for their future care and are actively and appropriately involved in those decisions.' More specifically, 'the unique needs of the child with a life-threatening condition and their families [should be] addressed through developing and implementing an agreed care plan'.

In its submission to the 2012 Senate inquiry into the provision of palliative care, the Australian and New Zealand Paediatric Palliative Care Reference Group recommended 'the development of a paediatric addendum to the National Framework for Advance Care Directives 2011'.

A considered and skilled approach to advance care planning can be expected to:

- reduce the suffering endured by children with life-limiting conditions
- increase the opportunity for families to choose non-acute settings for care
- reduce trauma for families as they are better prepared for the end-of-life phase
- enhance job satisfaction for doctors, nurses and allied health staff as a result of enhanced communication, increased clarity and a greater sense of delivering the best possible care for children.

How advance care planning is different in the paediatric setting

Advance care planning in the paediatric setting differs in a number of important ways from advance care planning in the adult setting.

One of the key differences lies in determining which children advance care planning should be offered to. It would not be appropriate to ask the families of all children who access paediatric health services to engage in advance care planning. Life-limiting conditions are relatively uncommon in childhood and the vast majority of children who access health services can be expected to survive their illness (Fraser et al. 2012).

This then raises the challenge of determining which children would benefit from advance care planning and when it should be undertaken (Lotz et al. 2015; Hain et al. 2013; Brook and Hain 2008).

There are also legal differences with regard to paediatric advance care planning. A child under the age of 18 years does not currently, clearly have the legal status to create an advance care plan. This may change with the Victorian Government's introduction of the Medical Treatment Planning and Decisions Bill 2016 which, if passed, will provide greater certainty as to the legal status and role of children with decision making capacity in advance care planning from March 2018. In the meantime it is important to solicit, consider and respect the views of children and their families.

Although parents may be present to participate in decision making at the time of an acute deterioration, the process of advance care planning remains important. Thinking in a crisis, when emotions are high, is difficult and parents and older children may have clear preferences to communicate. There may be interventions they do not want under any circumstances.

Advance care plans are particularly valuable in circumstances where the child may be in the care of extended family, carers, school or hospital staff at the time of an acute deterioration.

There are a number of other features that make paediatric advance care planning different from adult advance care planning:

- The course of many of the life-limiting illnesses that affect children are rare and can be difficult to predict (Brook and Hain 2008).
- Paediatricians, rather than general practitioners, tend to lead advance care planning in the paediatric setting due to the rarity and complexity of life-limiting illnesses affecting children.
- Advance care planning is not relevant for the vast majority of children who come into hospital, because they will recover and go on to live a full life. It is not appropriate for advance care planning to be a standard process in paediatric care in the way that it might be for older adults.

Barriers to advance care planning in the paediatric setting

In 2013, the Australian Commission on Safety and Quality in Healthcare reported that it is often much easier for health professionals to continue treatment than to talk with patients and families about the end of life (Australian Commission on Safety and Quality in Healthcare 2013).

Issues known to contribute to health professionals avoiding these conversations include systemic factors such as shortage of time or lack of appropriately private space; educational factors such as inadequate training and mentoring in the necessary communication skills; and personal factors such as fear of complaints and litigation or discomfort with talking about dying (Australian Commission on Safety and Quality in Healthcare 2013).

In addition to these, there are particular barriers to advance care planning in the paediatric setting (Forbes et al. 2008; Durall, ZuraKowski and Wolfe 2012). In developed countries such as Australia, parents and health professionals have high expectations of medicine in terms of its ability to cure disease or sustain life. As a community, we are not used to children dying and this may make it difficult to withhold or withdraw interventions.

Furthermore, many paediatricians experience feelings of grief, guilt and failure when they cannot cure a child's illness (Papadatou et al. 2002; Baverstock and Finlay 2006). These emotional responses can lead them to avoid conversations about advance care planning. Meanwhile, families may want to have these discussions, but have the sense that it is not an appropriate topic to raise.

Like their colleagues in adult medicine, paediatricians receive little training in communicating with families about advance care planning, and they face an additional challenge: the relative infrequency of childhood death makes it difficult to develop and maintain skills in this important area of practice.

The prospect of talking to a child or young person about serious illness and the possibility of death presents a great challenge. As a community and as individuals, we wish to protect children from emotional pain and distress. Well-intentioned efforts to shield children can result in their voice being absent from the decision-making process. This may, in turn, lead to them having to endure treatments they find intolerably burdensome.

Current approaches to advance care planning internationally are extremely variable and little research has been undertaken (Lotz et al. 2013; Fraser et al. 2010; Finlay et al. 2008; Weiner et al 2012). Common problems with documentation include difficulties accessing information and inadequate sharing of information between services (Beringer and Heckford 2014).

Triggers for advance care planning in the paediatric setting

It can be difficult to identify which children would benefit from an advance care planning discussion, and there is no universally accepted set of triggers (Lotz et al. 2015; Hain et al. 2013; Brook and Hain 2008). This will be an important area for future research (Hain et al. 2013).

One of the simplest indicators is known as the 'surprise question', in which the treating doctor asks him or herself, 'Would I be surprised if this child died within a year?'

If the answer is 'no [I would not be surprised]', the advance care planning process should begin (Murray and Boyd 2011; Feyi et al. 2015).

A list of specific conditions in which initiating and progressing advance care planning is recommended can be found in the *Thinking ahead framework*.



Ethical principles of decision making in the paediatric setting

'Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it the good we do can be breathtaking.'

– Atul Gawande (2014)

Advance care planning is based on the same ethical principles that underpin paediatric healthcare more generally: to promote the child's and family's values and preferences, respect the child as a developing person and respect the parents' role as protectors and decision-makers for their child. Advance care planning is a way to seek to do the right thing by children who have life-limiting conditions.

Over the last 50 years or so there have been huge advances in cancer treatment, immunisation, neonatal intensive care and a range of other interventions. Many children who would certainly have died from their illnesses decades ago are now cured and can be expected to live long lives. Some are not cured but live well with their illnesses long in to adulthood. Others struggle every day with the challenges of severe disability and chronic illness.

The same technical advances that have enabled this reduction in childhood mortality can also be used to sustain the lives of children who suffer from severe, chronic illness. In some cases this may be appropriate, but in other cases the disease may be so debilitating and the interventions so burdensome that continuing with such treatment may do more harm than good.

The core task of advance care planning is to achieve the best possible balance between the ethical principles of beneficence (doing good) and non-maleficence (avoiding harm) while reflecting the values and preferences of the child and their family. Children have a number of values, and in the context of a life-limiting medical condition, it is possible that some values may be in tension with others (for example survival, freedom from suffering).

An important part of advance care planning is to prioritise these competing values, working out what matters most for this child in this situation and determining the overall goal/s of care on that basis.

Deciding which interventions should be provided and when requires consideration of the following:

- What are the goals of care?
- What are the benefits and burdens of the proposed intervention?
- Who should decide?

What are the goals of care?

Goals of care can be viewed on a continuum. At one end is the prolongation of life, at the other comfort is the only concern. In between lies a zone where patients and families try to find a balance between prolonging life and optimising comfort.

The natural tendency in the face of an ill child is to want to save the child's life. Modern medicine has seemingly limitless options for different treatments but none are perfect. They come with side effects, have indeterminate outcomes and can increase suffering. For each of us there is a tipping point at which the benefits of treatment are insufficient to outweigh the burdens we are willing to tolerate. This point is different for all of us, and it's particularly difficult deciding where this point is for a child.

This ambiguity can lead to tension between the treating team and the family, and even between members of the treating team. Having agreement on the goals of care is crucial to minimising conflict and distress for all involved. The goals can be quite nuanced, for example the primary goal may be to prioritise comfort, but some efforts to prolong life, such as antibiotics, could be considered tolerable.

The shared understanding of the goals of care between the family and treating team can guide future interventions and ease decision making by focusing everyone's efforts on a common purpose.

For example, cardiopulmonary resuscitation would be appropriate if the agreed goal was to prolong life (and the intervention was likely to achieve that goal), but not where the primary goal was to optimise comfort.

What are the benefits and burdens of the proposed intervention?

Medical interventions should not simply be provided because they are technically possible. They should only be provided if they align with the primary goal of care and are expected to produce a net benefit to the child.

It is critical that all potential interventions are subjected to an analysis of the potential benefit versus burden. This is where the child and parent's perspective is so important, as individuals experience interventions differently. For example, some children find hospitalisation intolerable; others find it manageable or even enjoyable.

Sometimes parents and health professionals overestimate the possible benefits of medical intervention on the outcome for the child. It is important to step back and examine realistically what choices there are to make.

In some circumstances, the intervention in question has no chance of being effective. This should be gently explained to the family rather than framed as a decision. For example, the parents of a child who is clearly dying should not be asked if they want their child resuscitated. Instead, the process of dying should be compassionately explained and the parents supported to comfort their child through this.



The ethics of withdrawing and withholding interventions that sustain life

Some interventions (for example, mechanical ventilation) sustain life but come with burdens that may outweigh the benefits for a child who is approaching the end of their life. In this situation consideration needs to be given as to whether the intervention aligns with the goals of care.

It is accepted ethically and legally that life-sustaining treatments can be withheld or withdrawn if they do not provide a net benefit to the child (Larcher 2015; Canadian Paediatric Society 2008; American Academy of Pediatrics Committee on Bioethics 1994; Royal Australasian College of Physicians; British Medical Association 2007). This does not constitute euthanasia.

To withdraw an intervention is to cease treatment that has already been commenced. To withhold an intervention is to not start the treatment in the first place. In its recently published framework for practice in this area, the Royal College of Paediatrics and Child Health outlines circumstances in which it would be ethically permissible to withhold or withdraw life-sustaining treatment (Figure 1, page 14) (Larcher et al. 2015). The College is careful to say, however, that it is not obligatory to withhold or withdraw treatment under these circumstances.

It is generally accepted that no ethical or legal distinction can be made between withdrawing and withholding life-sustaining treatment. This is important, as it means there is no legal or ethical obligation to continue an intervention just because it has been started.

It is acknowledged however, that withdrawal of treatment may be more emotionally and psychologically challenging for parents and health professionals than withholding treatment (Larcher et al. 2015; American Academy of Pediatrics Committee on Bioethics 1994; British Medical Association 2007).

Figure 1: Circumstances under which life-sustaining treatment could be withheld or withdrawn.

When life is limited in quantity

This includes conditions in which treatment is unable or unlikely to prolong life significantly, or reflect the values of the child and family. These comprise:

- brain stem death, as determined by agreed professional criteria appropriately applied
- imminent death, where physiological deterioration is occurring irrespective of treatment
- inevitable death, where death is not immediately imminent but will follow and where prolongation of life by life-sustaining treatment confers no overall benefit.

When life is limited in quality

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
- where the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
- where the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

Informed competent refusal of treatment

An older child may be assessed as having capacity to competently consent to the withdrawal or withholding of life-sustaining treatment.

In these circumstances, and where the child is supported by his or her parents and by the clinical team, there is no ethical obligation to provide life-sustaining treatment.

Who should decide?

A decision that is shared between the treating team, the parents and, where appropriate, the child is the ideal. All have an important contribution to make.

The child

Many children with life-limiting conditions are too young, too disabled or too unwell to communicate, and they depend on their parents and doctors to make decisions on their behalf. There are however, some children who are able to contribute to the decision-making process.

Adolescents and even much younger children may have strong preferences about their care (Weiner et al. 2012; Lyon et al. 2009; Hinds et al. 2005). They know better than anyone what it is like for them to be unwell. They will certainly have something to say about what they enjoy, what they find difficult or frightening, what goals they have and what they are hoping for.

Their views can be extremely helpful in guiding parents and doctors in advance care planning, and they can be discussed even if the child does not know or understand their prognosis.

More mature children may undertake a greater role in advance care planning, but it is not possible to specify an age at which this should occur. The degree to which a child participates will depend on the individual child.

The United Nations Convention on the Rights of the Child places great emphasis on the child's views. Similarly, The Royal College of Paediatrics and Child Health (UK) believes 'there should be a presumption that children will be involved in decisions about treatment (including those concerned with limitation of life-sustaining treatment) wherever possible and at a level that reflects their ability, understanding and experience'.

The College outlines four ways in which health professionals can involve children:

- by providing information
- by listening and responding to their concerns
- by using techniques such as play therapy to increase the child's understanding and ability to express their views
- by using the child's views to inform actions.

From an ethical standpoint, older children may demonstrate decision-making ability by showing they understand the nature of their condition, its treatment and the consequences of their decisions. In this case, they should, if they wish, contribute significantly to decisions regarding their medical treatment.

The High Court of Australia has recognised that a young person may provide informed consent to treatment if he or she has achieved 'a sufficient understanding and maturity to fully understand what is proposed'¹

¹ *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218 (Marion's case) per Mason CJ, Dawson, Toohey and Gaudron JJ at 237–38.

The parents

Parents or a child's legal guardians² bring a crucial perspective to decision making regarding the health care of their child. They can share the family's values, as well as specific knowledge of the child and which treatments or situations they might experience as a benefit and a burden.

In thinking about goals of care, many feel torn between promoting survival and avoiding suffering.

'It is a dilemma. Because I don't want him to suffer, not for one per cent. At the same time, I want to have him with me for some more time.'

Parent (de Vos et al. 2015)

Parents will vary in the degree to which they wish to be involved and to lead decision making (Sullivan, Monagle and Gillam 2014). Some will seek guidance from or even defer to the treating team. Others feel it is their duty to take a lead role.

Parents bring to the decision making process their own understandings of illness, expected outcomes, trust of western medicine versus desire for alternative therapies, health literacy and religious and cultural beliefs. As a result their views on the best treatment for their child may not be the same as the views of the treating team. Ethically, parents are usually recognised as the decision makers for their child, but in some circumstances this role needs to be challenged by the treating team. This is of particular concern when the parents' decisions will lead to a child enduring significant suffering undergoing treatments that offer no chance of benefit.

The paediatrician

The paediatricians involved in the care of the child are also critical. They bring knowledge of the illness, the prognosis, the available treatments and the likely efficacy of those treatments.

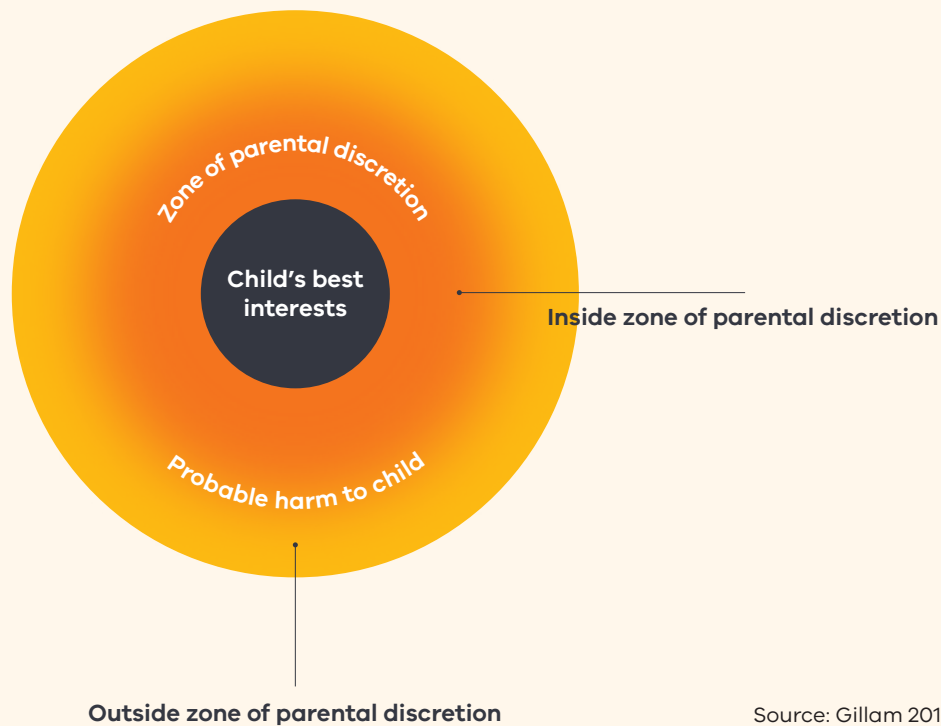
They are able to describe the benefits and burdens of treatment in general terms. Where the paediatrician has come to know the child over time, they also have specific knowledge of the child and their experience of treatment. They may also have had private conversations with the child about goals and values.

In practice

In most cases, decision making is shared between the family and the treating team, each contributing the elements outlined above. The child takes a role in this process to the extent their developmental level, ability and willingness allows.

When there is disagreement, this can usually be resolved through ongoing discussions, however, occasionally parents may insist on an intervention the treating team believes is not in the child's best interests, or request the withdrawal of a treatment the team believes is in the child's best interests.

2 For simplicity this document refers to parents as an inclusive term for parents or a child's legal guardians



It is important to first consider whether a decision is actually required. Where there is certainty that the intervention in question will not benefit the child, the treating team should compassionately explain to the family why this treatment will not be provided. In this circumstance, there is no decision for the family to make (Hayes 2013).

Where there is less certainty, a decision is required and in this situation, the concept of the 'zone of parental discretion' (Gillam 2015) may be useful. In this zone 'lie decisions where [the child's] best interests are uncertain or open to interpretation, as well as decisions that take into account the interests of siblings, parents and the family as the whole.' (Gillam 2015).

Put another way, there may be a range of different decisions that are reasonable in a given situation: the balance of benefits and burdens will be weighed differently by different individuals even given the same clinical situation. Children and their families will make decisions based on their individual values and experiences.

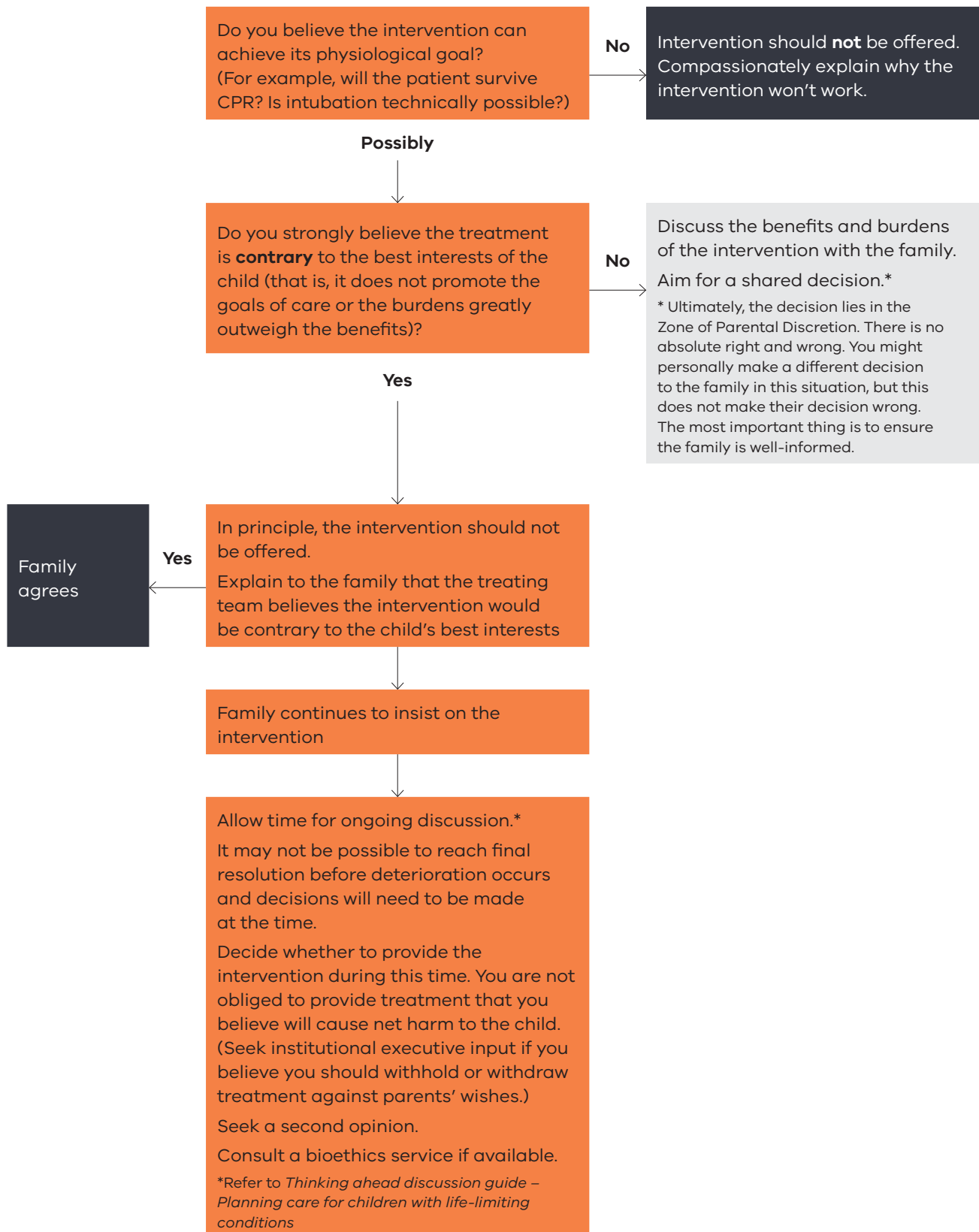
Health professionals may not always agree with these decisions but they fall within the Zone of Parental Discretion. There may be a point however, beyond which the treating team feels net harm will be done to the child if parents' wishes are followed, for example, because the chance of benefit is so small and the burdens of treatment so great.

At this point, the parents' decision falls outside the zone of parental discretion, and the treating team should not follow it. A second opinion, clinical ethics consultation or legal opinion may be necessary and institutional executive input should be sought.

Ultimately, a doctor cannot be compelled by a patient or family to provide treatment that the doctor believes would not serve the child's best interests. The seeking of a second opinion can be helpful in resolving disagreement. If an agreed treatment plan cannot be achieved in an appropriate timeframe, further discussion and clinical ethics involvement, or legal advice should be sought and it may be appropriate to seek input from the institution's executive team. (Gillam 2015).

The decision making process is outlined on Figure 2 (page 18).

Figure 2: Decision-making in practice



What advance care planning is not

As outlined in *Advance care planning: have the conversation; A strategy for Victorian health services 2014–2018*, advance care planning is not a ‘tool for ... equitable distribution of healthcare resources’ (Department of Health 2014).

Advance care planning is focused on the individual child and family and does not relate to healthcare costs.

Advance care planning is in no way related to euthanasia (Department of Health 2014). Euthanasia is ‘the act of knowingly and intentionally directly causing the death of a person ... to relieve difficult suffering’ (Department of Health 2014). Advance care planning is thinking ahead and possibly making decisions about what treatments would or would not be in the best interest of a patient if they were to suffer an acute deterioration.

Advance care plans are not immutable. They can be revised at any future time.



Advance care planning in practice: 'thinking ahead' with children and parents

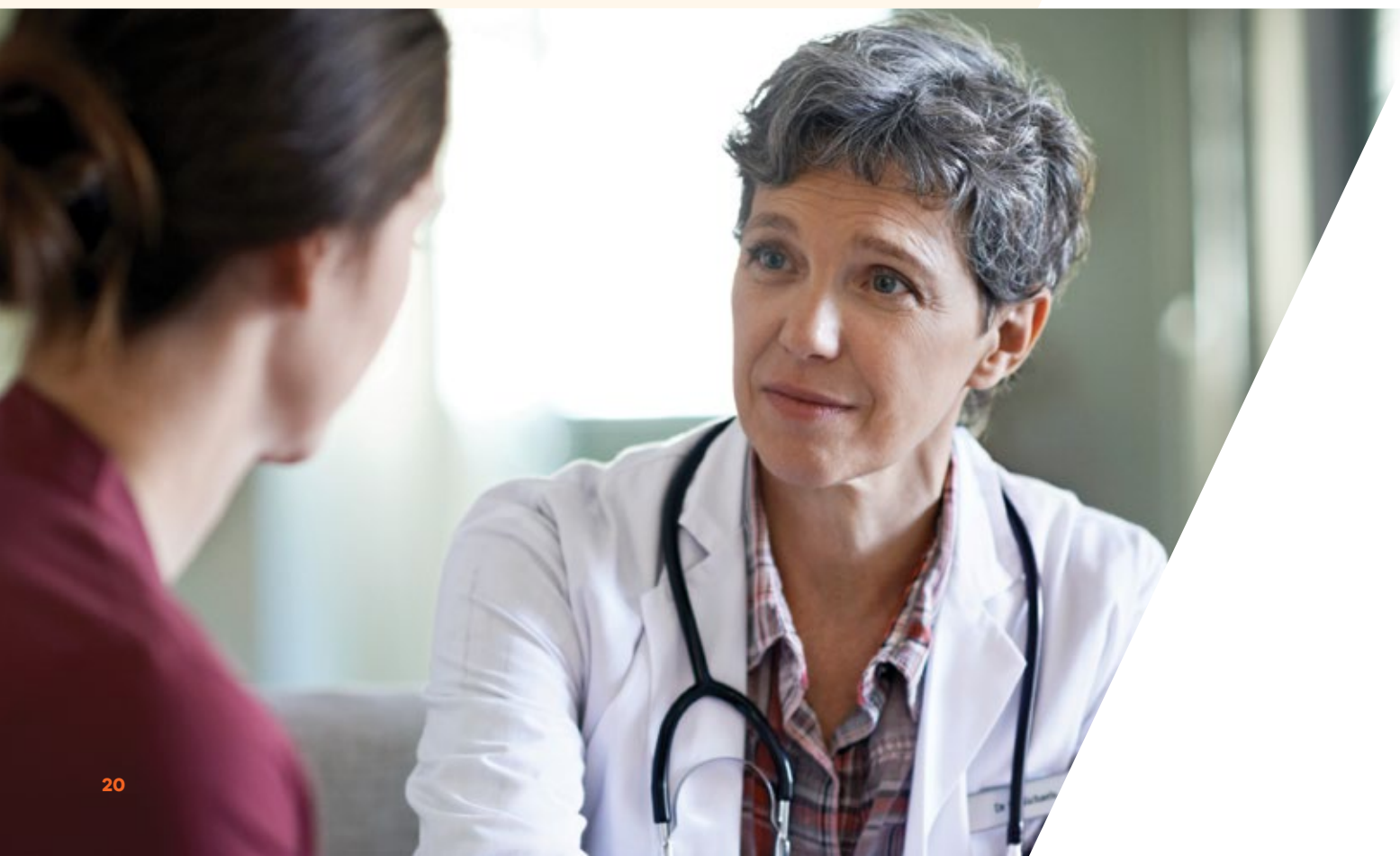
Talking with children and families about the possibility or probability of death is one of the most difficult things a doctor must do. It can arouse feelings of sadness, guilt and fear, including the fear of causing further pain to already suffering children and their families.

Like any difficult task, doctors might find themselves delaying these conversations, or avoiding them altogether. For this reason, a suite of resources called the *Thinking ahead framework* has been produced.

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.

The *Thinking ahead discussion guide* provides case examples, as well as a useful phrases to help staff frame and phrase the discussion.



The role of palliative care

It is crucial that families do not misconstrue decisions to withhold or withdraw certain medical interventions as withdrawal of care. The goal is always to provide the best possible care to the child and to help them live as well as possible within the limits imposed by their illness.

The commencement of advance care planning provides an opportunity to raise the question of whether the child should be referred to a palliative care service. Palliative care specialists may be helpful in a number of ways. They are trained in helping families think through priorities in the face of life-limiting illness and can offer a range of supports to the child and family. However, the offer of palliative care can be confronting for families.

Palliative care is often misunderstood as:

- terminal care
- giving up hope
- passive (for example, 'there's nothing more we can do')
- only for the elderly
- only for people with cancer
- euthanasia.

In fact, palliative care is for any person of any age with any condition that significantly limits their life expectancy and quality of life. It is an active, evidence-based and highly specialised area of practice.

A key message to families is that receiving support from palliative care does not mean they must forego disease-focused treatment. It is possible for palliative care to be integrated with other therapies, even those directed at a cure.

At a practical level, a palliative care service should be able to assist with:

- symptom management
- advance care planning
- supporting the sick child, parents and siblings
- providing links to supports such as a hospice (Very Special Kids) and community-based palliative care services
- providing families with information
- specialist equipment.

In Victoria, a statewide consultancy service (the Victorian Paediatric Palliative Care Program) is available to provide an additional layer of support to the child, their family and the health professionals caring for them.

Documenting advance care planning discussions and advance care plans

Advance care planning discussions generally progress over time. It is unusual for decisions to be made and a plan agreed upon after the first conversation (Wolfe et al. 2000; Wolfe et al. 2014).

It is critically important that the key elements of any advance care planning discussion are documented, even if a plan has not yet been decided. Simply knowing that the concept has been raised with the family can be very helpful for health professionals caring for a child in a crisis.

Examples of helpful information include the following:

'I raised the question of how we should approach a sudden deterioration in (child's) health with his mother today. She agreed that it was important but asked that we wait until her husband can be present. We plan to talk about it at the next outpatient appointment in six weeks.'

'(Child's) parents and I discussed what we should do in the event of a serious respiratory tract infection. At this stage, they feel that although they are tending toward prioritising her comfort, they cannot make specific decisions ahead of time. They have asked for guidance from the health professionals involved in caring for (child) when she next becomes ill.'

Documentation of advance care planning discussions may take the form of a letter or a note in the child's record. The *Thinking ahead framework* includes forms designed specifically for this purpose.

If decisions have been made about specific interventions, it is important to record them in a concise, readily identifiable and easily accessible document. Tertiary centres generally have these available. All health services in Victoria should have an advance care planning alert system to assist the treating team to quickly find the advance care planning documentation when required.

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.

The *Thinking ahead framework* includes a 'Goals of patient care summary' to help document decisions that have been made.

Documentation must be updated as discussions progress or as the child's condition changes.

Sharing advance care planning documentation

My Health Record

The most accessible place to store advance care plans is the My Health Record, available at <www.myhealthrecord.gov.au>. However, until all health services are utilising My Health Record, copies of advance care plans should be kept by parents and also stored within individual health service provider records.

Parents

Parents should be encouraged to carry a copy of the advance care plan so they can facilitate sharing it with health professionals when required. Some will find the document confronting and in these circumstances putting it in an envelope can help.

A parent who really does not want to carry a copy of the advance care plan should not be forced to do so.

If a parent does not wish to carry or distribute their child's advance care plan themselves, permission should be sought from the parent to allow the health professional to share the advance care plan with other services and facilities.

Ambulance Victoria

The Ambulance Victoria database stores patient details by address and not by name. An address is known as a Location of Interest and can be used to alert Ambulance Victoria about important patient information and helps them prepare appropriately for that patient. This facility can be used for patients who have an advance care plan in place.

To request a Location of Interest, email SPPTRequest@ambulance.vic.gov.au with the child's name, address, date of birth, contact details for the treating medical team and a copy of the advance care plan.

The child's hospital medical record

The advance care plan must be easily accessible, with a system alerting health professionals to its existence, so it is available regardless of where in the health service the child presents.

Other key health professionals and care services involved in the child's care

The advance care plan needs to be available to anyone involved in the child's care. Examples include other specialist paediatricians, the local paediatrician, local hospital, respite facilities, hospices, general practitioners, community palliative care service, and home services.

Other facilities involved in the care of the child

Examples include, schools, sporting and recreation clubs and other services providing care to children.

Using an advance care plan to guide clinical care

An advance care plan developed in the paediatric setting is a means by which the child, their family and treating team can capture their thoughts, discussions and decisions and communicate these to all the health professionals who might be involved in deciding on and offering treatment.

An advance care plan may be documented in a letter or on a dedicated form. Many tertiary centres have forms for this purpose. In the *Thinking ahead framework*, the form is referred to as a 'Goals of patient care summary'.

When parents are present

In the majority of circumstances parents will be available to assist with decision making, but they may be distressed and in need of guidance.

In this situation, the health professionals caring for the family (for example, emergency department staff, ambulance officers) can use the plan as a starting point for further discussions about the best way to care for the child.

For example:

'I can see you have been doing some thinking with Dr A. about what might be the best way to care for John if he were to become very unwell like this. Can you please tell me a little bit more about what you have been discussing?'

When parents are absent

Rarely, a child may experience a sudden, acute deterioration at school, a respite facility or even hospital while their parents are absent. In a clinical setting, the advance care plan can be used in conjunction with clinical assessment to determine the best treatment for the child until the parents can be contacted.

In a non-clinical setting an ambulance is likely to be called and the ambulance officers and other members of the treating team can be guided by the wishes expressed in the advance care plan.

Implementing advance care planning

The objectives of advance care planning implementation are to:

- ensure the opportunity to think about and discuss goals of care is offered to the right children and their families at the right time
- provide health professionals with the skills and knowledge required to ensure these discussions occur in an effective and compassionate way
- ensure discussions and any decisions made are documented and communicated to relevant services and health professionals
- enable those who respond to any acute deterioration in the child's condition to manage the situation in a way that reflects the preferences and values of the child and their family.

Achieving these objectives requires a system-wide approach.

Tertiary paediatric centres are involved in providing care at some stage to almost all children who have life-limiting conditions. Consistent with the priority action areas described in *Advance care planning: have the conversation; A strategy for Victorian health services 2014–2018* (Department of Health 2014), these centres should enable advance care planning by addressing the following priority action areas:

1. establishing robust systems (policies, governance, alerts, documentation, quality improvement)
2. ensuring an evidence-based and quality approach
3. increasing workforce capability
4. enabling children and families to think ahead.

Priority action 1: establishing systems

Successfully implementing advance care planning requires an organisation-wide approach that is multi-faceted, well supported and systematic in its approach. The following are enablers:

- creating an organisation-wide advance care planning policy that is endorsed by executive and clinical leaders
- identifying executives to actively lead the implementation of advance care planning by providing support, assisting to overcome barriers and allocating resources
- developing an implementation and communication strategy
- identifying systems for storage of advance care planning documentation
- creating alert systems for advance care plans and information pertaining to advance care planning discussions
- ensuring advance care plans and discussion records are readily accessible to clinicians
- ensuring advance care plans and discussion records are shared with relevant health professionals across the hospital – community interface
- auditing advance care planning to inform improvement and embed advance care planning within existing quality systems to ensure continuous improvement
- working across the broader health system to ensure advance care plans are shared and used appropriately.

Priority action 2: ensuring an evidence-based and quality approach

The systems developed to support advance care planning should be based on evidence and informed by quality assurance processes:

- update policies and procedures to ensure they are consistent with the best available evidence
- promote research into advance care planning and disseminate findings
- use information from audits to improve clinical practice (for example, revising clinical triggers for when to offer advance care planning)
- use mortality review committees to monitor the presence, adherence to and impact of advance care plans on the quality of child's death
- audit the documentation of advance care plans through medical record reviews.

Priority action 3: increase workforce capability

In thinking about supporting paediatric health professionals in this work, it is crucial to consider both of the following aspects:

- understanding and overcoming barriers to undertaking advance care planning discussions
- increasing capability and confidence by enhancing knowledge and skill.

Addressing only the second of these two areas will not improve advance care planning.

Overcoming barriers to advance care planning

Paediatricians often experience feelings of grief, failure and guilt when they cannot cure a child's condition (Papadatou et al. 2002; Baverstock and Finlay 2006). These emotional responses may lead them to avoid difficult and painful discussions with families.

Meanwhile, families may want to have these discussions, but have a sense that it is not an appropriate topic to raise.

Such a complex set of circumstances requires a sophisticated response.

Recommended strategies include:

- normalising advance care planning as a routine element of care in certain clinical conditions
- encouraging a team approach where nursing and allied health can be receptive to and gently explore child and parental readiness to discuss advance care planning
- creating a culture where doctors feel supported in this work
- identifying and engaging clinical leaders in advance care planning
- providing access to mentoring and supervision (including reflective practice through case-based debriefs to identify specific barriers to advance care planning and explore how best to address these)
- enlisting the support of palliative care specialists who often have particular skills in communicating about difficult issues.

Increasing capability and confidence by enhancing knowledge and skill

Enhancing knowledge (the 'what')

This includes knowledge regarding which children should have an opportunity to create an advance care plan and when, what concepts need to be discussed, and how to frame these discussions. The *Thinking ahead framework* provides an approach to paediatric advance care planning and includes:

- triggers for advance care planning
- a discussion guide for paediatricians and other health professionals
- documents for capturing discussions and decisions
- case examples.

Enhancing skill (the 'how')

Theoretical knowledge about what to discuss with families and how is not sufficient to ensure advance care planning will progress in a way that is optimal for families and health professionals. Nor does practice in and of itself improve skill level. In fact, it may simply reinforce patterns of behaviour that are not effective.

The available evidence shows that experiential learning is required to change behaviour (Kurtz, Silverman and Draper 2005; Fellowes, Wilkinson and Moore 2003). This involves practice with a skilled facilitator, such as with an actor in a small group setting. Practice through role playing, mentoring, and feedback can support people to improve skills and to become confident in conducting these difficult conversations. We recommend that paediatricians and other health professionals involved in advance care planning for children take advantage of opportunities to participate in such experiential learning.

Empathy and compassion are also crucial to good clinical communication, as are recognising patient and family cues, understanding their concerns and perspectives, and providing information in a way that is manageable (Silverman, Krutz and Draper 2005).

There is now a considerable body of evidence to demonstrate that effective communication leads to improved health outcomes for patients and families, including reduced distress, greater satisfaction and fewer complaints (Baile et al. 2000; Back, Arnold and Tulsy 2009; Buckman 2002; Clayton et al. 2007; Fischer, Tulsy and Arnold 2000). It can also lead to better outcomes for doctors in the form of improved work satisfaction and lower rates of burnout. Communicating better need not take longer, in fact, consultation times can be reduced as a result of greater focus and efficiency.

Discussing advance care planning with families will rarely be straightforward but as capability increases, health professionals can hope to feel more comfortable, knowing they are helping families make some of the most difficult decisions they will ever face.

With this in mind, tertiary paediatric centres should offer multifaceted training for staff in both the development and activation of advance care plans. Training should be tailored to staff individual needs:

- Specialist paediatricians working in tertiary centres are most likely to lead advance care planning, so would benefit from education regarding the practical, ethical and legal aspects as well as how and when to have these conversations. Experiential learning is important for this group.
- Junior medical staff should be offered education in advance care planning and should have the opportunity to observe advance care planning discussions wherever appropriate.
- Nursing and allied health staff will contribute to advance care planning discussions and activate advance care plans, so this group should be the focus of education regarding the practical and ethical aspects.

In addition, tertiary paediatric centres should:

- develop advance care planning procedures to guide staff
- provide information to staff through grand rounds and unit-based education sessions
- ensure advance care planning capability is included in position descriptions for relevant staff clinicians.

Priority action 4: enabling children and families to 'think ahead'

There is a delicate balance to be found between enabling children and families to participate in advance care planning, and not being intrusive about it. Families who find advance care planning confronting should not be forced to participate.

Tertiary centres should:

- identify triggers for advance care planning and embed this into care pathways for relevant conditions
- provide families of children who have life-limiting conditions with written information to help them with advance care planning. The Royal Children's Hospital Children's Bioethics Centre has partnered with staff at the University of Adelaide to produce *Caring decisions*, a booklet and website for parents of children with life-limiting conditions who are facing major decisions regarding their child's care (Xafis et al. 2015). These resources are designed to help parents think through these decisions. The website can be found at: <www.rch.org.au/caringdecisions/about_us/About_Us/>
- consult with the tertiary centre's community advisory committee in developing strategies for implementation
- incorporate patient and family experience of advance care planning into existing feedback systems.

Advance care planning terminology

This document adopts the following definitions.

Advance care plan

In the paediatric setting, an advance care plan is a document that captures the agreed goals of care for the child and documents the decisions that have been made regarding medical treatments that should or should not be provided. It is a communication tool, not a legal document.

Advance care planning

Advance care planning is 'a process of discussions between families and health care providers about preferences for care, treatments and goals on 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 potential efficacy and benefit versus burden of various interventions
- the family shares with the clinical team their values, goals and hopes and what they believe their child might experience as a benefit or a burden.

The objective is to determine what the overall goals of care are and what interventions should and should not be provided. This information will guide current treatment as well as future treatment in the event of a sudden, acute deterioration.

Goals of care

The goals of care for an individual patient are the overarching aims of medical treatment. It outlines what the person, family and medical team hope to achieve during the course of care. Goals of care can be viewed as a continuum of care from active treatment to prolong life at one end, to the prioritisation of symptom management and end-of-life care at the other. In between lies a zone where patients, families and clinicians try to find a balance between prolonging life and optimising comfort.

Life-limiting condition

Any condition that is likely to result in a reduced life span.

Life-sustaining treatments

Treatments that can sustain life in the presence of a potentially fatal condition. Examples include cardiopulmonary resuscitation in the event of a cardiac arrest, mechanical ventilation in the event of respiratory failure, dialysis in the setting of kidney failure, and artificial hydration/nutrition.

Withdrawing and withholding treatment

Withdrawing treatment is the removal of medical interventions that are burdensome and non-beneficial. It may result in the patient dying from their underlying condition.

Withholding of treatment is the decision not to provide medical interventions that would artificially prolong life, which may result in the patient dying from the underlying disease or illness. (Department of Health 2012)

Palliative care

Palliative care 'is an active and total approach to care that continues from the point of diagnosis or recognition throughout the person's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the person and support for the family. It includes the management of distressing symptoms, provision of respite care for children and families and care through to death and bereavement. Palliative care can be given alongside active interventions; it is not confined to situations where a decision to withhold or withdraw active treatment has been made' (Larcher et al. 2015)



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