



Thinking ahead discussion guide

Planning care for children with life-limiting conditions

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Foreword

This discussion guide provides an excellent and detailed resource to assist paediatricians plan care with the parents of children with life-limiting conditions. Good communication within the treating team, and between families and staff, is vital.

At The Royal Children's Hospital Children's Bioethics Centre, we have seen many case consultations involving children with life-limiting conditions. These cases are often characterised by difficulties in achieving a shared understanding of treatment goals.

This may have been due to a lack of consensus within the care team, or as a result of disagreement within families, and between families and the treating team. These situations often lead to widespread moral distress and anxiety for everyone concerned.

Overcoming these issues requires a clear understanding of the need for clinicians to take responsibility for clinical decisions, and to provide guidance to families based on their expertise.

It is crucial to appoint a lead clinician who has the responsibility to achieve a consensus view among the different specialists and treating teams. This person should also take the lead in communicating, counselling and negotiating with patients and their families.

Clear and early communication of diagnosis and prognosis helps families to understand what is happening and builds a foundation for discussions about goals of care.

The essential component to achieving all of these is effective communication.

Developing an advance care plan has always been an implied, if not explicit, part of good medical practice and with rapid progress in technical capability it is now more important than ever.

Every child's life tells a unique story and 'in life, as in any story, endings matter' (Jing 2015).



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Introduction

Talking with children and families about death is one of the most difficult yet most important things a paediatrician must do. It can arouse feelings of sadness, guilt and fear; including the fear that we might cause further pain to families who are already suffering.

Like any difficult task, we often find ways to delay these conversations, or avoid them altogether. But there is a downside to avoiding this conversation. Avoidance 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. This 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 to prepare emotionally and practically for their child's death reduces the likelihood of complicated grief.

Although paediatricians nearly always initiate conversations about advance care planning, at least 50 per cent of parents have seriously considered withdrawal of treatment before the question is raised (Meyer et al. 2002).

Families who need to discuss advance care planning may not raise it with their child's paediatrician for fear of upsetting them or being seen to be 'letting the team down'. Signalling your willingness to have the conversation can provide a sense of relief to families who often have no one else to talk to about these difficult decisions.

This guide is intended to help paediatricians approach advance care planning by offering ways of framing the discussion and providing examples of phrases that can be used. While words are important, it is your compassion and humanity in sharing this difficult task that families will remember.

'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)

Resources for advance care planning in the paediatric setting

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

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

This framework provides a progressive approach to advance care planning discussions, a series of suggested clinical triggers, illustrative case examples and documents for capturing discussions and decisions.

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. This resource is not intended to form the basis of legal advice. The legal elements of advance care planning are not discussed in detail in this discussion guide or the other resources, however, clinicians are less vulnerable legally if they can document they have considered the values and preferences of the child and their family in medical treatment decision making.

The Victorian Government introduced the *Medical Treatment Planning and Decisions Bill 2016* Parliament in September 2016 which, if passed, will commence operation from March 2018 and 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 in event they do not have capacity at any future time.



Who should discuss advance care planning

Senior medical staff, junior medical staff, nursing and allied health staff should all be equipped to discuss and then document elements of advance care planning discussions. This includes values and goals, hopes and fears, and preferences regarding place of care.

Senior medical staff are responsible for discussing, deciding and documenting goals of care, and which specific interventions should and should not be undertaken.

While much of this document refers to parents, we need to have a clear understanding of who is important in making decisions about the care of a particular child.

Who is the child's main carer? What are the custodial arrangements? Are there key members of extended family to consider? Are there any legal rulings in place? What is the family structure?

Some examples of different family structures may include divorced or separated households; grandparent, kinship, and extended family carers; same-gender parented families; foster families and single parented families.

Including the child

- **Hear the child's perspective on their illness and treatment**
- **Increase their involvement in advance care planning (if desired) as they mature**

Adolescents and even much younger children may have strong preferences about their care. 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.

All of these views can be extremely helpful in guiding parents and paediatricians, and they can be easily discussed even if children do not know or understand their prognosis.

As children mature, their role in advance care planning may increase, but it is not possible to specify an age at which this should occur. Rather, it is a discussion for the parent, paediatrician and if appropriate, the child. The degree to which a child participates will depend on the individual child.

Many adolescents wish to know if their prognosis is very poor (Pousset et al. 2009). How and when this should be communicated should be discussed ahead of time with the family if possible.

Advance care planning discussions can be stressful for all involved. Always make sure there is somebody who can accompany the child (or parent) if they choose to leave the meeting.

Things you can say:

'You know (child) best: do you think he would want to be a part of these discussions?'

'Would you like (child) to be in the room when we talk about difficult things, or would you like for us to talk with them afterwards?'

'(Child), some people really like to know all the details about their health straight from the doctor, while others would rather have their parents meet with the doctor first and then explain the information to them later. If we ever had anything serious or worrying to talk about, do you have thoughts on which way you'd prefer?'

'(Child), we need to talk about some plans for the future. Would you like your parents and I to talk about it first and then come to you, or would you like to stay and talk together?'

Cultural diversity

Parents of children with life-limiting conditions have much in common, but there may be cultural sensitivities around the use of language and differences relating to who in the family makes decisions.

In some cases, it is not acceptable to use the word 'dying' or to openly acknowledge that this is what is happening.

In some families, parents are not the key decision-makers. They may need to inform and consult with extended family or leaders in their faith or community.

It is important not to make assumptions about particular cultural groups. Interpreters can provide important insights into the cultural group they are representing.

The best approach is to invite the family to tell you who and what is important to them, and whether they have particular needs you should be aware of.

For Aboriginal families, it is helpful to consult with and involve dedicated Aboriginal liaison workers.



Introducing the need for an advance care planning discussion

- **Gently open the door to discussions about difficult decisions**
- **Normalise advance care planning as something that happens routinely for children with certain conditions**
- **Emphasise the fact that you want to provide the best possible care for the child**

Families are better able to deal with difficult or confronting information if it does not come as a surprise, and if they have effective supports to help them in decision making. Ideally, these discussions should begin while the child is well.

It is worthwhile flagging advance care planning discussions ahead of time, in order to give families the opportunity to rally their support networks and feel supported in their decision making. Many people find it hard to think clearly in a crisis.

Normalising the conversation can be helpful – let the family know that this is something you do for all patients who come to this stage of this illness.

Things you can say:

'While (child) is well, it's a good time to start thinking about what your family might want for them if or when they become more unwell in the future. Then you will not be trying to make difficult decisions about (child's) care for the first time when they're very sick and your mind is taken up with the stress of their illness.'

'For all my patients with (this diagnosis or trigger), I have a talk with the family about what we might do if (child) is more unwell next time. Maybe we can make a time when both you and your partner are available.'

'I'm concerned about how (child) is travelling, and I want to make sure we all have a chance to talk about our plans for their care next time they're unwell.'

Reviewing the child's situation before the family meeting

- **Agree on what medical recommendations should be made**
- **Agree on the team's objective for the family meeting**
- **Nominate a lead spokesperson**
- **Decide which clinical staff should be present (try to minimise the number who attend)**

It is crucial that treating teams have a discussion before meeting with the family. This ensures there is agreement between the professionals regarding the appropriate management of the child.

These discussions can be complex, as staff from different disciplines such as medical, nursing, social work, psychology, and physiotherapy might have very different perspectives and knowledge of the family, particularly if the child's condition has changed rapidly.

The primary objective of the pre-meeting is to reach agreement about what recommendations should be made to the family so that mixed messages are not given. It can be confusing for families to hear clinicians 'think out loud' about various treatments during a family meeting.

At the pre-meeting, participants should share their impressions of the child's condition and trajectory, and their understanding of the family's views and concerns.

It is useful for one member to offer a verbal synthesis of the information gathered, and to obtain an agreed overall view of the child's current health status. This will often lead to an understanding of the appropriate goals of care for the child. These should be verbally summarised to ensure all team members are in agreement.

It is also useful to revisit what discussions have already taken place, and what is already known about the family's thoughts and priorities. If an advance care planning agreement has already been reached, you may only need to reaffirm the family's previously stated wishes.

The discussion should include what interventions are possible and what the benefits and burdens of each of these are. The teams should reach a clear consensus about what interventions should be offered to the family.

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

Things you can say:

'Given our discussion of this child's trajectory, what would we achieve for them by inserting a vagal nerve stimulator?'

'If we were to intubate this child, what are the likely outcomes?'

'It seems to me that we all agree that further aggressive chemotherapy would be very unlikely to prolong this child's life and would be highly likely to cause significant suffering. I think we should explain to the family that, for these reasons, it is not an option.'



The treating team should decide which clinician will lead the discussion with the family. Ideally, this should be the clinician with the most rapport, trust or experience with the family. It is not necessary or even helpful, for the entire treating team to be represented in the family meeting, although if there are likely to be concerns around a particular issue it can be useful to have an expert in that issue available to answer questions.

The bedside nurse is an important person to include, as the family will return to their care immediately after the meeting.

Make sure you carefully consider who needs to attend the meeting, and try to minimise the number of health professionals as this can be intimidating for the family.

The team leading the discussion should set an objective for the meeting that reflects the urgency of the situation. Advance care planning is a process not an event and frequently takes a number of discussions to complete.

Examples of objectives for family meetings include:

- introduce the concept of advance care planning in simple terms
- inform the family about the team's increasing concerns about the child's condition
- explore the family's preferences around goals, fears, values and place of care
- discuss the benefits and burdens of various interventions, and the best way to care for the child given their clinical situation
- address conflict within the family
- develop a plan for care.

Preparing the space

- **Allow time and privacy**
- **Consider whether the child should be part of the discussion**
- **If the parents need to leave the child, ensure they are comfortable that the child is being cared for appropriately**
- **Ask the family who they would like to include as a support for them**
- **Optimise communication for families from culturally/linguistically diverse backgrounds (for example by organising an interpreter or Aboriginal liaison officer)**

Discussing the potential for deterioration or death with families can be difficult even in the best circumstances. Some simple environmental measures can help you have a productive discussion.

There must be an appropriate space for the meeting available for the time required. It should be completely private with a closed door, and have low ambient noise. Ideally, it should be in a place familiar to the family, such as in a familiar ward or consulting room.

If the family need to leave the room during the meeting, there should be a safe place nearby for them, such as a tea-room or family space. If the child is not going to attend the meeting, ensure a trusted person is caring for them in the parent's absence.

There should be enough seats for all participants in the meeting. A 'round table' or circle of chairs is ideal, as it avoids creating a physical division between the family and the medical staff. It can be good for a trusted healthcare worker to sit beside the family to create a sense that everyone is on the same team.

It should also be possible for any participant to easily leave the room without being disruptive. If a family member has in the past been upset during distressing discussions, make sure they have easy and direct access to the door. Tissues should always be available but they don't need to be 'on display'.

It is rare for meetings in a hospital to start exactly on time, so have some leeway to enable ongoing use of the room for a reasonable period of time.

Try to ensure that participants will not be interrupted during the meeting (for example, phones set to silent or switched off, pagers silent or covered) and that no time-sensitive, unrelated meetings are planned to immediately follow on from the family meeting.

Family meetings usually need at least 30 minutes, however they may go substantially longer.

If the family are non-English speaking, ensure that an appropriate interpreter is booked for the required period of time. Using an interpreter can increase the duration of the discussion, so take this into account.

Interpreters can provide useful insights about how a cultural group makes decisions and views death. For children who are of Aboriginal or Torres Strait Island descent, Aboriginal liaison officers can provide important support for the family and assist with understanding the cultural issues.

Ensure the interpreter is aware of the nature of the discussion before commencing the meeting. Interpreters may be distressed or traumatised by being required unexpectedly to interpret about the possible death of a child.

Communication – what families value

Research into family perspectives on advance care planning has revealed some clues as to how to improve communication with parents (Xafis, Wilkinson and Sullivan 2015; Clayton et al. 2007).

Families value:

- playing it straight
 - be honest
 - answer questions clearly and without hedging. Families generally want clear prognostic information, even if it is painful to hear.
- making it clear
 - reduce uncertainty
 - communicate prognosis and risk directly and clearly
 - use plain language. Avoid euphemisms – it can be important to use the words 'death' or 'dying', even though they are hard to say.
- showing you care
 - use verbal and non-verbal expressions of empathy and compassion
 - listen to family viewpoints
- giving time
 - have uninterrupted, unhurried discussions
 - schedule follow-up appointments
- pacing information
 - ensure understanding
 - reiterate information
 - respond to cues from the family that they are ready to hear more
- staying the course
 - be present with the family in times of distress
 - ensure there is continuity of care
 - persevere so the family understand the clinical situation
 - reassure the family they won't be abandoned.

Beginning the conversation

- **Introduce everyone present**
- **Ensure you know the child and parents' names**
- **Establish objectives for the meeting**
- **Check the family's understanding of the clinical situation**

Introduce everyone present. It is crucial you know the child's correct name, age and gender, and that you use these when referring to the child. It is also important you know the parents' names and if possible, the names and ages of any siblings.

You can start by discussing the objectives for the meeting. This prepares the family for a potentially difficult conversation, and allows them to express their own aims before being overwhelmed by medical information.

Things you can say:

'There are some things I need us to talk about in this meeting today that can be difficult to discuss, but I feel we need to. I also want to make sure we cover any questions you have. What would be helpful for us to talk about, from your perspective?'

Using open questions helps build rapport, and it can be a useful way to find out about the family's understanding of the child's clinical condition.

Things you can say:

'I understand that (child) has been seriously ill. I have been updated and I have read through all the notes and test results but can you tell me in your own words what has been happening and how you understand things at the moment?'

'Looking back over the last six months, what have you noticed?'

'What is your understanding of what is ahead for (child)?'

'Would it be helpful to talk about how (child's) illness may affect them in the months and years ahead?'

'As you think about what is ahead for (child), what would you like to talk about with me? What information can I give you that would be helpful to you?'

Discussing values and goals, hopes and fears

- **Explore the experience and values of the child and family**

Start by talking about what the family is hoping for and expecting. This will allow you to find out about their values and goals. Discussing their hopes can also act as a springboard for talking about fears and worries.

Things you can say:

Open questions

'When you think about (child's) future, what is most important to you?'

'What does (child) enjoy at the moment? What do they find hard?'

'What are you looking forward to most of all?'

'When you think about your child's illness, what are your hopes?'

'What are your worries?'

'What keeps you awake at night?'

'What are you most afraid of?'

'Is there anything or any outcome you would hope to avoid? A nightmare scenario?'

'What is the best case scenario for you and (child)?'

'Is there anything that you feel it is important that you achieve together?'

(Gauvin and Cyr 2015)

Directive statements

'You mentioned that what is most important to you is that your child be cured of their disease. I am really hoping for that too. I would also like to know more about your hopes and goals for (child's) care if the time comes when a cure is not possible.'

'I hope that we can control (child's) disease for as long as possible. At the same time I am hoping that they feel as good as possible each day, and I would like to talk about how we can achieve that.'

(Mack and Wolfe 2006)

Make reference to previous advance care plans and clarify the family's preferences. Remember that these plans are dynamic, and that the family's sentiments may have changed over time. Do not simply assume that the family's position has not changed since previous discussions.

Things you can say:

'When (child) was last ill, I remember you wanted to hold off on decisions about breathing tubes and other sorts of intensive care support. What is your thinking about those decisions and discussions at the moment? Has anything changed for you?'

'When we last spoke, you were having doubts about whether or not BiPAP would be right for (child) if they became sick again. Have you had any further thoughts about that?'

Discussing possible deterioration and death

- **Provide an opportunity to plan ahead for sudden deterioration**
- **Normalise advance care planning as part of the care of children with serious illness**
- **Use hypothetical scenarios to safely explore values, goals, place of care**

In their reflections on the child's illness and current status, the child or their family may have given clues about their readiness to discuss the possibility of the child's death and future planning around this.

It will rarely be productive for you to 'force' a discussion that the family is not ready to have, although this is sometimes necessary. Creating a safe environment for families and sensitively encouraging them to articulate their fears can sometimes allow a family who are reluctant to talk about advance care planning to begin the process.

Things you can say:

Reflect the family's language

'You've told me you're really worried about (child) deteriorating at home. Would it be helpful to get it all out in the open and talk about what we might do if that happened?'

Normalising advance care planning

'Lots of parents have thoughts about what they might do or what might be needed if we were unable to cure their child. Do you have thoughts like that?'

'Some parents are planners – they like to think well in advance about what happens if or when their child can't get better. Does that ring true for you?'

Sometimes it can be helpful to create some distance between the discussion and the child's situation. Thinking about a hypothetical scenario can slightly reduce the emotion and help facilitate thinking.

Things you can say:

Using hypotheticals

'I really hope (intervention) is successful. If there ever were to come a time when (child) was deteriorating despite all of our efforts, have you had any thoughts about how you would want that time to be? For example, where you would want to be.'

Some families will want to make decisions only when death is imminent – to 'cross that bridge when we come to it'. Some will wish to be a part of the decision, but have the medical team as the ultimate arbiter. Others will never feel able to participate in a discussion or decision making about their child's death.

While it is your responsibility to ensure that the family has every opportunity to participate in such a discussion, if you have explored the barriers to discussion and the family still does not want to participate in the conversation, it is inappropriate and counterproductive to insist that they do.

Framing the conversation

- Explore the idea of what it means to be a 'good parent'
- Introduce the idea of benefits and burdens
- Allow room for hope
- Offer a flexible approach in the face of uncertainty – trial of treatment

Exploring the struggle to be a 'good parent'

Parents want to do what is best for their child, but sometimes it can be very difficult for a parent to determine what 'the best' is.

The complexity of the struggle to disentangle their own wants and needs from the interests of their child should not be underestimated.

You can build trust and defuse potential conflict by naming the struggle, and providing a gateway to deeper discussions about how the team can support the parent to 'be a good parent' (Hinds and Patterson-Kelly 2010). Many parents feel inadequate and helpless, so it can be good to acknowledge the positive things they have been doing and the importance of their role.

Things you can say:

'I can see how much you love (child). What do you need to do to feel you are being the best parent you can be for them?'

'Many parents tell me how they feel caught in a dilemma. On the one hand they want to give their child every chance to survive. On the other, they don't want their child to suffer. I was wondering if you might feel that way too.'

Exploring the difference between 'could' and 'should'

There may be many interventions that are technically possible. The challenge for the treating team and the family is to determine which interventions are in the child's best interest. Thinking about the benefits and burdens of the various options requires a meeting of minds. The paediatrician will understand this from a clinical perspective, but only the child and parent will know what they experience as individuals.

For example, some children do not find hospitalisation burdensome. Others are terrified.

Things you can say:

'There are many things we could do ... the question is what should we do?'

Allowing hope

Hope is important and it is not always necessary for families to 'give up'. It is possible to hope for many different things at the same time. Parents can understand their child's prognosis intellectually, but emotionally they may hold on to a secret wish that the team is wrong. Sharing a family's hope for a good outcome can be very helpful (Back, Arnold and Quill 2003; Wolff and Browne 2011).

Things you can say:

'Many parents tell me that in their head they understand how sick their child is, but their heart tells them not to let go. Is that how you feel?'

'We are all hoping things go well for (child). It is important to also have a think about what we would do if things don't go so well. So we can hope for the best and plan for the rest.'

'I wish I could tell you that we could cure (child's) illness.'

People generally hope for more than one thing. Exploring the range of hopes can be very helpful (Feudtner 2009; Feudtner 2007).

Things you can say:

'It will help me care for (child) if I know what it is you are hoping for at the moment.'

The initial response is likely to be something unachievable (for example, cure, survive to Christmas).

Empathising with that hope rather than trying to correct it can be a powerful intervention.

'I really wish that could happen. Can you tell me what else you are hoping for?'

Dealing with uncertainty – trial of treatment

In circumstances where there is uncertainty, a trial of treatment may be appropriate.

It is important to explain two things:

- the time period required to demonstrate success or failure
- what the indicators of success and failure would be.

Things you can say:

'At this stage, we are not certain whether this deterioration is due to (child's) underlying illness or an infection that they will recover from. We should have a better picture after 72 hours. At that time we will be looking for them to be needing less help with their breathing (for example, lower BiPAP pressures). It will be important for us to sit down together again at that time to discuss how they are going and whether continuing the BiPAP would be the right thing to do.'

During the discussion

- **Try not to rush**
- **Listen – aim to talk less than 50 per cent of the time**
- **Allow parents to express their emotions**
- **Ensure a ‘quiet’ parent is given opportunities to speak**
- **Demonstrate that you care about what is happening**
- **Demonstrate that you understand how much they love their child**
- **Sit with silence – families often say something important at the end of a pause.**

It can be difficult to slow down when there are so many competing pressures, but an investment of time during advance care planning discussions is worthwhile.

Dedicating time to a discussion sends a signal to parents that you care about what is happening to them.

It’s also important to allow for periods of silence during the meeting. Families often provide profound insights after a long silence.

Check regularly that the parents are following what you are saying.

Things you can say:

‘I’ve just given you a lot of information. I just want to check I am not going too fast. Can you tell me what you understand of what I have said so far?’

Advance care planning is usually highly emotional for both families and staff. Parents will struggle to focus and think clearly when they are very sad, angry or afraid. It is important to allow some time for them to express these emotions.

Things you can say:

‘I can’t imagine how difficult this must be. Can you tell me what you are feeling right now?’

‘I can see how sad you are feeling.’

‘This must be so hard to hear.’

It is not uncommon for one parent to be quiet or even silent during the discussion. Ensuring they are given opportunities to contribute is important. In some cases, it may be that one parent is better able to communicate in English than the other.

Things you can say:

‘Sometimes it is hard to talk about these things. (Parent), I just want to make sure we give you the chance to ask questions or let us know what is on your mind.’

One of the most common complaints from parents is that doctors, nurses and other professionals often seem ‘unmoved’ by these discussions. This is probably because health professionals wish to convey a sense of calm and professionalism. It is possible and appropriate, even helpful, to show genuine emotion while remaining strong for the family.

You may find yourself talking quickly or a lot, perhaps taking refuge in long-winded medical explanations, particularly if the family is very quiet or very distressed. Talking can help you manage your own anxiety and can provide a distraction from powerful emotion – but you may miss something important. Remember also that patients and parents often say something crucial after a long period of silence.

Sharing your perspective and experience

- **Share your concerns**
- **Use plain language**
- **Check understanding.**

There are times when you will need to direct the conversation towards 'planning for the worst'. It is important to be honest about your concerns for the child, but allow the family to maintain hope if possible (Mack et al. 2006).

Try to use plain language as much as you can. It can be hard to say the words 'death' and 'dying' but euphemisms are often confusing. Some parents report that they had to work out what was happening for themselves because clinicians avoided using direct language. Obviously, such words need to be said with empathy and compassion.

Only use medical terminology if you are sure that the family understands it and you feel that it will advance the conversation.

Always check the family's understanding of the information you have presented. It may be important to pause to allow the family to take in the information you have provided.

Things you can say:

'I am hoping that we will be able to control your child's disease. I am also worried that this time we may not be successful.'

'Although we do not know for certain what will happen for your child, I am worried because in my experience most children with this disease eventually die.'

'I have been noticing that (child) seems to be sick more and more often. I have been hoping that we would be able to make them better, but I am worried that their illness has become more difficult to control and that soon we will not be able to help them to get over these episodes.'

'In my experience, a child with (child's) underlying illness, who has this many severe lung infections, is coming to the end of their life.'

'It's important to plan for changes in your child's health. It will be so much more difficult to discuss these things when they are very unwell or dying and everyone's emotions are very high.'

'Would it be helpful to talk about what to expect as (child's) illness worsens?'

'I am so sorry to say that (child) is dying now. We don't have a say in that but we do have a say in what that will be like for them.'

Prognosticating

It is often very difficult to accurately prognosticate because the trajectory of many childhood diseases can be variable. However, families often want to have some idea of the prognosis so they can plan for the future.

To maintain honesty and accuracy, it is useful to prognosticate in broad or general terms (for example, days to weeks, weeks to months, only a year or two).

Try to avoid terms like 'not too long' or 'soon' as these are open to interpretation.

Things you can say:

'When I think of children I have looked after with the same condition, I am concerned that (child) will die in the coming days.'

'The most likely course for (child) is to gradually become more tired and, I'm so sad to say, they are likely to die in the coming months.'

'The pace of change can give us some idea of what to expect. If we see that this week is worse than last week and the week before that, we are generally thinking in terms of weeks. If we see that today is worse than yesterday and the day before that, we are thinking in terms of days.'

'We often feel very humble at times like this because we cannot always predict the future but we will do our best to guide you based on what we see and what we know.'



Offering guidance and recommendations

- **Distinguish between 'clinical decisions' and decisions that fall in the zone of parental discretion**
- **'Clinical decisions' should be explained, not offered as a decision for parents to make**
- **Offer your medical opinion**
- **Provide reassurance that you have carefully thought your recommendations through**
- **Emphasise the things that will be done for the child**
- **Avoid leaving parents feeling alone with the burden of decision making.**

Some decisions are 'clinical decisions'. These relate to interventions that have no chance of success or where the burdens greatly outweigh the possible benefits.

Take medical responsibility for these decisions and do not present them to the family to make. Instead, offer a gentle and compassionate explanation.

Things you can say:

'There are some things that we can change with medicine, and some that we can't. We can help (child) with medicines to make them comfortable and stop their seizures. But if they stop breathing, their body is telling us that it cannot go on. And if we tried heart massage or a breathing tube, it would not change that. It would be uncomfortable for them and would not bring them back. That's not what we want for (child).'

'(Child) is dying now. It is important that you be with them. We will be here to support you to do that.'

Other decisions fall in what might be termed the zone of parental discretion (Gillam 2015). This is where the balance of benefits and burdens will be weighed differently by different families.

Given the same clinical situation, children and their families will make decisions based on their individual values and experience. Even in these circumstances, it is always appropriate to offer a medical opinion and advice about what medical treatment is likely to be effective for the child.

Explain why you are making these recommendations in terms of your experience, the available evidence, consultation with experts and the child's clinical situation.

Parents will feel supported if you emphasise the treatments that will be provided – although it is also important to let them know about treatments you feel will be ineffective or too burdensome.

Create a sense of shared goals by reflecting the family's values in your recommendations.



Things you can say:

'You have told me in the past how important quality of life is to you, and how, especially as (child) gets weaker, they are most happy and calm when they are in their own bed. With that in mind, I think our treatments should focus on keeping your family together at home.'

'I do not think that putting in a breathing tube will offer (child) any chance of longer survival. (Child's) lungs are so weak that, if they got severe pneumonia again, we would not be able to save them even if we did put the tube in. Putting in the tube would be uncomfortable, would not make them live longer and would mean they would die in ICU. Instead, I would like (child) to be supported on the ward or at home with oxygen and medication to make their breathing comfortable. Then they can be with their family who love them, rather than in ICU surrounded by machines that can't help.'

It is helpful for parents to hear that you have been thinking carefully, consulting widely and examining the available evidence.

Things you can say:

'Sometimes people ask about (you may have read about) tracheostomies for children with this condition. We have thought carefully about that too and we feel certain that it would not be helpful for your child because ... '

Share the burden of decision-making. Avoid asking parents, 'What would you like us to do next time (child) deteriorates?'

'It is very important to me that you don't feel alone with these decisions. It is something we share together.'

Exploring disagreement between family and team

- **Avoid repeated efforts to 'convince' parents**
- **Listen to the family's concerns and try to understand their perspective**
- **Allow the expression of emotion**
- **Avoid efforts to 'make the family understand reality'**
- **Be patient (rushing to achieve consensus may be counterproductive).**

There may be times when the family's understanding or opinion of what is best for the child differs from that of the medical team.

The family may have misperceptions about what the medical team is proposing. There may have been previous miscommunication or misunderstanding of the child's status, or the medical team may have made incorrect assumptions about what the family's true concerns are. There may be a lack of trust.

In this situation it is crucial to slow the process down and attempt to better understand exactly where the family's concerns lie in order to reach a consensus about the child's care.

Try to put aside your personal feelings and prior assumptions, and listen very carefully to the words the family uses.

Acknowledge the emotions they express and their desire to do their best for their child. These validations can help build trust.

Things you can say:

'I can see that you are very distressed with what I have said. Can you tell me what you are thinking?'

'I've heard you say that you wish to do everything to keep your child alive. What is in your mind when you think about "doing everything"?''

'Can you tell me what you hope a tracheostomy will do for (child)?'

'Many parents tell me they feel trapped in a dilemma: should they make every effort to keep their child alive or should they make sure their child doesn't suffer? Is that how you feel too?'

Common themes in disagreement include:

- overestimating the likely success of treatments and interventions
- feeling mistrust of clinicians, medications or procedures
- families feeling overwhelmed by grief or guilt
- families not wishing to be the instigators of their child's death.

It can be very powerful to empathise with a parent's wish for their child to survive. This creates common ground. After all, in these terribly sad situations, we all hope for things to be better (Quill, Arnold and Platt 2001).

Offer a simple, short statement and try to remain silent afterwards.

Things you can say:

'I wish we were wrong.'

'I wish there could be a miracle.'

'I wish CPR could change what is happening.'

Different spiritual beliefs can also feed into a difference of opinion between medical staff and families.

'Unpacking' and exploring the source of the disagreement can reveal gaps in parental understanding, improve clinician understanding of family dynamics and perspectives, and offer opportunities to find common ground.

Time and good communication resolve most disagreements. During this process, clinicians may need to tolerate and manage uncomfortable ambiguity. It is rare that the impasse persists.

In these circumstances it can be helpful to seek a second opinion, consult with a clinical ethics committee if available, or seek input from the hospital's executive team. It may be necessary to seek a legal opinion.

Exploring disagreement within the family

It is not uncommon for parents to disagree about the goals of care for their child. People's values, beliefs and their responses to grief vary.

Sometimes one parent is more aware of the child's suffering than the other. Reassuring parents that disagreement is not unusual and validating the concerns of each can help avoid positions becoming entrenched.

Time and good communication will assist in finding common ground in most cases.

Sometimes parents agree about the goals of care but struggle with members of the extended family. Offering to meet with those family members can be helpful. They are often extremely influential and important in the decision-making process, but may not necessarily know all the facts.

Social workers have particular skills in conflict resolution, so it is crucial to include them in meetings.



Ending the discussion

- **Summarise the discussion so far**
- **Agree on next steps**
- **Acknowledge the family's courage**
- **Check if there is anything else important they would like you to know**
- **Ask if they need some time to sit quietly and absorb what has been said**
- **Indicate your availability to answer questions in the next few days and beyond**
- **Providing written notes of the discussion may be helpful for some families.**

It may not be possible, practical or appropriate to reach an agreement about the child's future care in one meeting. In this case, it is important to make a time for further discussions.

Summarise the discussion so far, ideally agreeing to some shared goals for the child. Even if the family refuses to enter into a discussion about advance care planning, it is an opportunity to leave the door open to questions and discussions in the future.

You should ensure the next steps for the child are clear, whether that is withdrawal of life-prolonging therapies, specific symptom management or simply further discussion at a defined time.

Things you can say:

'I know that talking about these things can be hard to do. If you find you have questions or worries about these issues later on, I would like to help to answer those questions when you're ready.'

'I think we agree that you need some time to think about whether going to the intensive care unit is still the best thing for (child) next time they become unwell. In the meantime, I think that we can do a better job with making them more comfortable. Maybe we can discuss your thoughts further at our next appointment.'

'Thank you for your courage in talking with me about these difficult things. Knowing how you're feeling and what is important to you really helps me plan the best care for your child.'

Acknowledge the family's courage. These are harrowing conversations. Close the discussion by asking if there is anything else the parent would like to ask or say.

Things you can say:

'Is there anything else you want us to know about what you are thinking or how you are feeling about this situation?'

At the end of the discussion, acknowledge the profound nature of what has been discussed and ask if the parents need time and a quiet space to sit and absorb what has been said.

It is also helpful to let them know you will be available to talk further and answer questions. Let them know when you will be available and how they can contact you.

'We've talked about some very difficult things today. You are welcome to sit here for a while if you would like to. I am expecting you will have questions in the next few days and that we will need to talk again. Would it be OK if I came back tomorrow at this time? Please let the nurse or my registrar know if you need to talk before that.'

Documenting and sharing information about discussions and decisions

Communication is vital to ensure a family's wishes for their child's care are carried out.

If the discussion has led to a consensus about goals of care or limits of treatment, ensure that the appropriate form is filled out, placed into the child's records, and an advance care planning alert is created as a matter of urgency.

Even if specific decisions have not been made, it is important to document the discussion so far including the family's feelings, concerns and wishes.

It can be useful to use the family's own words to convey the tone of the meeting and highlight more subtle concerns such as approaches that are unlikely to be helpful in future meetings.

Documentation can be in a letter or on a dedicated form if available. It is not necessary to complete forms with the family as some will find this confronting. It is enough to tell them you will be documenting what has been discussed.

Things you can say:

'It is important that if (child) deteriorates suddenly, the people who will be caring for them at that time know what we have been thinking and talking about. We have a special form here at the hospital for recording our decisions so that doctors, nurses and ambulance officers can quickly gather important information in a way that helps them provide the best care. The team looking after (child) will always talk to you further at the time.'

All teams involved in the child's care should be informed of the discussion.

Ensure the emergency department and the ambulance service have alerts regarding the child on their computer systems.

Remember to inform the child's school and respite facility if applicable. The team should negotiate who will do these various tasks.

It is often helpful for the family to have a copy of any written material, but this is not essential.

If a parent does not wish to carry or distribute their child's advance care plan themselves, you should seek permission from them to share the advance care plan with other services and facilities.

Language with unintended consequences

Some commonly used phrases or statements may be counterproductive when discussing advance care planning and resuscitation status.

Presenting advance care planning as a 'choice' for which families have sole responsibility may provoke great distress and guilt, and misrepresents the medical decision-making process.

In their desire to be honest with families, clinicians may unconsciously present only information about what treatments they think should be withheld, not what active and engaged management will still be offered.

Euphemisms may render the clinician's intentions unclear to families and cause misunderstanding.

Some commonly misunderstood phrases are listed below, with an explanation of the possible unintended consequences and an example of an alternative phrase that might be used (Stone 2001).

Statement	Problem	Alternative
<p>'Do you want us to do everything possible?'</p> <p>or</p> <p>'What do you want us to do?'</p>	<p>Shifts responsibility away from doctor and on to parents.</p> <p>Likely that parent will 'want everything done'. What parent does not want 'everything done' to care for their child?</p> <p>Does not explain options or provide guidance; may include treatment choices that are futile or inappropriate to patient care.</p>	<p><i>'There are many things we could do for your child, the question for us both is which of those things should we do. Everything we do has a benefit and a burden. We should only do those things that have an overall benefit for your child.'</i></p>
<p>'Will you agree to discontinue care?'</p>	<p>Implies dichotomous choice between treatment and abandonment by team.</p> <p>Implies child will not be cared for.</p> <p>Shifts responsibility away from doctor and on to parents.</p>	<p><i>'I want to give (child) the best care possible. Their body is telling us it's time for us to focus on you being with them and us making sure (child) is not suffering.'</i></p>
<p>'There's nothing left to be done.'</p>	<p>This is untrue and will provoke great distress. There may be no curative options, but other active treatment is always available.</p>	<p><i>'I think we should focus on your child's comfort and dignity as our top priority now. This is how ...'</i></p>
<p>'I think we should stop aggressive therapy.'</p>	<p>Negative framing suggests abandonment of child by family. Unclear meaning.</p>	<p><i>'I think we should focus on your child's comfort and dignity as our top priority now. This is how...'</i></p>
<p>'I'm going to make it so they won't suffer.'</p>	<p>Implies euthanasia of child and assumes that suffering is inevitable in dying children.</p>	<p><i>'I will focus my efforts on treating any symptoms your child might have.'</i></p>
<p>'We could give more chemotherapy. Or we could stop and send you home with palliation, and the cancer would gradually get worse and ultimately they would die.'</p>	<p>Portrays palliative care in a negative light.</p> <p>The term 'palliative care' already comes laden with negative connotations and mythology.</p>	<p><i>'We could give more chemotherapy but I am worried that will mean they will need to stay in hospital and experience a lot of side effects with almost no chance of ever going home or being well again. We could instead, focus on helping them feel better and getting you all home. Palliative care can help us do that.'</i></p>

Statement	Problem	Alternative
<p>'I just need to go through this form with you to document what treatments we are and are not going to provide.'</p>	<p>Confronting. Perceived as reducing child's life down to a form. Perceived as a legal process.</p>	<p>After having discussion. <i>'I am just going to write down what we have decided today so that if someone is called to assist you in an emergency, they can quickly see what we have been thinking. We have a special form that we keep in the medical record and send to the ambulance service. It is just a way of us communicating information quickly. Staff helping you at the time will always discuss this with you. Some parents like to have a copy of it. Others don't.'</i></p>

Useful resources

Recommended reading

Clayton JM, Hancock KM, Butow PN, Tattersall MHN and Currow DC 2007, 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers', *Medical Journal of Australia*, vol. 186, no. 12, p. S77.

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