

Difficult decisions

A resource for parents and carers



Acknowledgements

We would like to thank the parents and carers who helped us with the development of the difficult decisions booklet. The knowledge you shared was invaluable and gave us a deeper insight into the emotional challenges that are experienced by families when taking on the courageous task of planning their child's end of life care.

If you require further information or would like to speak with a health professional after reading this booklet, we encourage you to talk with your child's medical team; alternatively you can contact any of the NSW Paediatric Palliative Care Services listed below:

- The Children's Hospital at Westmead
Telephone: (02) 9845 0000 (page 6794)
- Sydney Children's Hospital, Randwick
Telephone: (02) 9382 5429
- John Hunter Children's Hospital, Newcastle
Telephone: (02) 4921 3387
- Bear Cottage Children's Hospice, Manly
Telephone: (02) 9976 8300

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Introduction

If you are a parent or carer of a child with a life limiting illness, this booklet is to help support you with the difficult decisions you make for your child – particularly if they have started to become more unwell (deteriorate) or taken a turn for the worse. You may have been part of many new discussions with your child's medical teams as it is difficult to know what treatment options are best at this stage of their illness. You may feel anxious and overwhelmed about the choices you are being asked to make. Families always want to do what is best for their child. However sometimes it is hard to know exactly what 'best' is.

"Difficult decisions: a resource for parents and carers" has been written by specialist paediatric palliative care nurses who have supported many families through the difficult decision making process as their child's condition changes. Families often tell us that decision making is easier when they understand the information that is discussed with them by their child's medical team. This is sometimes not easy because new words and terms are introduced that are supposed to help with decision-making but sometimes make it more confusing. It can be hard to know what questions to ask during these times or perhaps you feel afraid to ask. You therefore can miss the opportunity to say and do the things that are important during this time.

This booklet aims to assist you by discussing common questions that are often asked by parents/carers when their child's condition has deteriorated or worsened. We hope the information will address some of your concerns and help you to know that it's 'ok' to ask as many questions as needed to the health professionals caring for your child. You will also find a list (glossary) of common medical words/terms to give you a better understanding and explanation of the language used by health professionals.



Changing the focus of care

“The doctor said my child is deteriorating. What does this mean?”

There are a number of possible scenarios when your child’s medical team begins to use the word ‘deteriorate’. These may include:

- Your child’s condition may have remained the same for a long time and then their condition changes suddenly and they may become weaker or less mobile than before and may never fully recover. This means that your child may not return to their previous health state. This deterioration can be difficult for families to see.
- Your child has suddenly become more unwell resulting from another illness – such as a bad infection. Your child may spend a long time in the intensive care unit or another hospital ward making it very difficult to determine if your child will get better.
- It may have become clear that your child is no longer able to fight their illness. They may begin to have more symptoms (such as pain) and their doctors may think that they will die in the next few days or weeks requiring further conversations and considerations about the best treatment options for your child.

Considerations

You may like to consider asking your child’s medical team some of the following questions to help you decide the best treatment options for your child and your family.

- Is this treatment going to cure the disease?
- Is this treatment going to stop the disease getting worse?
- What will happen without the treatment?
- What impact will the treatment have on my child’s quality of life? (for example less time spent in hospital and more at home being a family)
- Will the treatment improve my child’s symptoms? (such as better pain management, fewer secretions and need for suctioning)
- Will the treatment make my child feel worse?
- How long will my child feel worse for?
- Will this treatment cause my child to suffer?
- How will these changes affect our family life?



Deciding what is important for your family

Goals of care

1. What is important to my family and what are our goals of care?

When your child is very unwell and difficult treatment decisions are necessary, it can be helpful to think about what is most important to you and your family at this time. Health professionals will often refer to this as 'your goals of care' or 'priorities'. Every family is unique and there are no right or wrong answers when deciding your goals of care. They can often be influenced by your personal beliefs and experiences, culture or religion. We encourage you to talk to your child's medical team to ensure there is a good understanding of what is most important to you and your family.

The following are some examples of goals of care that have been identified by parents and carers:

- We want to take Kate home and care for her there
- We don't want Mary to suffer
- We don't want any more painful procedures or appointments
- We want to spend time together as a family
- We don't want to come to hospital for treatment
- We want to go on a family holiday
- We don't want Jayden to be sleepy all the time
- It is important that Leo gets back to school, to enjoy being with his friends

2. What can I do to ensure my child has the best quality of life irrespective of their illness and prognosis?

When thinking about quality of life it may help to consider the balance in your child's life. For example "what gives my child happiness and pleasure balanced against feeling pain, sadness or discomfort?" All treatment-related choices have risks and benefits. Sometimes the benefits will outweigh the risks and sometimes the treatment may do more harm than good. When we focus on a child's quality of life we try to minimise suffering by planning ahead; this can be helpful to prevent and manage difficult symptoms and pain.

Your feelings about what gives your child the best quality of life may change as the illness progresses. More thought will be given about certain treatment options that, although it may help your child live longer, will also limit their involvement in activities that bring enjoyment and happiness. Your thoughts and feelings about these may change from week to week or day to day.

3. Are we 'giving up' if we make decisions that focus on the quality of life of our child instead of choosing treatment options aimed at making their life longer?

It is important to understand that you are not 'giving up' when you begin to make choices that are focused on giving your child and family the best quality of life.

This does not mean you will be asking to withdraw or withhold treatment; there will always be options available to keep your child comfortable so that they are able to do things that they enjoy. The paediatric palliative care team have lots of experience in supporting families through this difficult decision-making process and are available to help you. The palliative care team's role is not to make your decisions but rather to listen and help you reach decisions that are right for your child and family.

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"In the end we realised Lucy only had a small chance of survival even after all the medical interventions. We decided to choose quality over quantity which was the hardest decision we have ever had to make; but deep down we knew it was the right one for her"

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4. **How do I know what treatment is best for my child?**

It can often be difficult for both you and the health professionals caring for your child to know what treatment is “best”. This can create added pressure for parents/carers. Extended family members and/or friends may also have strong views about what treatment interventions are best for the child; these beliefs may differ from parents/carers which can create more stress within the family.

Every child will respond differently to certain treatments. It is important to gather as much information as possible by talking with your child's medical team. You know your child best and you can decide what treatment is right for them when you feel you have been given all the information.

5. **Is it ok to stop some treatments and continue others?**

Yes absolutely. Some treatments will offer great benefits for your child while others may have negative side effects that cause discomfort and may increase suffering.



“It was important that Luke continued to receive physiotherapy to help him remain mobile and participate in things he enjoyed. I chose not to do further blood tests because they made him really distressed”.



6. **What can I tell my family, other children and friends?**

Palliative care teams believe that truth and honesty are what makes both children and adults feel safe. You can, however, give as much information as you feel able to or comfortable with. This will often depend on the relationship you have with the person or child. If you need extra support, it can often be helpful to talk with a staff member from your child's palliative care team.

Resuscitation plans

1. **The doctors asked me if we had a Resuscitation Plan. Why would they ask me about that?**

In most situations the need to start cardiopulmonary resuscitation (CPR) on a child is a medical emergency where every treatment is carried out to save their life when their breathing or heart has stopped. For children with a terminal illness, a time may come when you may begin to think about withholding certain resuscitation interventions (such as CPR, intubation and ventilation) because there may be little or no benefit to your child's quality of life or hope of resuscitation being successful. Beginning these conversations is difficult and requires the guidance and support from health professionals you trust. It is better to have these conversations when you have the time and space to ask questions, have options explained and feel comfortable with your choices. It means that in the event of an unplanned crisis clear instructions are in place for medical staff and you have a greater understanding of what is happening.

A Resuscitation Plan is a medical document that is written by the medical team that knows your child best. It aims to clearly communicate your end of life decisions and planning that has taken place for your child when they become very unwell and their recovery is uncertain. Having your decisions and choices written down in advance removes the need to have repeated and stressful conversations with health professionals who may not know your child very well (such as emergency staff or ambulance drivers). The Resuscitation Plan clearly documents your resuscitation goals for your child to ensure the focus of care is about their comfort rather than life-prolonging measures (for example using oxygen or suction to assist with breathing instead of commencing CPR and/or intubation).

A Resuscitation Plan, does not mean that your child will die soon or that it will be needed immediately. It also does not mean that people will stop trying to help your child. What it does do is improve communication for health professionals who care for your child when they deteriorate by ensuring there is planning and preparation in place to meet your goals of care. Some children who have Resuscitation Plans do not need to use them for months or years. In these situations, the medical team caring for your child will review the Resuscitation Plan routinely to ensure it accurately reflects your goals as these may change over time.

2. Should my child have a Resuscitation Plan?

The benefits of having a Resuscitation Plan are to:

1. Document clear and consistent information about end of life care discussions you have had with various medical teams caring for your child.
2. Document clear and consistent information about resuscitation goals that focus on your child's comfort rather than invasive interventions.
3. Improve communication between families and medical teams caring for your child who is deteriorating or dying.

If you feel your child and family could benefit from having these plans in place, we encourage you to talk with your child's medical team and/or palliative care service.

3. What if I change my mind?

These plans can also be changed or stopped at any time.

Changes to the Resuscitation Plan are most commonly made to reflect changes in a child's condition. If your resuscitation goals change, we encourage you to talk with the medical team caring for your child. It is important that there is clear communication and that any changes are updated on a new document. Ideally this should not occur during a crisis.

Remember the Resuscitation Plan is not an 'order'. Its purpose is to provide written medical information, when necessary, to communicate your goals of care to all health professionals caring for your child and avoid repeated conversations that can be distressing.

Locations for end of life care

1. What location choices are available for my child to receive end of life care?

Hospital: For many families, hospital provides a place that you can be close to trained staff that are able to help you care for your child during end of life. This may be at the paediatric hospital or you may choose a smaller hospital closer to home. In both these situations, your palliative care team can provide advice and support to the hospital staff caring for your child.

Home: Many families will choose to remain at home to care for their child during end of life. This may be because home is a familiar and private location. It may also enable many more family members to be with you if this is important. Your palliative care service can work with local community services to ensure you have as much support as possible at home.

Hospice: In NSW Bear Cottage is the only residential children's hospice. Bear Cottage has a team of experienced staff who work closely with your child's medical team and are available throughout the day and night. Siblings and other extended family members are welcomed. At Bear Cottage, you are able to stay for a couple of days with your child after they have died if this is important to you.

2. How will I know where the best place is for my child when they are dying?

The best place for your family to be when your child is dying is where you and your child feel most comfortable and supported. Your location choice will often be guided by:

- Your goals of care
- Your child's symptoms
- How well you feel you can manage your child's needs
- What your child's wishes may be
- How rapidly or unexpectedly your child's condition is changing or deteriorating

Your location of care can also change if you wish or your child's care needs change. Your palliative care team can help to give you all the information that is needed so you feel more confident to make the decision. It is very important you feel well supported and prepared during this time.

3. If we choose to be at home will there be support?

Yes, if you would like to be at home, the palliative care team will identify services in your local area and explain the support that they can provide. Local services vary across NSW. You will need to have a doctor (often a GP) who can see your child before and after death to issue a legal document called a death certificate.

4. If we go home will my child have to stop receiving treatment?

Your child will not stop receiving treatment if you choose to remain at home. Most of the care interventions that have previously been available in hospital can continue to be provided at home or during a brief visit to the outpatient's clinic at the hospital. This will ensure your child is comfortable and any difficult symptoms are well managed. Ongoing communication will continue with the palliative care team (through home visits, videoconferencing or teleconferencing) to discuss your child's condition and assess their plan of care.



Other decision making considerations

1. How will I support my other children during this difficult time?

For many children maintaining a normal routine as much as possible is very helpful (school, outings with friends, sports), whilst for others spending time with their family is important. It may be a good idea to take advantage of help if it is offered by family and friends. The palliative care team can provide advice and assistance to schools so that siblings are well supported in the school environment. Siblings will all experience grief and loss in an individual and age-appropriate way. It may be helpful to explore different types of supports and services that are available to help them with their feelings of grief and loss.

2. How will my child's symptoms be managed at end of life

The symptoms experienced by a child who is dying are often similar to those they already have but may be more intense. These could include pain, nausea, vomiting, breathing difficulties, excess mucus (secretions), constipation or diarrhoea.

Palliative care teams are skilled at managing these symptoms and ensuring your child is as comfortable as possible. They are also able to think and plan ahead for possible new symptoms that may occur during end of life so that your child's care is well managed whether they are in hospital or at home.

3. How do we make decisions about my child's nutritional intake?

Feeding or eating can be an emotional and sensitive issue for some families for many reasons. Nutrition is an important part of life so when a child can't swallow or eat, or vomits continuously or just refuses food it can be very distressing for their family. It is natural for a person who is close to dying to lose hunger, no longer tolerate food or not want any food or fluids.

We encourage you to talk to your palliative care team. Some questions to consider may include:

- My child is finding it difficult to swallow- can I still feed them?
- I'm upset that my child hardly eats any more, what can I do?
- Every time I try to feed my child they feel nauseous/vomit/refuse to eat, what can I do?
- If I don't feed my child am I starving them?
- Are dying children hungry if they don't get fed?
- Will my child suffer if I don't feed them?
- My family says I should be feeding them more but I can't, what should I tell them?
- Do I have to agree to a tube into the stomach (nasogastric tube)?
- If my child can't eat, will they need intravenous fluids?
- Why have my child's medical team decreased my child's feeds?



Grief and loss

1. **Is it normal to experience grief and loss when making end of life care decisions for my child?**

Thinking about the end of your child's life is extremely difficult, and requires a lot of emotional strength. You may grieve the losses you have experienced. Grief is not a mental illness, while it can be painful, grief is a normal expected process that can include a wide range of reactions and changes in our emotions, behaviours, spirituality and bodies. No one can anticipate quite how they will feel or react; most people describe experiencing a 'rollercoaster' of emotions, ranging from numbness to anger, profound sadness to relief that their child's suffering is over.

2. **Should I access support services?**

As well as helping with the practical issues, planning for end of life gives all family members the time to mentally prepare for this event, and the opportunity to talk about things that they are worried about or to ask questions they may have. Grief and loss counselling can help parents or carers as well as siblings to be better emotionally prepared before and after the death of their child. It can assist with anxiety and depression, relationship issues or provide advice on how to talk to other family members and tell them what has happened. Support services that specialise in grief and loss in paediatric palliative care can also provide helpful information following the death of your child. You may wish to speak with a social worker or mental health professional to support you through the emotions and reactions that are experienced. Many families say that they do not know what they need or what might help. It is really important to get rest, eat well and get some exercise, even if you don't feel like it.

3. **What support services are available to help me?**

There are many options available and everyone is different in terms of what works for them. Parents/carers are encouraged to seek professional support by talking with their GP, social workers or other members of your palliative care service.

Specific information about paediatric palliative care grief and loss can also be found online: **nswppcprogramme.com.au**

Please be assured support and care for your family does not end when your child dies. Support services are available as long as you need them.

A glossary for parents and carers

The following list has been created to help parents/carers understand terms that may be used by health professionals when discussing end of life care decisions for their child. It is not intended for adult patients.

Cardiac arrest: Occurs when the heart stops beating; no blood is pumped around the body and the person will usually die.

Cardiopulmonary resuscitation (CPR): An emergency intervention that may be done when a child's heart suddenly stops pumping. Breathing support is provided alongside chest compressions to pump the heart and deliver oxygen to the brain in an attempt to restart the heart. CPR is often not successful.

Comfort care: care is provided when there has been a change in the goals to care for a child with a life limiting illness. Treatment options that aim to prolong life are reduced or stopped and the goal of this care changes to promote their comfort. This includes the easing or prevention of symptoms that may cause distress or suffering.

Community nurse: A nurse who works in the community (your local area) and provides care in the home of a patient and family. A community nurse works alongside your child's team at the hospital but does not replace them.

Dyspnoea: The feeling of breathlessness, or being unable to breathe adequately. Dyspnoea can cause anxiety, being anxious can make it harder to breathe. Dyspnoea can be treated with medications.

End of life care: The care given to a child when their condition has deteriorated and they are close to death. The period of end of life can be different for each child and may vary from hours to days to weeks or months.

Goals of care: How much treatment parents/carers want for their child. This may include the location where they want them to be or things they might like to achieve (such as birthday, holiday, and school dance). Discussions that establish the goals of care and treatment options (for example intubation, ventilation, CPR) usually occur with the medical team when a child's condition has deteriorated.

Hospice: In Australia, hospice generally refers to a place where children with a life limiting illness and their families can go for a break (respite). For a child who is deteriorating, some families choose to go to a hospice for end of life care. Hospices have experienced palliative care staff available and provide care in a home-like environment. An example of a children's hospice is Bear Cottage in Manly, Sydney.

Informed decision-making: Parents and carers are able to make informed decisions when they have been given enough information about their child's condition. Parents/carers need to have a good understanding of this information and the treatment options that are available to help them make an informed decision that is right for their child and family.

Location of care: The place where a child is receiving care. This is commonly at home, in hospital or a children's hospice.

Noisy breathing: When death is near, breathing can often become rattly or noisy, due to pooled secretions in the throat. This can be distressing to listen to, but is rarely of concern to the patient. It is usually a sign that death is near.

Paediatric: Infants, children and young people aged up to their 18th birthday

Palliative care: Skilled support and symptom management given to improve the quality of life of patients who have a serious or life-threatening illness

Palliative Care Team: Specialist health professionals (doctors, nurses, psychologists, social workers, physiotherapists, occupational therapists and child life therapists) who have skills and experience to provide a high level of care for a person with a life threatening illness and their family. They also guide and support other health care professionals involved in the care of the child.

Quality of life: An assessment of a person's own sense of wellbeing, such as their level of comfort or ability to enjoy or pursue daily activities without suffering.

Spiritual support: Spirituality can be difficult to describe but can be anything that shapes beliefs and brings understanding and meaning to our lives. It is those things that bring hope, purpose, comfort and a source of strength. It is often through connection with people or things that have meaning or are sacred. Spirituality can be defined through religion or belief in a God, being, or higher power. It can be through faith, prayer and meditation or, for example, time to reflect on your own or with someone else. For some people, spiritual support is just having those they love around them and for others strength is drawn from a deep faith.

Terminal care: Care provided in the last few days or weeks of life

Breathing (respiratory) support terms:

Bag and mask: Handheld emergency resuscitation equipment used to provide oxygen to a patient who is not breathing. The mask is fitted over the patient's mouth and nose using a tight seal to optimize breathing. The attached air bag can then be squeezed to push oxygen into the lungs.

Bi-Pap/CPAP (Bi-level Positive Airway Pressure/Continuous Positive Airway Pressure):

A non-invasive machine (that is, there are no tubes going into the child's body) that can assist children to breathe. It does not require the insertion of tubes into the child's airway. The child will need to wear a fitted face mask that is connected to the BIPAP/CPAP machine. This type of breathing support can be given at home. This is a non-invasive treatment.

Intubation: An airway tube that is inserted into the mouth or nose of a child to help them breathe if they are unable to properly do so themselves. Intubation is used to assist breathing. It is regarded as 'invasive' treatment.

Oral airway suction: Occurs when a tube is inserted into the mouth or nose of a child and removes secretions. Suctioning is necessary when a child has difficulties swallowing or has increased secretions that affect their ability to breathe.

Oxygen: Children may require extra oxygen (supplemental oxygen) for a number of reasons (such as a severe respiratory infection). A child's respiratory doctor will usually decide whether extra oxygen should be given. Oxygen is considered a medication because of its ability to affect the body.

Oxygen saturations or 'sats': A measurement or estimation of how much oxygen is in the blood.

Terminal breathing: Irregular and very shallow breathing, usually with long pauses. This can be a sign that death is near.

Tracheostomy: A surgical procedure to cut an opening into a child's windpipe (trachea) so that a special tube can be inserted to assist with breathing. A tracheostomy can be permanent or temporary. This is an invasive procedure.

Ventilator: A breathing machine designed to breathe for a child when they are unable to do so themselves. A ventilator is a common piece of equipment used in intensive care units. When a patient is on a ventilator they are often referred to as being "ventilated".

We would like to thank the children (patients and siblings) who have generously contributed to the beautiful artwork that has been used for this booklet.



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