

When your child is diagnosed with a suspected life-limiting condition, your journey begins.

This section:

- looks at the early information needs many families have
- outlines palliative care and what kind of care you can expect to receive
- describes the roles of the different health professionals you may come across
- provides hints on how to find reliable health information about your child's condition and possible treatment options
- includes information about your rights and responsibilities
- provides information on accessing financial support.



## 2 – GETTING READY

'I wish we had understood palliative care better—we would've used them more if we knew then what we know now.'

'Our first thought was: Who's going to help us?'

'You don't get information unless you know the right questions to ask.'



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## 5 – WHAT IS PALLIATIVE CARE?

### Key points

- Palliative care is care for people who have a life-limiting illness for whom the primary treatment goal is to maximise quality of life.
- A life-limiting illness is an illness that is expected to result in early death.
- Palliative care incorporates a ‘whole-person’ approach to caring—managing physical pain and other symptoms, together with emotional, spiritual, social, and cultural care of the person, their family and carers.
- Palliative care can be provided in many care settings including hospitals, hospices and with the right support—your home.

### About palliative care

The focus of palliative care is on improving the quality of life of the patient and their family and carers. It is also about maximising care choices.

Palliative Care:

- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help children live as actively as possible until death
- will enhance quality of life and may positively influence the course of an illness
- provides relief from pain and other distressing symptoms
- can be introduced early in the course of an illness alongside cure-oriented treatment or treatments that are intended to prolong life - this may include chemotherapy or radiation therapy, and investigations needed to better understand and manage distressing clinical complications
- offers a support system to help the family cope during the child’s illness and in their own bereavement
- uses a team approach to address the needs of children and their families, including bereavement counselling if required.<sup>1</sup>

<sup>1</sup> Adapted from: World Health Organization, 2010, *WHO Definition of palliative care*, [www.who.int](http://www.who.int).



See Journeys Resource List  
Palliative care information

'We didn't realise that palliative care was more than just end-of-life care... We wish we had understood the true role of palliative care and the importance of maintaining a constant relationship with the local team.'

### About palliative care for children and teenagers

The national standards for palliative care are the same for all Australians.<sup>2</sup> However, palliative care for children and teenagers is slightly different from palliative care for adults because of the need to provide care that:

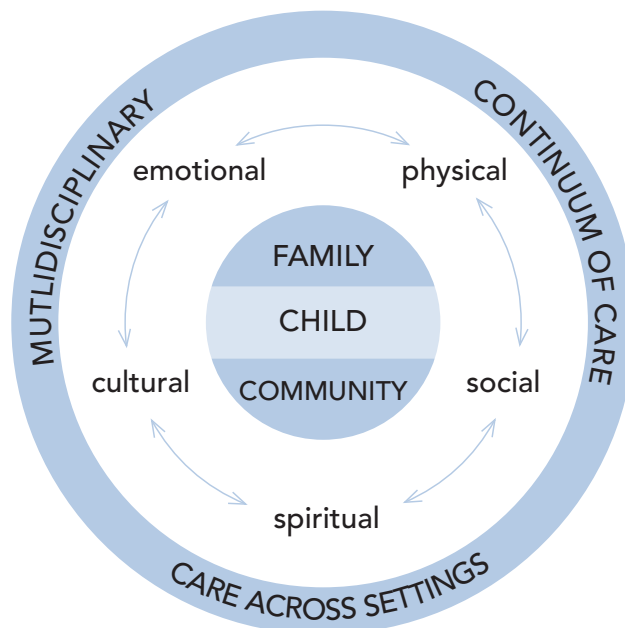
- embraces the whole family as well as the child
- involves health professionals with specialised skills in the care of children
- supports families as they care for their sick child and their other children
- understands the different responses by children to symptoms and their treatments.

Because there is often uncertainty about the child's prognosis, palliative care may require an approach that combines palliative care with cure-oriented treatment. The delivery of palliative care seeks to ensure the best quality of life and a 'hope for the best, prepare for the worst' approach.

The timing of referral to a palliative care team is your choice, but starting the relationship early can mean better preparation and support. Palliative care for children and teenagers is about maximising choice — choice about the care your child and your family receive. You will be supported by your care team in making decisions about the care of your child. Having choices and making decisions may also help you feel more involved and in control.

The diagram below illustrates the palliative care model and how the child, their family, and community are the centre of care regardless of where the care is provided and who is involved in providing this care.

### Palliative care for children and teenagers



Adapted from: Australian Government Department of Health and Ageing, 2004, *Paediatric palliative care service model review: Final report*, Canberra.

<sup>2</sup> Palliative Care Australia, 2005, *Standards for providing quality palliative care for all Australians*, Canberra

## 6 – WHO PROVIDES PALLIATIVE CARE?

### Key points

- Palliative care is provided by a number of people working together as a team with a shared goal to meet your needs when and where you need it.
- Your team may include nurses, doctors, social workers, volunteers, pastoral care workers, and allied health practitioners.
- You and your child are the most important members of the care team.
- Identify a key coordinator (e.g. general practitioner, clinical nurse consultant) to work with you to plan, coordinate and communicate all the care provided by the different members of the care team.

### Care providers

Care providers may be based in a hospital or in the community. They may visit you at home, at school or in hospital. A multidisciplinary team has members from different areas of expertise in health care who work together.

#### Your care team

The members of a care team will depend on your child's and your family's needs. The aim of the care team is to provide the best continuous care, even though the actual members of the care team may change over time.

You are the primary carer and the care team is there to provide guidance, education and support for you and your child. Open and honest communication between you and your care team will help make this happen.

A typical care team includes:

- care providers from your local community e.g. district or community nurse, general practitioner, local pharmacist
- specialised medical consultants e.g. paediatrician, palliative care nurse
- allied health professionals e.g. social worker, physiotherapist, occupational therapist
- pastoral carers e.g. priest, chaplain, rabbi
- complementary therapists e.g. massage therapist, music therapist.



See Tool 1

Care team contact list  
Page 45



See Chapter 4

What do people do?  
Page 20

'We met with a metabolic paediatrician and a paediatric palliative care nurse and straight away started planning for what would happen and how we could cope with each hurdle. I still believe that without these wonderful medical support people, Leon and I would have been crushed.'

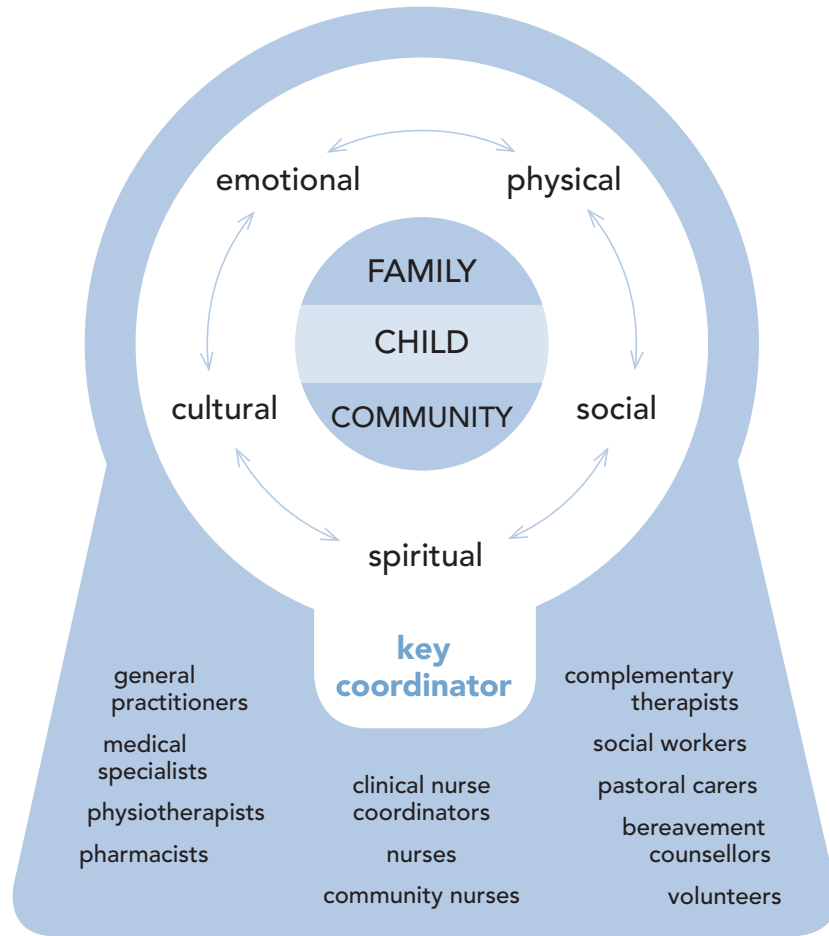


See Journeys Resource List

Community and social support

'A very important part of dealing with Brianna's illness was the vital people around us who kept us afloat. Our GP was brilliant. The women's health nurse from community health came out occasionally to look after Brianna and also organised a cleaner. We had a carer who came for two hours each day just to hold Brianna while I went for a walk or did a bit of gardening or picked up my boys from the school bus.'

### Roles of people involved in the care team



Your key coordinator is the person from your care team who has the role to plan, coordinate and communicate, to all care team members, the current care arrangements for your child. The key coordinator ensures the whole team is working well together on your behalf. Identify who your key coordinator is and make sure you have their contact details so you can ask for assistance if new issues or problems arise.

Your key coordinator will also help you and your family prepare and learn new skills in caring for your child.

### Other support groups

A wide range of other services are available to your child and family. Being able to use some of these services may depend on where you live. See the resource list at the end of this book for more information on:

- palliative care organisations
- community support organisations
- voluntary organisations
- pastoral care services.



## 7 – RELIABLE HEALTH INFORMATION

### Key points

- Knowledge about what might happen and how to respond will help you and your family to make choices and plans
- The best source of health information can be your child's care team.
- Reliability and appropriateness are important considerations when searching for health information.
- Do not be afraid to ask questions. Your care team is used to hearing and responding to all types of questions. Asking the same questions again is okay too.
- Sometimes your questions may not have any answers. Sometimes questions cannot be answered with absolute certainty.

### Finding reliable information

You may feel a need to find out more about your child's condition, including treatment options and disease details and supports.

Knowledge about what might happen and how to respond will also help you to be more informed and give you a greater sense of control.

This chapter will help you find sources of information about your child's illness.

#### *Ask your care team*

The best source of health information can be your child's care team. Don't be afraid to ask for more information. You are entitled to have access to the most reliable information possible. Chapter 9 has further information on your rights and responsibilities.

Sometimes, your questions may not be answered with absolute certainty. A child can have a set of life-limiting symptoms but not a complete diagnosis of what the causes or illness are. However, you can expect to have your questions answered honestly by your care team.

*'I spent endless hours on the internet each night searching for information, answers and miracles. It was exhausting, but it was one of the few things I could do to feel useful.'*

'I called the association and they sent me booklets and pamphlets on MPS. The information was a big help though a little confronting at first as all this was new and I thought everything they said in the booklet was going to happen today, not gradually.'



See Chapter 9

Your rights and responsibilities  
Page 39

### Asking questions

Write down questions or concerns that are important to you and ask members of your care team.

After attending meetings or important decision-making sessions, it may be helpful to ask for a written summary from your key coordinator.

Take a support person with you. It would help if it was the same person each time.

If possible, plan on talking about sensitive issues while your young child is not present.

Take notes in a diary or journal. This is the best way to keep track of what was said and when.

It's all right to ask the same question a few times if you don't understand something.

Your care team members are used to hearing all sorts of questions and answering questions is part of their job — just ask.

Ask your key coordinator how you can get answers to other questions you may think of later.

Ask for advice on where to get more information, including written information.

Ask to reschedule meetings if significant family members are unable to be present.

Adapted from: Hudson, P. 2004, *Supporting a person who needs palliative care: A guide for families*, Palliative Care Victoria.

Some general questions for you to consider are:

- What can be done to keep my child comfortable?
- What can I expect as my child's condition progresses?
- What can we expect from this treatment or procedure?
- How are services provided after hours?
- How and where can my child receive short-term in-patient or respite care?
- Are there any new treatment options we can try?

Don't forget to ask the questions that nag at you in the early hours of the morning.

### Assessing sources of health information

Seeking out further information on your own is something that many parents do. It can give you a better understanding of your child's disease, progression and impact. It can also give you a greater sense of control over your situation and the choices available. However, seeking out information on your own is a personal choice and not for everyone.

Not all information is wholly accurate. When looking for health information, the reliability and appropriateness of the information are always the most important things to consider. You can share the information you have found with your care team so that they can work with you. The following checklist may also help.

#### Questions to ask about health information

Who is providing the information?

When was this information published? How up to date is it?

Do you understand the information or is it full of medical jargon?

Does this resource provide links to other reputable resources?

Does this person or company have a commercial reason to promote a particular product?

Does the resource discuss the risks as well as the benefits of a particular approach?

Adapted from: Consumers Health Forum & National Prescribing Service, 2007, *Using the internet to find reliable health information*; Consumers Health Forum, 2008, *How to assess health information websites*, [www.chf.org.au](http://www.chf.org.au).



See Journeys  
Resource List

Health information  
and services

## 8 – TREATMENT OPTIONS

### Key points

- There may be many treatment options available for your child.
- All treatments require careful consideration on what is involved, the possible benefits and whether the benefits outweigh the possible risks or side effects.
- Conventional medicine involves treatments practiced by medical doctors and by other health professionals.
- Complementary therapies are treatments that may be used together with conventional treatments.
- Gather as much information as you need, in writing if you prefer, and take time to be certain about treatment options before making a decision.
- Your care team is a good source of information about treatment options.

### Thinking about treatment options

*‘Although we longed for a miracle, we didn’t want to put our son through unnecessary treatments and trusted our doctors’ advice—their compassion was what helped us know they had our best interests at heart.’*

As your child’s illness and symptoms change, so may treatment. This can be a challenging time as parents and care providers are required to make decisions about treatments in the best interests of the child. There can be a difference between what someone can do and what someone should do.

All treatments, whether conventional, complementary or alternative, require careful consideration. The potential benefits need to be balanced with a clear view of the risks and whether the risks are worth the possible improvements. It is helpful to get as much information as you need and take as much time as your situation allows before making a decision about treatments.

Each child is different and each illness is different and can behave differently in each body. It is important to learn, with the help of your care team, about your child’s illness and how it affects your child. Sometimes, you may find that certain treatments are not the best option for your child.

Knowing exactly what is involved in the possible treatment will help everyone involved have a clearer picture about what to expect.

A list of useful questions you might use when considering different treatment options is included later in this chapter. Your care team is a good source of information about possible treatments and you can discuss the various options with them.

## Conventional medicine

Conventional medicine involves treatments that are practised by medical doctors and by other health professionals, such as physiotherapists, psychologists and registered nurses.

It is usually through conventional medicine, such as scans, blood tests and x-rays, that families find out about their child's illness. Life-limiting illnesses can be complex and conventional medicine cannot always provide a clear diagnosis or promise a cure. However, at all times, the care team will use all its skills to ensure the children in their care live the most comfortable and active lives possible. Doctors and nurses who have experience with your child's illness will help you work out which medications and therapies will best help your child.

Monitoring your child's condition may involve ongoing medical tests, and visits with your care team will allow you to discuss how well your child's treatments are going and when changes are required.

*'I was under so much pressure from friends and family sending me information and stories about cures. I was losing confidence in my ability to decide what was best. Luckily, I could discuss this openly with my care team.'*

## Complementary treatments

Complementary treatments can also be known as traditional treatments. The term traditional, in this context, refers to the treatments that have been recognised by different cultural groups and indigenous peoples. Examples of complementary treatments include vitamins, minerals, nutritional and herbal supplements, massage, aromatherapy, music therapy and homoeopathic remedies.

Although usually not evidence-based, care teams generally recognise certain complementary therapies can be an important part of your child's medical care, particularly when they improve general wellbeing.

Most palliative care professionals will be sympathetic if you choose to explore complementary treatments. Your care team may warn against any they believe are harmful, but you will always have the right to choose treatment options without this changing in any way your right to the best care from your care team. You may like to review Chapter 9 on your rights and responsibilities in palliative care and Chapter 7 on reliable health information.



See Journeys  
Resource List

Complementary  
treatments

## Questions to help guide you

The box below contains questions to think about when considering different treatment options.



See Journeys  
Resource List

Health information  
and services

'My son (16 yrs) had a moderate to mild intellectual disability so he did not take part in decisions affecting his treatment. The only option we were offered was to operate on his heart but the chances of the operation being successful were very low. We decided against it. We felt we wanted quality of life not quantity of life for Bwembya. He had been through too much pain already and we didn't want to put him through more pain.'

### Questions about treatments, therapies or products

Is it safe? What are the expected or possible side effects?  
Do the benefits outweigh the risks?

Will it interfere with the amount of quality time you have left with your child?

Is it intended for the same condition your child has?  
And for the same age?

How does it work? Is there any proof that it works?

Can you get a second opinion?

Is it compatible with medications your child may be taking? Are you allowed to continue with your current medications on this treatment?

Do care team members know about the complementary therapy you are considering?

What does it cost?

What's involved? Will it be uncomfortable for your child?

Is the person giving the therapy qualified or experienced? Are they an accredited member of a professional society or similar group?

If you are worried or not satisfied, will you be able to say so?

At what point do you review the treatment and how do you measure if it has worked?

Tool 2 contains more information on making decisions about your child's treatment and care.



See Tool 2

Decision making  
Page 46

## 9 – YOUR RIGHTS AND RESPONSIBILITIES

### Key points

- You, as primary carer for your child, have a number of important rights as well as responsibilities.
- Knowing these rights and responsibilities will help you communicate with your care team and ensure the best care for your child.
- If your child is under 16, or you are the legally appointed guardian of your child, you have the legal responsibility to make decisions in the best interests of your child.
- At age 16, a child is legally able to make their own decisions, independent of your views. However, in practice, this will depend on many factors such as their intellectual, health and communication abilities.
- Decisions are not set in stone — you and your child have the right to change decisions at any time.

### Understanding your rights

In caring for their ill child, parents and primary carers have the most important role. However, this can also be a difficult role. They are their child's voice and are required to 'stand up for' or advocate for their child's wishes when decisions about care are made.

'Having a non-verbal, intellectually disabled teenager did impact on our responsibilities. We were ultimately responsible for ensuring his rights first and then our rights as carers.'

## Your palliative care rights as parents and carers for children and teenagers

### Your right to be informed

- to have any question answered as honestly and as fully as possible
- to be given information in a way and form that you can fully understand and use
- to seek further information or a second opinion before making a decision - including understanding the benefits, risks and side effects of all treatment options
- to have access to other organisations and government services that may be helpful, for example bereavement support.

### Your right to be involved in decision making

- to participate in all decisions about the care options for your child — including the decision to refuse treatment to the extent permitted by law
- to say no at any time you and your family are not comfortable
- to choose someone else to make the decisions on behalf of you and your family
- to have access to a professional mediator.

### Your right to change your mind

- to change your mind about your child's treatment or care at any time — even if the treatment has started.

### Your right to be heard

- to have your opinions heard and respected
- to be able to say no to things that you do not feel comfortable doing, including participating in research projects
- to have any issues or complaints about the care being provided to your child discussed.

### Your right to receive compassionate, supportive care that respects your child's and your family's needs, regardless of beliefs, religion, lifestyle, social or economic background

- to have access to respite or other care as required.



### Your palliative care rights as parents and carers for children and teenagers

Your right to receive care in a professional, safe environment

- to have all care provided in a competent and professional manner
- to know the professional qualifications of all people involved as members of your care team.

Your right to confidentiality of your child's personal records

- to have your child's records only given to those persons directly involved in the care of your child
- to have your privacy respected at all times.

Your right to decide the role you play in the care of your child

- to decide the role you wish to play in your child's direct care without the pressure to choose any specific option
- to change your mind, and be able to access other care setting options at any time.

Adapted from: Palliative Care Australia, 2005, *Standards for providing quality palliative care for all Australians: Patient rights and responsibilities*, Canberra.

If your child is under age 16, or you are the legally appointed guardian of your older child, you are required to be the decision maker in your child's care. At age 16, a child is legally able to make their own decisions about their care. However, this can present many significant challenges. The child needs to be fully informed and able to make decisions based on this information. When a child is sick, there are many situations where this may not be possible, for example when the teenager no longer has the capacity to communicate. Every child is different and as this aspect of decision making can result in conflict, it should be carefully discussed with everyone involved.

## Understanding your responsibilities

As the key member of your child's care team, you have a number of responsibilities. Your care team is there to help you with these responsibilities.

'Because Lewis was 16, I assumed he had rights to decide his treatment, although it was never made explicit. I respected the choices he made because it gave him some control over his life, but it was hard for me. For instance, when he was in the hospice and very weak, he was given the option of taking another course of chemo. He wanted it, because he was so optimistic, but I felt it was futile and probably harming him more. However, I let him do it because he needed to affirm that for himself.'

'I wanted to care for John (age 19) at home. However he was determined to be in the hospital as he said he felt safe with all his friends around him. It took me a little while to come to terms with his decision – as I felt so helpless – but in the end he was really happy with his decision and we worked out how I could be more involved.'

### Your palliative care responsibilities as parents and carers for children and teenagers

Your responsibility to keep well informed

- to ask all your questions and find answers, with guidance from your care team
- to find out the benefits, risks and side effects of all treatment options being considered.

Your responsibility to be actively involved in treatment and care decisions

- to be involved or to choose someone to be involved and make decisions on your behalf
- to try to make decisions based on reliable accurate information from trusted sources
- to seek advice from your care team and others to help make decisions.

Your responsibility to communicate openly and honestly with all members of your care team

- to provide all relevant information to the care team. Your team can only provide the most appropriate care if they know all the necessary information about your child. This includes many issues such as use of alternate treatments that you sense may not be agreed with.
- to answer questions honestly
- to always tell the care team if you have issues or complaints with the care being provided.

Your responsibility to look after yourself and your other family members

- to encourage yourself and your family to practice self-care activities to reduce stress and promote wellbeing
- to give each other permission to take time out to reenergise and rest, so that everyone is able to provide the best care for the child.

### Health complaints

It is important that you communicate clearly with your care team about your experiences, expectations and issues. Feedback that you provide to your care team is very helpful for making improvements to services provided.

There may be times where you feel it is important to lodge a formal complaint. Complaints are best lodged, in the first instance, with the complaints officer or other relevant person at the service with which there is a problem. Complaints can also be lodged with the Health Ombudsman or medical and nursing registration boards in your state or territory. See the resource list for contact details.



See Journeys Resource List  
Rights and responsibilities

## 10 – FINANCIAL SUPPORT

### Key points

- A number of government and non-government services and charities can help with the costs of caring for your child.
- Ask your key coordinator about which member of your care team can help you gain access to these services.
- The Australian Government, through Centrelink, provides a number of support payments. These payments can cover support for carers and may extend up to 12 weeks after the death of your child. Establishing a single person as your contact with a Centrelink office will help you access all the benefits you are entitled to.
- Your doctor will often be required to complete certain forms to confirm your child's condition.
- The Australian Government under Medicare subsidises healthcare costs through the Medicare and Pharmaceutical Benefit Scheme safety nets.
- Other financial support services include equipment programs, accommodation services and travel services.

### Financial support options

The resource list at the end of this book includes information and contact points for financial assistance you may be able to access.

Accessing services may require completion of forms and paperwork. Don't hesitate to ask for assistance from your key coordinator and social worker to help complete these forms.



[See Journeys  
Resource List](#)

[Financial support](#)

The following types of programs should help reduce the financial burden on this journey. Your care team can provide more information.

*'Our finances were hurting—we had both taken work off to care for our child, wanted the best treatment for him, and had to borrow money from family just to get through. It was a part of his illness we weren't prepared for.'*

### Types of support

#### Income support

Parents and carers may need income support to help them during their child's illness if they are not working. This support may include the Carer Payment and the Carer Allowance. The amount of the allowance will depend on your personal circumstances. It is helpful to locate a single contact person within Centrelink to help you access all the benefits you require.

#### Subsidised healthcare costs

Your child is likely to have care provided in a range of care settings. Every Australian is entitled to access public hospitals at no cost. If relevant, you may wish to check your entitlements with your private health fund and identify any gap payments with your provider.

When your child is in the care of your GP, x-rays and blood tests are covered by Medicare, while medications are covered by the Pharmaceutical Benefits Scheme. It is helpful to speak with your doctor, pharmacist and Medicare to ensure you are obtaining all the benefits you are entitled to. Centrelink may provide you with a Health Care Card which will further reduce the health care costs for medications and doctors' visits.

#### Equipment programs

Specialised equipment such as oxygen pumps and syringe drivers may be important to help you care for your child at home. A number of programs can loan equipment or help cover the costs.

In the case of long-term home care, you may qualify for modifications of your home to help make it safer and easier to care for your child.

#### Respite and accommodation services

Accommodation may be required for times when you travel to a distant hospital or when your child spends time in a respite home. There are a number of options that may suit your and your child's needs.

#### Travel support

Your child and your family may have to travel long distances to receive the required care. There are government schemes which contribute to the cost of travel.

#### Home help services

Help with shopping, gardening, general chores and child care support may also be available.

## TOOL 1 – CARE TEAM CONTACT LIST

It is helpful to keep a list of your care team members with you. Include their location/address, phone and pager numbers, and role to identify who they are—for example, key coordinator/team coordinator, doctor, nurse, general practitioner.

Name:

Location:

Contact #:

Role: **key coordinator**

Name:

Location:

Contact #:

Role:

Name:

Location:

Contact #:

Role:

Name:

Location:

Contact #:

Role:

Name:

Location:

Contact #:

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## TOOL 2 – DECISION MAKING

### *Making decisions and planning care*

While there are many things we cannot control, there are important choices that can be made about the care of a child with a life-threatening illness. Parents share the difficult task of making these decisions with the help of doctors, nurses, and other health professionals. Parents know their children better than anyone else. Doctors and the rest of the care team bring experience and specialist knowledge.

It is often helpful to think about and discuss what the best approach would be if your child were to deteriorate suddenly. This is called advance care planning. Sometimes doctors and parents are unsure how to raise the question of decision making. Signaling to your child's doctor that you are ready to talk about some of the more difficult aspects of the illness and its treatment can help facilitate important discussions.

### *What decisions will I be asked to make?*

#### **What is the overall goal of care?**

When a child cannot be cured of their illness, or when a cure is extremely unlikely, the focus of care may shift. This may involve attempting to prolong the child's life for as long as possible, or to ensuring the time that remains is as full of life and happiness as it can possibly be. Sometimes there is a choice to be made between length of life and quality of life.

Prolonging life or pursuing a cure when this is unlikely nearly always comes at a cost, and parents can find themselves torn. Do you leave no stone unturned in the search for a cure or do you ensure your child does not suffer? These can seem impossible choices and different families may make different decisions when faced with identical circumstances.

It is important to know that palliative care, including the management of pain and other symptoms, can be combined with ongoing efforts to cure your child's disease or prolong their life, if such efforts are considered to be in the best interests of the child.

#### **What treatments are and are not appropriate?**

There may be many treatments that are possible. But distinguishing between what **could** be done and what **should** be done is important. What are the benefits and burdens of the various treatments? Only the individual child or those who know and love them can know what is a burden and what is a benefit to them. For example, some children feel frightened and distressed when they are in hospital, while others feel safe and may even enjoy the activities on offer there.

### *The process of decision making*

The key word here is 'process'. Where circumstances allow, take time to seek information, to think, and to talk with experts and with friends and relatives.

#### **Gather as much information as you can**

Meet with the health professionals involved in your child's care and ask questions. You may need to ask the same question a few times to fully understand the answers. It may also be helpful for you to see blood test results or scans.

#### **Ask yourself some key questions**

- What are the most important things to you and to your child?  
It can be hard to distinguish between what you may want for your child and what they might want for themselves. Even if your child is very young, it may be helpful to think what they might say if they could speak for themselves.
- If time was limited, what would make this time the best it could possibly be?
- Ask your child some key questions. An older child may not be able to participate fully in decision making but may be able to offer a perspective on how they experience their illness and treatment.

What is most important to them?

What are their hopes?

What are their worries?

Talk together as parents. You may not always see things the same way at the outset so it is important to respect each other's views and continue talking.

Seek support from family, friends, and from your spiritual or cultural community. There may be key individuals who are of special value. It's okay to ask if they can be included in discussions with the care team.

### *Once a decision is made*

Once important decisions are made, it's crucial that everyone involved or likely to be involved in your child's care is informed. Many hospitals and palliative care services have documents where these decisions are recorded. This does not necessarily mean the decision is legally binding. Decisions will need to be reviewed as your child's condition changes.

### *A word on hope*

Even in circumstances where there seems to be no hope for a child's survival, many parents find they simply cannot accept it. In their head they understand, but in their heart hope remains. This is okay and hoping for the best while preparing for the worst may be a helpful way to approach the situation. Hope can also be refocused on goals such as going home, comfort, or time.







