

'Sun shining on a tree laden with pink flowers' by Nicholas, 7 years old



A Family Companion

Paediatric
Palliative Care

A Family Companion

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Palliative Care Australia

P.O. Box 124

Fyshwick ACT 2609

T: 02 6232 0700

E: pcainc@palliativecare.org.au

W: palliativecare.org.au

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Palliative Care Australia has collaborated with Paediatric Palliative Care Australia and New Zealand to produce *A Family Companion*.

A Family Companion is an updated version of *Journeys: Palliative Care for Children and Teenagers* (2nd ed. 2010), which brought together many extraordinary parents, health professionals, family members and carers to share their personal experiences to help others.



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Introduction

'A Family Companion' is designed for parents and carers of babies, children and young people with a life-limiting condition or illness. This resource aims to prepare you for the situations and challenges you may face with regards to your child's illness.

The information seeks to support parents and carers in their role as champions and decision-makers for their child, with each section exploring stages of your child's illness and what you might expect.

The resource is also helpful for extended family members, close friends and your support network to read and understand the difficult issues that may arise after the diagnosis or recognition that your child has a life-limiting illness.

Additional resources on a range of topics are available to further assist you and your family. To access these resources please visit palliativecare.org.au/children.

Throughout this resource, we refer to the child or children as any age from before birth up until 18 years of age.

The only exception to this is on page 4 under the heading *what are my child's rights?* in which information is provided on legal age for decision making.

A life-limiting illness is an illness with no reasonable hope of cure and from which babies, children or young people will probably die. Throughout this resource, the term life-limiting illness also includes life-limiting conditions.

How do I get more information?

Educating yourself about your child's illness is an important part of managing their care. There may be a large amount of information available about your child's illness however it is important to try and ensure that it is reliable and relevant to your situation. The best source of health information is your child's care team.

Speak to your child's care team

Don't be afraid to ask for more information. Sometimes, your questions may not be answered with absolute certainty, especially if your child has a number of life-limiting symptoms but not a complete diagnosis.

Even if there is uncertainty about your child's illness, you can expect to have your questions answered honestly by your care team.

Some questions to consider asking your care team include:

- › What can I expect as my child's illness progresses?
- › What can I expect from this treatment or procedure?
- › What can be done to keep my child comfortable?
- › How and where can my child receive care?
- › How are services provided after hours?

Other sources of health information

While health information can be widely available, it may not be as reliable as the information given to you by your care team and other health care providers. It is best to carefully assess other sources of information as they may not be accurate and can be dangerous or misleading.

Chatting with friends on social media sites can be very helpful for social support, however is no substitute for professional medical advice. If you are interested in learning more about a specific treatment that you have heard or read about, you can discuss the information with your care team so that they can work with you to determine the best treatment options available. If you are interested in learning more about what you have read in a scientific journal, take a copy of the article with you when you next talk to the care team so you can discuss the information together.

Some questions to ask when searching for additional information include:

- › Who is providing the information?
 - › Are they qualified in health care?

In Australia, most health professionals are required to be registered with a regulating National Board (e.g. Medical Board of Australia). You can check if someone is registered on the Australian Health Practitioner Regulation Agency (ahpra.gov.au).
 - › Or if they are a scientist, how many articles have they published and how often do other people refer to their work?
- › How up to date is the information?
- › Is the information clear or is it full of unknown words?
- › Are there links to other reliable sources?
- › Is there a reason why a source is promoting a particular product?
- › Does the source discuss the benefits and risks?
- › Is there a way to contact the author?

For additional information please see the factsheet:

– *Finding reliable information*

What are my rights?

All children have the right to the best quality of life. When they have a life-limiting illness, they have the right to high-quality palliative care to meet their needs.

This includes:

- › Access to age appropriate palliative care within the health care system
- › Access to appropriate pain and symptom management (including medications) for all children
- › Supporting all children and their families to be able to live their lives to the best of their ability for as long as possible

International Children's Palliative Care Network, The ICPCN Mumbai Declaration 2014.

What are my child's rights?

In Australia, a child may be legally able to make their own decisions about their care from the age of 16, if they are capable to do so. Each state has its own laws regarding when a young person can make decisions, however all young people should be informed about their illness and involved in decision-making according to their level of capacity and willingness to be involved.

For a child younger than the legal age, as a parent or a legally appointed guardian, you are required to make decisions about your child's care.

What are my rights as a parent or a legally appointed guardian?

You have a right to be informed:

- › To have questions answered honestly, respectfully and as fully as possible
- › To be given information in a way you can completely understand with good explanation of medical language, use of interpreters and minimal jargon
- › To seek further information or a second opinion before making a decision
- › To have access to other services that may be helpful (e.g. social worker, bereavement support)

You have a right to be involved in decision-making:

- › To participate in all discussions about your child's care
- › To refuse or request treatment to the extent permitted by law
- › To choose someone else to make decisions on behalf of you and your family
- › To have access to a professional mediator — someone who will act as a go-between you and your health care team
- › To be able to change your mind about any aspect of your child's care at any time

You have a right to be heard:

- › To be able to voice your opinions and needs
- › To have your opinions respected in a calm and mindful manner

- › To be able to say no to things you are not comfortable with
- › To voice any issues or complaints about your child's care

You have a right to receive care in line with your family's needs:

- › To have access to respite and other services as required
- › To have care adapted to include beliefs and values according to your spiritual, religious and cultural wishes

You have a right to receive care in a professional and safe environment:

- › To have all care provided in a capable and professional manner
- › To know the professional qualifications of every member in your care team

You have a right to confidentiality:

- › To have your privacy respected at all times
- › To have your child's medical records only given to those directly involved in providing care
- › To give permission to share your child's medical records and health care information with other people

You have a right to decide the role you play in the care of your child:

- › To be your child's voice
- › To be involved in care decisions
- › To decide without the pressure to choose any specific option

Adapted from the Standards for Providing Quality Palliative Care for all Australians, Palliative Care Australia 2018

How do I provide feedback?

It is important that you talk to the care team about your experiences, expectations and any issues regarding your child's care. The feedback you provide is not only important to your child's care but it is also helpful to make improvements to services for others families as well.

If you raise a concern about your child's care, you should receive a timely response from a suitably skilled health professional or team. It is important to note that the type of response from the care team and/or health service will depend on the nature of the concern and the person who raised it.

If after speaking with your care coordinator or another member of your child's care team you still feel that your concerns have not been adequately addressed, there are other avenues to provide feedback. You may wish to speak to someone outside of your care team or the health service should have a complaints officer who you can speak to.

If you feel that the health service has not addressed your concerns appropriately, you can contact the Australian Health Practitioner Regulation Agency or the Health Commissioner or Ombudsman in your state or territory.

Diagnosis or recognition

This section introduces palliative care and provides an overview of treatment decision making and goals of care.

What is palliative care?

Palliative care is not only about end-of-life care. Sometimes it is also referred to as comfort care, comfort treatment or supportive care. It focuses on helping children and families to live as well as they can with a life-limiting illness.

Palliative care for children with a life-limiting illness is an active and total approach to care. From the time of diagnosis until death, and beyond into bereavement, palliative care includes physical, emotional, social and spiritual care.

Palliative care focuses on improving quality of life for the child, managing symptoms, and providing support for the whole family. Some children receive palliative care for a short time, while others may receive palliative care for many years.

It is common for children to receive palliative care alongside medical treatment aimed at a cure.

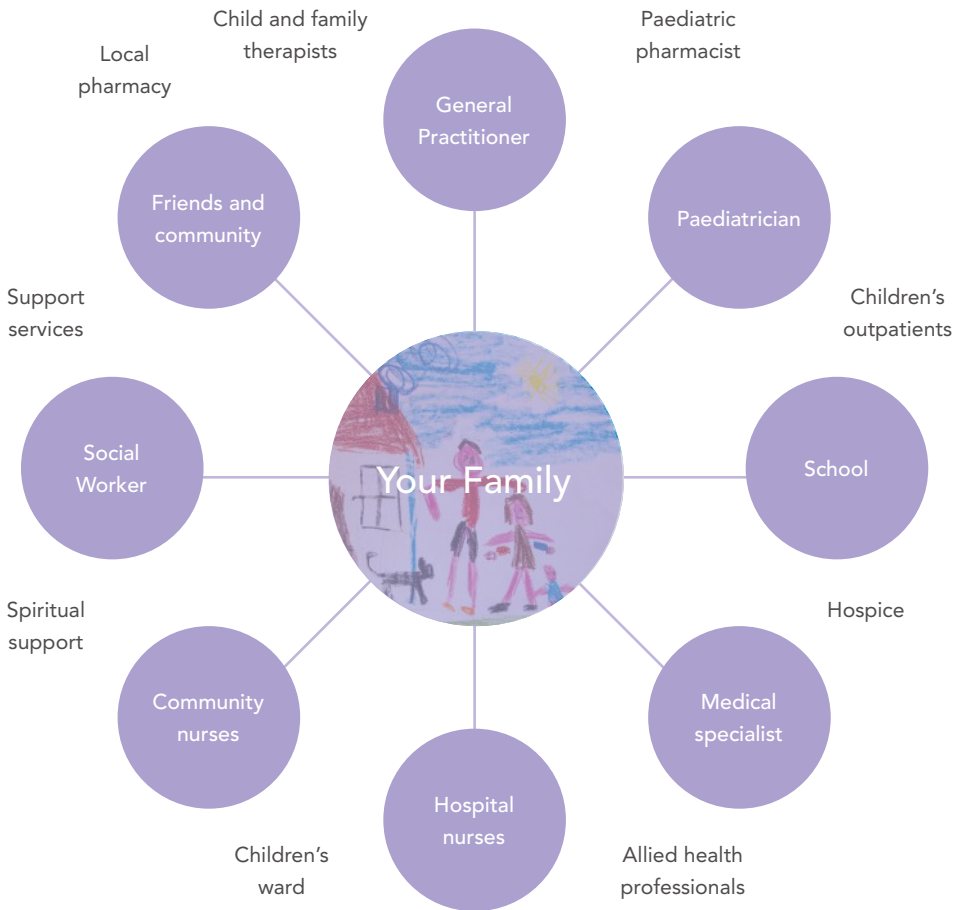
The timing of referral to a palliative care team is your choice, however starting the relationship early can result in improved preparation for yourself and better support for your child. Your primary team may recommend referral to a palliative care team to assist with your child's care. The teams will work together to provide the best care and support for your child and family.

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

Who provides palliative care?

Palliative care is generally provided by a variety of health professionals and health care providers working together in a care team. Each family will have a care coordinator in their care team who is responsible for bringing together different health professionals to support your child and family.

The care team will be different for each family, but may include many types of health care providers:



What are the treatment choices?

Every child, illness and family is different. With the help of your care team, it is important to learn about your child's illness and how it affects them. There may be a variety of treatment choices available for your child. It is worth noting that all treatments require consideration of what is involved, the possible benefits and risks and whether the benefits outweigh the risks. You may decide certain treatments are not the best option for your child.

Gather as much information as you need and take time before you make a decision. It is important that you don't feel alone with decision-making and to speak with your care team who can answer questions and offer support.

Some therapies may not be recommended as they may interfere with your child's treatment and/or increase side effects, or be ineffective. Always talk to your care team before commencing any therapies.

Participation in a clinical trial may be offered by your care team. Trials undertaken by large children's hospitals are held to very high standards and are offered when the hospital has sufficient evidence there may be a potential benefit of the trial. Sometimes, 'trials' or experimental therapies are offered by unqualified or unregulated people so it is important to check with your care team if you are considering participation.

For additional information please see the factsheets:

- *Finding reliable information*
- *Decision making*

What are goals of care?

How do we talk with our care team?

'Goals of care' refer to the overarching goal/s everyone wants to achieve for your child. In some cases this might be survival at all costs or it might be a focus on comfort. It may also be something in between where families and the care team will try and find the best balance between these two goals.

You will have an opportunity to talk about your hopes, wishes and concerns for your child and family, which will be central to the planning process.

You will be supported to play an active role in the care your child receives and to have a say about how and where they are cared for.

It is important that your child's and family's needs are reviewed regularly. If you feel you need an earlier or later review, you can ask your care coordinator.

When discussing goals of care, you can expect the following:

- › A good allocation of time for open discussion
- › A room to ensure privacy
- › The staff to be respectful of your values, wishes and concerns
- › Someone with you to support you
- › Written material to support your discussion
- › The opportunity to ask questions
- › Availability of an interpreter

How do we choose?

Care choices are made between you and your care team as your child's illness progresses. These choices will also be part of an end-of-life care plan and will be different for every child.

Before you make care decisions it may be helpful to consider the following:

- › What are the most important things to you and your child?
- › If time was limited, what would make it the best it could be?
- › If possible, ask your child what are their hopes and worries?
- › What will be your child's experience of these decisions?
- › How involved is your child able to be in the decision-making process and is this something they want to be included in?

What if we disagree?

Parents share the difficult task of making decisions and planning care for their child, however parents may not always agree on what they want to do. If you have different views, it may be helpful to speak with a member of your care team who can help answer questions and offer support.

"We felt as long as we had some sense of control, we could handle most things."

How will people know about our decision?

Once important decisions are made, it is essential 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. These decisions may be recorded in different documents, for example in a care plan or an Advance Care Directive. Decisions and plans will need to be reviewed as your child's condition changes. If you have any questions or concerns about the documentation and/or how your decisions will be communicated to those caring for your child, speak with a member of your care team who can help answer your questions.

For additional information please see the factsheet:

– *Decision making*

Artwork by Zoe



Ongoing care

This section explores places of care, care planning, symptom management, family concerns and support from your family, friends and community.

Where can my child be cared for?

Children can be cared for in their home, in hospital, or in a hospice where available.

As your child's illness progresses and transport becomes difficult, your child may spend time in more than one place. Your care team will make arrangements so the care provided reflects your choices.

You can change your mind about place of care at any time during your child's illness.

Can I care for my child at home?

In the early stages of a life-limiting illness, children will often be active and have little discomfort. They are likely to be at home, attending school and participating in activities.

It may be possible for your child to be at home with you throughout their illness. Some of the benefits of home care may include:

- › Sick children are often happier in their own space with their toys, pets and family
- › Your family can be together and be as involved as they like in your child's care

- › You may feel like you are better able to provide support to the whole family
- › Privacy and comfort are easier in a familiar environment
- › You may feel more in control of your child's care

Speak to your care coordinator about care and other support services that may be provided in your home. The care and support services offered to you will depend on where you live, what your child's care needs are and the resources available. Your family General Practitioner (GP) may be a key member of the care team for you at home.

Can we go to a hospital or children's hospice?

A hospital or hospice provides full-time care for your child and onsite access to health professionals. These services aim to meet the physical, emotional, social and spiritual needs of children and their families. Children's hospices deliver care in a child and family-friendly purpose built building and offer a wide range of support, which may include respite care, transitional care between hospital and home and for end-of-life care.

You may choose to be in a familiar hospital ward when your child is very unwell or to attend a more local hospital if this can be arranged.

Each hospital and hospice has its own set of programs and arrangements. Talk to your care team about your wishes and the option that is right for your child and family. You can also talk to them about personalising your child's room in the hospital or hospice.

There are three children's hospices in Australia:

- › Bear Cottage
Sydney, New South Wales
(02) 9976 8300
- › Hummingbird House
Brisbane, Queensland
(07) 3350 1563
- › Very Special Kids
Melbourne, Victoria
(03) 9804 6222

What is Respite Care?

Taking breaks from caring for your child can help you to care for yourself and your family, these breaks are known as respite.

Respite can assist in recharging your energy and can allow you to spend special time with your other children, your partner and people and activities which support you. There are different types of respite care available, some examples include:

- › In-home care provided by support workers
- › Short-stay admission into a hospital, hospice or disability respite centre
- › Sibling programs like camps, day programs and support groups

- › Asking a trusted friend or family member to spend some time with your child while you take a break

Your care team can help you access in-home and respite care services, if available.

The following suggested questions provide a starting point for these discussions about any worries or concerns you may have regarding respite care.

- › What options of respite care are available to our family?
- › Are there any services which might provide access to a carer, nurse or volunteer for in-home respite?
- › Are there any services available to provide night care?
- › What is the cost of respite care and is it covered under Medicare or private health insurance?
- › What happens if a longer break is needed?

Additional information is also available from: Carers Gateway (carersgateway.gov.au or 1800 422 737) — Carers Gateway is a national service funded by the Australian Government. Carers Gateway includes a website and phone service for carers to access practical information and support.

For additional information please see the factsheets:

- *Child hospice services*
- *Decision making*
- *Where will my child will be cared for*
- *Looking after yourself whilst caring*
- *Supporting someone who is caring for a seriously ill child*
- *Contact list*
- *Helping your partner*

Care plan

How does someone know how to care for my child?

Caring for someone can be a rewarding experience but it can also be exhausting, especially as a child's illness progresses. A care plan is a very helpful tool that communicates your choices to those caring for your child.

The care plan is based on the goals of care, your child's illness, your family lifestyle and the needs of your child and family. It communicates your choices and wishes to those who are caring for your child. The care team can assist you with developing a comprehensive plan to suit your child's individual needs.

Your care plan may include:

- › A basic medical history for new care team members
- › Instructions on routines, playing, feeding, comforting and sleeping
- › Photographs and diagrams to show your child's preferred sleeping, lying, seating or bathing position
- › Helpful tips for solving problems (e.g. if your child becomes restless)
- › What to do and who to call in an emergency
- › Which situations are considered to be an emergency
- › Instructions for medicines and symptom management
- › How to involve and support any siblings

Depending on what works best for you and your child, you may also consider:

- › Developing a care plan for each place of care (e.g. a home care plan and a hospital care plan)
- › Taking the care plan everywhere with your child

You will need to revisit and update the care plan as your child's and family's needs change. Your care coordinator should discuss and coordinate these changes with you. If you are unsure whether your child's care plan needs reviewing, speak to your care coordinator.

For additional information please see the factsheets:

- *Decision making*
- *Symptom management plan*

Symptom management

How do I make sure my child is comfortable?

With the right support and planning, your child's comfort can be well managed.

Your care team will help you to understand:

- › The symptoms to expect with your child
- › What to look for that shows they are uncomfortable (e.g. facial expressions, signs in their body)
- › What you should do if any problems arise including who to call for help
- › How to use medicines correctly and safely

Contact your care team if you have any questions about your child's symptom management, ensuring you have the contact details of the individuals or team/s who you can call at any time.

What can I do about managing my child's pain?

Most parents worry about their child suffering from pain, below are some common signs of pain:

- › Looking tense or stiff
- › Frowning, moaning or crying
- › Not feeling like eating
- › Not feeling like joining in activities
- › Being unusually quiet or cranky
- › Irritation or restlessness
- › Reluctance to move

The key to managing pain is making sure you have your child's medications on hand when you need them. This means having medications with you, understanding how and when to use them and giving them to your child. The care team will assist you in learning how to give your child their medication and how to use any special equipment needed. Children will often need to have regular pain medication to prevent pain from coming back. This will usually be given at the same times each day as well as some extra medication being available if needed. These extra medications are often known as "breakthrough doses".

You will also need to know how long the medication will take to work, how often to give a dose, and how long they are likely to

work for the pain. Ask your team to write a medication plan down for you. A medication chart or simple diary in a notebook will also help with recording the time and amount of medication given. This can also help your care team to work out the correct medications and their dosage level needed to improve your child's pain management because they can see how much you have needed to use.

Other ways to manage pain include resting, positioning, using ice packs or heat packs, massage and distraction.

It is important that you know the common side effects of your child's medications and what to do if they experience side effects. If you are concerned about the side effects of certain medications or the effectiveness in managing your child's pain, speak to your care team.

What do I do if my child is having trouble eating or drinking?

Illness can make eating and drinking difficult. Talk to your care team if your child:

- › Is unable to eat food or drink fluids
- › Is eating with hesitation
- › Has difficulty swallowing
- › Is coughing
- › Is choking or gagging
- › Has no interest in food

Your care team can provide tips on your child's body positioning and food textures. You may also like to discuss further assessment and the possibility of feeding tubes.

What do I need to know about my child's breathing?

Changes in breathing are common with illnesses and whilst these may not make your child uncomfortable, changes in breathing can be difficult to watch.

If your child is having difficulty breathing, speak to your care team as they may be able to help with:

- › Positioning
- › Chest physiotherapy
- › Managing saliva
- › Medicines to ease feeling short of breath
- › Relaxation techniques
- › Access to fresh air or a fan
- › Access to oxygen if it makes your child feel better. Sometimes oxygen masks or nose prongs can make a child feel worse.

How can I care for my child's skin?

Illness can have an effect on your child's skin because of poor circulation, weight loss, decreased activity or other illness-related factors. Protecting their skin with cushioning, moisturising, massage and regular position changes can help.

This can mean using special bed mattresses, sheepskins, skin creams and dressings. If you notice any changes or redness in your child's skin, let your care team know.

What can I do if my child is nauseous or vomiting?

The causes of nausea and vomiting are often difficult to identify. Speak to your care team so they can help you to identify if there is a cause which can be avoided or managed.

Medication can help control nausea and your care team can work with you to find the right medication for your child and how best to give this.

Sometimes, as children become more unwell, they are less able to tolerate food and drink and they may feel less hungry. It may be necessary to reduce what they are eating and drinking to avoid nausea and vomiting.

Practical things that may help your child include:

- › Keeping smells down
- › Mouth rinses
- › Distraction
- › Providing fresh air
- › Using a fan
- › Cool face washers

What can I do if my child is constipated?

Constipation can cause extreme discomfort, behaviour changes and nausea and may be a result of:

- › Medications
- › Lack of physical activity
- › Poor fluid and fibre intake
- › Illness that causes slow bowel movement

The use of oral laxatives can be important and may need to continue to be used to prevent constipation returning. Sometimes, your child may also need an enema or suppository to clear a blockage.

Make sure your child is as comfortable as possible on the toilet or bedpan.

Comfort aids include:

- › A padded seat
- › A pillow to hug
- › A foot stool to rest their feet on

It can be helpful to keep a record of your child's bowel movements and give them extra fluids if possible. Gentle clockwise stomach massage may also help.

What can I do if my child has seizures?

Children with a neurological disorder, brain tumour or epilepsy may be at risk of seizures and your child may already be taking medications to prevent seizures.

If your child is prone to seizures or there's a possibility they could develop them, you should have extra medication on hand to use if needed. Your care team can help you with medication, and provide a written plan of what to do.

For additional information please see the factsheets:

- *Care team contact list*
- *Symptom management plan*

Family considerations and concerns

How can I ensure my spiritual, religious and cultural wishes are respected?

If English is not your first language and you need support to help you talk about your wishes or cultural preferences, ask a member of the care team for an interpreter. You could also ask a community leader to come and talk to the care team, to help explain your cultural background and how this may affect your wishes for your child's care.

Every family is unique in their spirituality, religion, culture, beliefs and values. Whatever your wishes for your child's care, these should be respected by the team supporting you and your child and the team should work to accommodate your wishes as closely as possible. Whilst the care team will often be aware of different cultural, religious and spiritual preferences, it may be helpful to speak to the team about your specific wishes to avoid potential misunderstandings.

*Every family is
unique in their
spirituality, religion,
culture, beliefs
and values.*

Is it normal for us to experience feelings of loss and grief?

Families often experience feelings of grief and loss at their child's diagnosis and/or prognosis. This may include struggling with the diagnosis, feeling a loss of future hopes, dreams and worries about what life will be like afterwards. Your child may also have many reactions to their own illness and sense of their future.

This experience can be called 'anticipatory grief' which describes the mourning we do when looking towards a time of loss and worrying what that will be like. It is also normal to be grieving a loss of lifestyle and plans for the future.

How will we cope?

Your family will have their own way of coping, which is influenced by your life experiences, values, family supports and your child's illness. It is important to remember that you do not have to manage everything on your own.

Your care team are available to support your family through the emotions you may be feeling and can also provide practical support related to employment and financial concerns. Your care coordinator is there to support you, so speak to them about arranging local support for your family.

Over time, it is normal to experience a number of different and even conflicting feelings, including sadness, anger, denial, fear, blame and guilt. There will also be times of joy and happiness with positive experiences.

"...endless nights of thinking, how are we ever going to get through this?"

It's important to remember each family member will have different ways of responding and behaving. Some may keep themselves busy, as a distraction from the progression of their child's illness while others may isolate themselves. It is important to accept each family member's way of coping, even if it is not clearly understood by the rest of the family. Some people will find comfort in sharing their feelings, hopes, wishes and concerns with a trusted person. Others may be afraid of being overwhelmed by their feelings and choose not to express them. Both ways need to be respected. If people have concerns about themselves or someone they care for, it may be helpful to speak to a health professional.

Spending time with each other, enjoying activities and communicating your individual coping needs to each other is important.

Palliative care may last for some time and not every moment needs to be spent with your child. A trusted relative or friend may be prepared to stay with your child to allow you to spend time with your family and friends or to catch up on tasks or sleep.

What do we tell people?

The decision of what to say and who to tell about your child's life-limiting illness will be different for each family. Some families may decide to tell only a small group of close friends and family, while others will tell the majority of their contacts and welcome the community support this can bring. Your relationships with your family, friends and community will help guide you in this decision and it is important to remember that it is your choice who you share any information with.

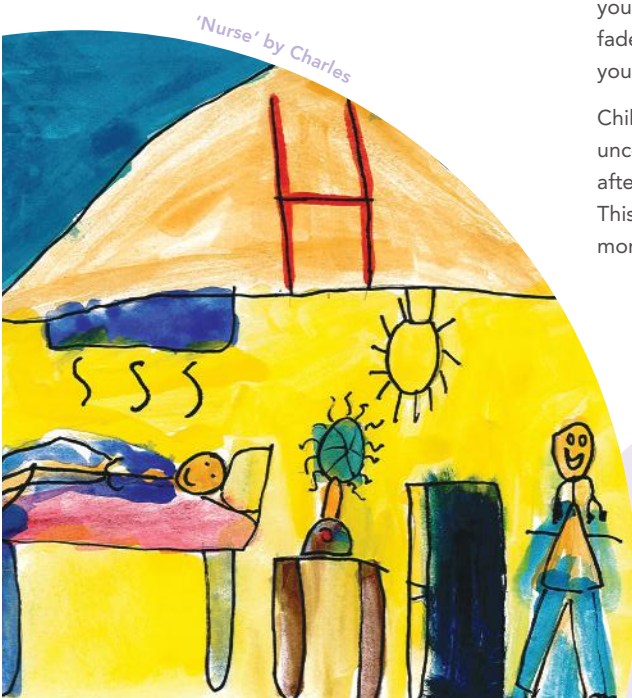
One strategy that families may find helpful is to ask a trusted friend or relative to contact other people you have identified to let them know about your child's life-limiting illness. If you decide to inform people this way, it may be worth discussing with your friend or relative whether you would be happy for people to contact you after they hear the news or whether you would prefer to reach out to them when you are ready.

Do we tell our other children?

Hearing the news that your child has a life-limiting illness that will shorten their life is devastating. Dealing with your own feelings, as well as coping with new, challenging and practical matters can be difficult and the thought of sharing this news with your children can be overwhelming.

Many parents worry about how they can share their child's diagnosis with their other children and worry about how they will react. You may want to protect them from the truth and might not feel emotionally strong enough to say the words you need to, or worry about crying in front of your children. You may be concerned about using the right words to describe what is happening to their brother or sister. Often there is so much happening at this time. Giving as much attention as you can to all your children will help to reassure them and if they know what's going on, it's easier for them to adjust to changes in family life. These are all normal feelings and you might find some of your fears start to fade when you have started opening up to your children.

Children have limited 'sad time' and it is not uncommon for children to go out and play after they have received sad information. This response is normal and children will ask more questions when they feel ready.



Below are some practical tips to guide communication with your children and give your children the clear message that they are a valued part of your family.

- › Ask your children what they understand is happening
- › Give your children information gradually and repeatedly
- › Answer the questions your children have
- › Be honest
- › Be careful not to overwhelm your children with too much detail
- › Involve your children in decision making as much as possible
- › Reassure your children that the situation is not their fault
- › Do not be afraid to show your children how you feel. Show your children that it is okay to express their feelings by showing yours

Should we expect any changes in behaviour in our children?

Your child with a life-limiting illness may experience anger, fear, confusion and/or sadness. These feelings may be in response to their illness, the limits it places on them or could also be due to some medications which can cause behavioural changes. If you do notice a change in your child's behaviour let your care team know as things like irritability and being withdrawn can also be due to pain or other symptoms.

On hearing the news or having their suspicions confirmed about their brother or sister's health, siblings react in different ways depending on their age and personality. Some become quiet and want to be by themselves, some ask if they can go out to play, others get very upset and cry or get angry. Negative changes in behaviour may make parents feel that they have done the wrong thing, however it is normal for things to get worse in the short term and then get better.

Many children respond well to creative outlets as they can help your child to express their emotions. Social workers, occupational therapists and music/play/life/art therapists can work with your children in the hospital or at your home to encourage your children to process and express their feelings. Social workers can also provide the whole family with emotional support and assist people to access counselling.

How do we manage financially?

While your child is receiving palliative care, you may find it harder than usual to continue your normal working hours. This may impact your family income and combined with the costs of living, may create financial difficulties for families.

“How can we best support our other children?”

Many families are reluctant to seek financial help, yet at this difficult time it is important to reduce other stresses and allow you to focus on your child and family. There are services which can help with the costs of caring for your child.

Ask your care coordinator about which members of your care team can help you access financial assistance as the below options may be available to you:

- › Centrelink benefits or carer's allowance
- › Financial assistance for bill payments
- › Income protection insurance claims
- › Superannuation advances
- › Other support services including equipment programs, transport services, accommodation services, chemist vouchers and food and clothing services.

Additional information is also available from: Carers Gateway (carersgateway.gov.au/money-matters or 1800 422 737) — Carers Gateway is a national service funded by the Australian Government. Carers Gateway includes a website and phone service for carers to access practical information and support, including money matters (e.g. payments for carers, carer cards and concessions).

National Disability Insurance Scheme (NDIS) (ndis.gov.au or 1800 800 110) — the NDIS will provide all Australians under the age of 65 who have a permanent and significant disability with the reasonable and necessary supports they need to enjoy an ordinary life.

For additional information please see the factsheets:

- Sibling support
- Looking after yourself
- Looking after your partner

- Supporting someone who is caring for a seriously ill child
- Spiritual, religious and cultural wishes

Family, friends and our community

How can we help people understand what we need?

Often people do not know what to say or do so they may not do anything and wait for you to reach out to them. This can leave your family feeling isolated and can find it difficult to ask for or accept help. Family members, friends and community members can provide support to you and your family. You may like to talk to them about what would be helpful so they can give you the support you need.

The way others react to your situation is not always predictable and may surprise you. Some people may not know what to do or fear saying or doing the wrong thing. By communicating with them, you can give them practical ideas or set boundaries to help you. Some suggestions include:

- › Be specific about what you and your family need and don't need, e.g. "We have enough food thanks, but we'd love if you could take the dog for a walk or pick up our other children from school."
- › Write a list of practical ways people can help you
- › Contact them and let them know what you need
- › Give them some information about your child's illness or whatever you'd like them to learn about

It may be useful to have a roster to assist in coordinating the help provided by friends and family. A roster can help you identify tasks you would appreciate some assistance with and could include meals, transport and household chores. To reduce the number of things you have to do, it may be helpful to appoint a trusted friend or family member to coordinate the roster on your behalf.

What do we do about school?

Aside from family, school can be a significant network in your child's life. You may need to consider the role you wish the school to play throughout your child's illness and how much you want the staff and school community to know.

Continuing to attend school in some capacity for as long as possible provides benefits for your child and family, as it can nurture your child's social and emotional wellbeing and provide a routine and sense of normality. There may also be a possibility of extra supports being provided by the school to allow your child's continued attendance.

If your child is well enough, school can give your child the opportunity to maintain friendships and continue learning. Even if your child is not well enough to attend for a whole day, they may be able to attend for their favourite class or at lunch time to see their friends.

If your child is not well enough to go to school at all, your child's friends may be able to visit or write a card. Your child's teacher can also suggest other ways to continue friendships. Their education may continue through home schooling support services or hospital schools for as long as they are well enough and enjoying it.

It is important to keep your child's teacher informed, as well as the teachers of your other children with as much information as you feel comfortable with. If teachers are aware of what is happening, the school can offer emotional support. They will also be aware of the need for days off and extra days to complete any homework. You can say what level of confidentiality you want kept and the school should check any communication about your child to others with you.

Many families feel comfortable talking to their school on their own but if you would like support, your care coordinator can organise someone to be with you. Often teachers welcome the opportunity to speak with health professionals, which can be a visit or a phone call, as they can answer any questions the teacher and broader school staff may have and offer suggestions for supporting your children, their friends and the school community.

What about work?

Your workplace can be a place of support to you and your family and will probably be understanding and flexible if you need to reduce your hours or take leave. It is generally preferable to let your employer know about your situation and discuss what options are available. This may include modifying your hours or accessing an employee assistance programme. It is your decision what information you choose to share with your colleagues. Some parents choose to keep their situation private whilst others find it helpful to confide in their colleagues. Your care coordinator or general practitioner can help support you to provide supporting documentation as required.

Additional information is also available from:

Carers Gateway (carersgateway.gov.au/working-while-caring or 1800 422 737)

— Carers Gateway is a national service funded by the Australian Government. Carers Gateway includes a website and phone service for carers to access practical information and support, including information about working whilst caring (e.g. talking with your employer, employers of carers).

For additional information please see the factsheets:

- Supporting someone who is caring for a seriously ill child
- Siblings support
- Spirituality, religious and cultural wishes

“We knew when something felt right for us.”

'Book Bunker' by Marie



End of life and bereavement care

This section explores end-of-life care choices, talking to children, making memories, what to do at the end of your child's life and bereavement support. It describes 'end of life' as the last few days or weeks of life, which is also sometimes known as 'terminal care'. Bereavement is help with the process of grieving and the support you may require.

What are our end-of-life care choices?

While there are many things that cannot be controlled, there are important choices that can be made about the care of a child with a life-limiting illness. Planning ahead can help to ease stress as you know what to expect and how you will be supported, it also means that you won't have to make difficult choices if your child were to deteriorate suddenly. This may be known as advance care planning and whilst a member of your care team will generally approach you about it, you may need to signal to the team you are ready to talk about some of the more difficult aspects of the illness.

“We mostly felt torn — hoping for the best while preparing for the worst.”

You may want to speak to your child about what is important to them and what their hopes and their worries are. Even if your child is very young, it may be helpful to think what they might say if they could speak for themselves. Talk together as parents and even if you don't always see things the same way, it is important to respect each other's views and continue talking. You may also want to seek support from family, friends or your community. If you would like to, you could ask if they can be included in discussions with the care team. Your care team will provide recommendations on the best approach based on their knowledge of the disease and likelihood of improvement with various possible interventions.

Decisions and plans can be reviewed at a later date. If this is something you would like to do speak to one of your care team.

What does “withholding treatment” mean?

It is important to know that ‘care’ is never withheld and your child will always be cared for. Providing the best care means thinking about which treatments will help your child and which treatments could hurt them without providing any benefit. When it is agreed that a certain treatment will do more harm than good, this treatment should be withheld (not started) or withdrawn (stopped). These decisions are made by you and the care team together. Treatment for discomfort, pain management and other symptoms will always be provided for your child.

A member of your child’s care team will discuss with you the options available if your child’s condition does deteriorate. Depending on which state or territory your child is receiving care in, these decisions may be documented as:

- › Goals of Patient Care (GoPC)
- › Allow Natural Death (AND) order
- › Advance Care Plan/ Directive
- › Do Not Resuscitate (DNR) order
- › Do Not Attempt Resuscitation (DNAR)
- › Resuscitation and End of Life Care Plan

Once you and the care team have made decisions, it should be recorded in your child’s medical notes by a member of your care team. Treatment decisions should also be recorded in your child’s care plan and shared with all people caring for your child so that your wishes are respected.

You can change your mind about this at any time, however it is important that you let your care coordinator know if and when you do. If your care team considers an intervention or procedure to not be beneficial to your child, they will discuss this with you and work towards a new agreed plan.

Considering organ and tissue donation

You can ask your care coordinator for information about organ and tissue donation at any stage throughout your child’s illness. If your child has had a long-term illness, it may not be possible to donate major organs but tissue donation may still be an option. It is important to let your child’s care coordinator know that you are considering this option as there are specific processes that will need to take place.

What do I need to know about end-of-life care?

Parents usually wish to be prepared and want to know what to expect, but at the same time, they do not want to know, or may be too frightened to ask. Talking or reading about how your child may die and what to do at the time will be terribly sad and painful. However, discussing what will happen at the time of your child’s death may help to alleviate some of your fears and concerns. You can use the following questions to help you think about it:

- › Who do you want to have with you?
- › Who will take care of your other children if they are not with you?
- › Which health professional will you call?
- › Who will make the calls to other people?

Some parents find it helpful to know what physical changes to expect in the last days and hours of their child's life. For detailed information on what to expect please refer to page 28 or the factsheet on *What to expect in the final days*. Please note this information may be difficult to read but has been provided to hopefully reduce your fears about the last days and hours of your child's life.

For additional information please see the factsheets:

- *Where will my child be cared for*
- *Decision making*
- *What to expect in the final days*
- *Looking after yourself whilst caring*
- *Helping your partner*

How do we talk to our children?

How do children understand death?

It is hard to divide children's understanding of death into age groups because children have different life experiences. Children may have had a family member, friend or pet die whilst others have had no experience of death. This will have an influence on their understanding of what death is.

It is important not to make assumptions of what your children's understanding of death is. You may be able to gain an understanding of what they think death is and why it occurs by listening and talking to them about it.

In general:

- › Children aged 0–2 years understand 'here' and 'not here' and whilst they can sense loss they cannot understand death.
- › Children aged 3–5 years see death as temporary and expect the person to return.
- › Children aged 6–10 years understand death is forever and there are different causes of death. They may be curious about death, funerals and cemeteries.
- › Children aged 11 and older start to perceive death as an adult would. They may look for the meaning of death and ask more questions. Children with a life-limiting illness and their siblings are more aware of death. They often have a greater understanding of death due to exposure to hospitals and care teams.

Do we tell our sick child?

Many parents struggle with the decision on whether to tell their child they are dying. Your decision to talk with your child about dying and death may be guided by:

- › Your own instincts
- › Your knowledge of your child
- › Your child's condition
- › Your cultural, religious and spiritual beliefs
- › Your child's questions

Children who know when they are dying can have time to prepare, share and create memories. This also gives you and your child some time to say goodbye.

“Our ultimate goal became to help our daughter die well and to help our son survive as a whole person.”

Children who are very sick often observe a change in behaviour in those around them. They also notice changes in their own body and see what happens to other children with similar illnesses. Even when the people they love try to protect them, they generally have some information. They may not always make sense of this and this can leave them frightened and feeling alone. They may not want to worry their parents and it can be hard to know how to help them.

Some families find it helpful to give their child some basic information and then say, ‘If you ever want to ask us any questions, we will be very honest with you.’ This gives the child control over what they want to know and when. It also lets them know that if they ask, the response will be honest.

You can ask your care team for advice and support and they can help you speak to your child if you wish. Make sure your care team, family and friends are aware of your decision about what your child knows.

How do we support our other children?

It is important to create a safe space for your other children so they know they can ask questions. Your other children may like to be with you, to talk and touch their brother and sister, to cuddle them, read a story, draw and say goodbye in their own way. Below are some suggestions based on the experiences of other families that may be of assistance:

- › Involve your other children as much as their age allows
- › Provide clear information about what is happening by using simple and honest language
- › Try not to have particular expectations of how your children may react
- › Offer encouragement and support them to react in their own way
- › If your child does visit their sibling, it is important to prepare them for any physical changes their sibling has experienced
- › Give your children a time to say goodbye
- › Talk to your children about what they can expect when your child dies and at the funeral
- › Be prepared for any questions your children will ask
- › It may be helpful to ask a trusted relative or friend to spend time with your children

You can also ask your care team for advice and support when talking to your other children.

Grandparents

When a child is dying or has died, grandparents are deeply affected by both the death of their grandchild and the deep distress of their son or daughter. Many grandparents look after their grandchildren and the child's death may mean a huge change in their daily life. Their grief is often overlooked and they will need support too.

For additional information please see the factsheets:

- *Spiritual, religious and cultural wishes*
- *Sibling support*
- *Siblings and grief*
- *Looking after yourself whilst caring*
- *Helping your partner*

What can we do about memory making?

For most families, the focus is ensuring their child is free of pain and distress and this can provide an opportunity to do whatever the child's health allows. Often there is a sense of wanting to make the most of life and to experience good days as defined by the child.

Some children and families have specific requests. Each family's wishes are unique, but common requests include:

- › Bringing the child home
- › Going on a special outing or holiday
- › Spending time with friends and extended family
- › Taking photos together as a family
- › Making handprints and footprints
- › Recording special times through video or a journal, this may include recording their height, weight and any other details you want to remember
- › Keeping a lock of hair

'Hand-painted chicks outside the chook-house' by Nicholas, 7 years old



“How do you know when the time comes?”

Does it help to do some funeral planning?

Some families find comfort in planning their child's funeral ahead of time because it stops them worrying about forgetting details or making choices. Others feel it is something they can't think about until after their child dies.

A funeral is a time to honour your child and celebrate all the wonderful things about them. It is a time to share their story, your memories and sorrow and an opportunity to say goodbye with family and friends. It is important to say goodbye to assist with your grieving and provide an opportunity for your healing journey to begin.

Planning can be helpful to understand funeral costs and what services can be provided. You may wish to speak with a number of funeral directors before deciding what is comfortable for you. Funeral costs can vary considerably and it is important to know what services you will receive and how much each part will cost. You may wish to obtain a written, itemised quote to help you make a decision.

If your older child knows they are dying, they may find it a positive experience to plan their own funeral. Your child might also choose to include their siblings in their funeral planning.

A funeral can be a time to celebrate your child's life and attend to important cultural, religious and spiritual rituals. Take the time you need to plan your child's funeral and make it as personal as you would like.

Personal touches may include:

- › Your child's favourite songs and music
- › Photos and videos
- › Flowers, balloons, candles or other items

If you are uncertain whether you would like your other children to attend the funeral it may be helpful to let them decide. Letting them be involved in this decision may help in their adjustment to the death of their brother or sister but is important to let them know what to expect and how they might participate in the funeral.

For additional information please see the factsheet:

- *Selecting a funeral director*

How do I know when the last hours or days are near?

There are many signs you might see or feel as your child approaches their last days and hours, these include:

- › Changes in body colour, with pale/bluish hands, feet and lips
- › Cooling of hands and feet
- › Interrupted, irregular and/or noisy breathing
- › Restlessness or unsettled behaviour
- › More time spent asleep
- › Loss of appetite and thirst
- › Incontinence or strong urine
- › Sunken or glazed eyes

Spiritually, you may also sense that your child's death is approaching and you may feel the need to be close to them. You may also choose to involve other family members and friends at this time.

Even when sleepy, your child can still hear and feel so you should talk to them, cuddle them or play their favourite music.

At the time of death, some muscles will relax, facial features will relax, and there may be a bladder or bowel movement. There may also be some small fluid loss from the mouth or nose. Being aware of this will help you prepare for these changes. Many parents comment on how peaceful and beautiful their child looks.

You may touch your child as much as you like after they have died. You may wish to prepare your family for how your child will look once they have died. The following changes occur:

- › Their skin colour becomes pale
- › Their skin can look bruised
- › Their body may feel cool and clammy to touch
- › Their body may feel stiff

For additional information please see the factsheet:

– What to expect in the final days — please note, this factsheet provides detailed information that may be difficult to read.

What do I do after my child dies?

After your child dies, it is important to take the opportunity to spend time with them as there is no need to rush. This is your time to be with your child and to say goodbye for as long as you need. If you wish, you can just be with your child, touch, hold or cuddle them. You may wish to wash, dress or just spend time with your child by yourself or with family and friends.

Contact your care coordinator if you are unclear about any of the steps listed below or if you need extra support.

If your child dies at home

If your child dies at home, these are the things you need to do when you feel ready:

- › Phone your care coordinator or the person nominated as your after-hours contact to let them know. They will then lead you through the next steps.
- › A doctor or specialist nurse will come to your house and certify in writing that your child has died. At this time a medical certificate of cause of death may be written by the doctor attending or it may be done the next working day.
- › When you are ready, contact a funeral director who will come to your home. Let them know if you would like to keep your child's body with you or at the funeral home. The funeral director will organise transport, if required and negotiate the timing of this with you.
- › Generally there is no need to call emergency services as there will not be a need to notify the Coroner or Police. The health care professional attending will confirm this for you.

If your child dies in a hospital or hospice

If your child dies in a hospital or hospice, there are certain processes that will need to take place when you are ready. The care team are there to support and assist you, if you wish. When you are ready, a funeral director will need to be contacted to make funeral arrangements, as well as transport your child's body and to collect the necessary paperwork.

If you have not yet chosen a funeral director, your child's body can remain in the care of the hospital or hospice. If you would like to take your child's body home for a last visit, this may be possible and you can arrange for the funeral director to collect your child's body from the home when you are ready.

Leaving the hospital or hospice without your child can be overwhelming and emotional for the whole family. The staff will be there to support you but you may also want the support of loved ones at this time.

Post-mortems, autopsies and organ/tissue donation

You may request a post-mortem (autopsy) or biopsies if you feel it would be helpful to understand your child's illness and cause of death. Your care team may also ask you to consent to a post-mortem and/or biopsies for research or teaching purposes. It is your choice whether you would like a post-mortem or biopsies.

If you have chosen organ or tissue donations, speak with your care team to discuss the next steps.

If you are not sure about what you need to do or the choices you need to make, talk to your care coordinator.

Coroner's notification

In some circumstances it may be necessary to notify the Coroner of a child's death. Ask your care coordinator if this is likely for your child and what it will mean for you.

Telling others

There are often a lot of practical issues to deal with following your child's death. There may be other people and organisations that may need to be notified however you may want to arrange a trusted relative or friend to help you with these tasks.

Some of the people and services your care team will help to notify include:

- › Your family doctor
- › Department of Human Services (Medicare and Centrelink)
 - › You may be eligible for a bereavement payment
- › Your private health fund
- › Other health professionals (e.g. dentist or optometrist)
- › Any service where you may receive an appointment reminder
- › Your bank
- › Your child's school
- › Recreational clubs (e.g. sports clubs or the library)
- › Religious, cultural or social organisations

For additional information please see the factsheets:

- *What happens if my child dies at home*
- *Selecting a funeral director*
- *Spiritual, cultural and religious wishes*

How will I respond?

No one can anticipate how they will feel or react after the death of their child and nobody can prepare you for how you will grieve. Parents and families often report feeling overwhelmed and experience intense and unfamiliar feelings. Initially people may struggle to believe their child has died and many parents report they do not know what they need or what might help. It is important to get rest, eat well and get some exercise, even if you don't feel like it.

While painful, grief is a normal expected process that can include a range of reactions and changes in our emotions, behaviours, spirituality and bodies.

There is no right response to death or right way to grieve. Grieving can last a long time, and for many, may not come to an end. It may help to know that your grief will become less raw over time. You will never forget or stop missing your child, but in time, you become better at living with the loss.

'Butterflies' by Naomi, 8 years old

Common reactions to death

Below are some common reactions to death:

| | | |
|------------------|-------------|----------------|
| Emotional | › Anger | › Helplessness |
| | › Confusion | › Loneliness |
| | › Crying | › Numbness |
| | › Denial | › Panic |
| | › Distress | › Relief |
| | › Fear | › Shock |
| | › Guilt | › Stress |

| | | |
|-----------------|-----------------------|-------------------------|
| Physical | › Body aches | › Lack of concentration |
| | › Discomfort | › Nausea |
| | › Dizziness | › Shaking |
| | › Insomnia | › Sweating |
| | › Headaches | › Tiredness |
| | › Hot or cold flushes | › Trembling |

| | | |
|-----------------------------|---|---|
| Social / behavioural | › Avoidance of or needing to be with others | › Loss of or extra appetite |
| | › Don't want to get out of bed | › Loss of or extra interest in being social |
| | › Feeling isolated or detached | › Loss of or extra interest in hobbies |

| | | |
|------------------|--------------------------------|--|
| Spiritual | › Feeling a sense of emptiness | › Loss of joyfulness |
| | › Feeling out of control | › Loss of meaning and purpose |
| | › Loss of direction | › Questioning or affirming religious beliefs |

“How will our family cope with our loss and grief?”

Some things that might help

When you are grieving it is important to look after yourself, this may include:

- › Get as much rest as possible
- › Gentle movement or exercise
- › Slow down and give yourself permission to let go of some of your responsibilities
- › Being gentle with yourself and taking time out to do things you like
- › Accepting help
- › Keeping a journal or diary
- › Give yourself permission to grieve and to be happy
- › Creating a memory book or box for special belongings and photos
- › Giving yourself time to talk and share your feelings
- › It can help to prepare ahead for some of the questions people may ask

How do I get bereavement support?

Bereavement support is help with the process of grieving. Grieving is the expression of loss when someone dear to you dies and may also be experienced beforehand.

There is no 'right' way or time to grieve. Many people find additional support and counselling can be helpful at this time.

If you are concerned about yourself or someone you care for, it is advisable to contract a health professional and discuss your concerns.

Everyone in your family will be grieving in their own way and may have less capacity to provide the comfort their family members need. Close friends and family members may be a good source of bereavement support for the whole family. There are also many people, support groups and other resources that can help, including:

- › Pastoral care workers
- › Community-based support groups
- › Church-based support groups
- › Hospital or hospice-based support groups
- › Professional counsellors
- › Internet-based support groups

“...endless nights of thinking, how are we ever going to get through this?”

How might my other children respond?

A brother or sister's reaction to the death of their sibling will be unique and is greatly influenced by their age, developmental stage, personality and the family, cultural, religious and spiritual influences in their lives. Children's grief can vary significantly from adults and often will have three main concerns:

- › Did I cause the death?
- › Will I die?
- › Who will care for me?

Speaking in an open, honest and age appropriate way with children can help them cope better with their loss. Children need time and to feel safe in order to express how they are feeling. Be prepared to revisit conversations a number of times, as children need time to process information. Reassure them that grief is normal and it is okay to be upset about what has happened.

For additional information please see the factsheet:

– *Siblings and grief*

How do I readjust to my changed life?

Making memories and marking occasions

There are no rules about anniversaries, birthdays and special days. What you regard as a special occasion will be unique to you and your family. Whatever you decide, do whatever is helpful and meaningful to you and your family. Grief can be heightened by anniversaries, special occasions or something unexpected however this is normal.

Some suggestions from other families to honour your child's memory include:

- › Keep a journal to record your thoughts, feelings and memories with your child
- › Write or share the story of your child's life
- › Make a photo album
- › Create a memory box to put all your special keepsakes in (e.g. toys, clothes, cards and letters)
- › Display special artworks around your house
- › Compile memories of your child from family and friends
- › Create a special space, corner or garden where you can go to reflect
- › Adopt a star in honour of your child
- › Use your child's clothing to make a memory quilt

Some suggestions from other families to mark special days include:

- › Add a special plant to your garden or at your child's gravesite
- › Make or buy celebration candles
- › Write a poem, song or letter to your child
- › Make a special Christmas decoration
- › Browse through a photo album or watch a video of your child
- › Place a message in your local newspaper
- › Hold a memorial service
- › Visit the gravesite with flowers, balloons or a picnic

“People who love each other are always connected by a very special string made of love. Even though you can’t see it with your eyes, you can feel it deep in your heart, and know that you are always connected to the ones you love”.

— *The Invisible String*,
Patrice Karst

Returning to work

It can be difficult to go back to work, but it can also be a healthy escape for you. Have a talk with your work place and decide how, or whether you would like to share your loss with your colleagues. In returning to work, you may wish to consider:

- › How many hours a week you would like to work
- › Flexible working hours
- › What to do if you’re having a bad day and can’t be at work
- › Whether you are happy for people to speak to you about your child’s death
- › Options to work from home, if possible
- › Your financial needs

You may like your care team to assist you with these discussions by attending with you or helping you to prepare.

Deciding on another baby

It is normal for parents to have doubts and uncertainties about having another baby after their child has died. If you are thinking about having another baby, it may be worth considering the below points:

- › It may take time for you and your partner to agree on whether to have another child
- › It is important to discuss your feelings openly and honestly
- › Respect and acknowledge your partner’s feelings
- › Be prepared to answer any questions your other children have

Many parents also worry that they may pass on a life-limiting illness to their children. If you are concerned about a condition or disease running in your family, speak to your general practitioner about it, who may suggest you consider genetic counselling. Genetic counselling is provided by a number of professionals, including clinical geneticists and genetic counsellors. The genetic counselling team can provide advice and support about your risk of another baby with an inherited condition. They may speak to you about specific tests that you and/or your partner could have to determine if you could pass on a genetic condition to your children.

Other organisations and support

Parents

Australian Centre for Grief and Bereavement

Australian Centre for Grief and Bereavement provide information including a pamphlet — “After the Loss of a Child. A resource for parents of children in palliative care”.
grief.org.au

beyondblue

beyondblue provides information and support to help everyone’s mental health and improve the lives of individuals, families and communities affected by anxiety, depression and suicide.
beyondblue.org.au • 1300 224 636

The Compassionate Friends

The Compassionate Friends is a world-wide self-help group for parents that have lost a child of any age and through any cause. They offer support and understanding
thecompassionatefriends.org.au/contact

Griefline

Griefline provides a dedicated grief helpline service providing counselling support services free of charge
griefline.org.au • 1300 845 745, 12pm–3am

Lifeline

Lifeline provides access to a 24 hour crisis support and suicide prevention for anyone experiencing a personal crisis.
lifeline.org.au • 13 11 14

National Association for Loss and Grief

National Association for Loss and Grief (NALAG) provides free loss and grief support to those who are grieving, either face to face or via telephone.
nalag.org.au

Red kite

Provides information and emotional and financial support to parents and families whose child has cancer.
redkite.org.au

Red Nose Grief and Loss

Red Nose Grief and Loss services are available to anyone who has experienced the sudden and unexpected death of their baby or child during pregnancy, birth, infancy and early childhood.
rednosegriefandloss.com.au

Relationships Australia

Relationships Australia provides of relationship support services for individuals, families and communities.
relationships.org.au • 1300 364 277

Children

Canteen

Support for siblings 12–25 who have a sibling affected by cancer. Provides information, online resources & support.

canteen.org.au

Headspace

Provides early intervention mental health services for 12–25 year olds.

headspace.org.au

Kids Helpline

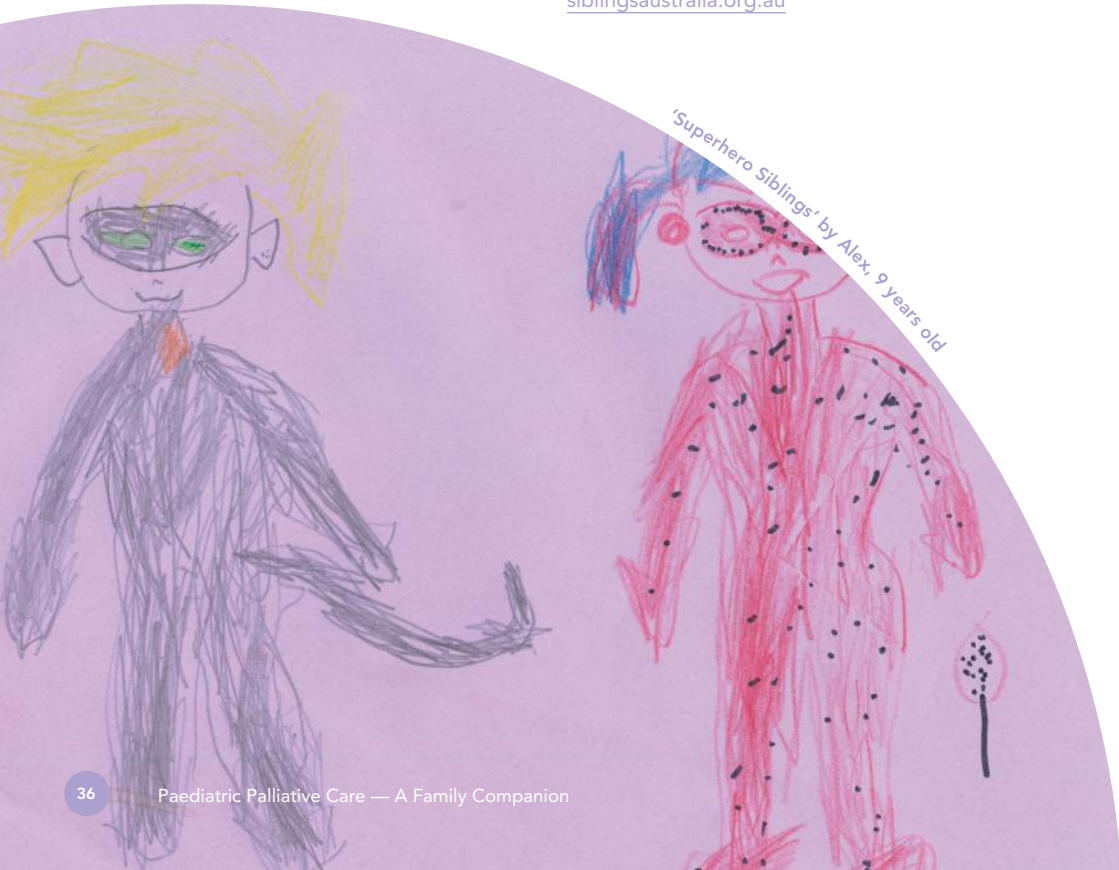
Kids Helpline provide free, private and confidential 24/7 phone and online counselling service for young people aged 5 to 25.

kidshelpline.com.au • 1800 551 800

Siblings Australia

Siblings Australia is a national organisation committed to providing support for brothers and sisters of people with special needs; including disability, chronic illness and mental health issues. They provide workshops, print and web-based resources and networking opportunities for families and providers across Australia and overseas.

siblingsaustralia.org.au



'Superhero Siblings' by Alex, 9 years old

About this resource

Palliative Care Australia has collaborated with Paediatric Palliative Care Australia and New Zealand and the families they have cared for to develop resources to support the parents, children and families who come into contact with palliative care. Our aim is provide practical information about paediatric palliative care so people have some information to assist them to think about what may lie ahead following the news that their child has a life-limiting illness.

The artwork used throughout this resource, and on the website (palliativecare.org.au/children) were created by children involved with the paediatric palliative care teams around Australia. Palliative Care Australia would like to thank all of the children, their families and the art therapists for their contributions. All of the artwork that was received as part of this project is available to be viewed on the gallery page on the website.

If you have any thoughts or feedback about this resource please contact Palliative Care Australia either via the feedback page on the website or via email at pcainc@palliativecare.org.au.



Palliative Care Australia is funded by the Australian Government.