

Talking to Kids About Cancer

A guide for people with cancer, their families and friends



For information & support, call **13 11 20**

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this book.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.



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About this booklet

Explaining a diagnosis of cancer to children or teenagers can feel difficult and overwhelming. This booklet offers practical tips to make these conversations easier. Talking sensitively and openly can reassure children during a time of uncertainty and change.

Talking to Kids About Cancer focuses on when a parent has cancer, but much of the booklet will be useful for anyone who needs to explain a cancer diagnosis to children or teenagers. Mostly, the booklet is addressed to “you” as a parent with cancer, but it can be read by any adults supporting young people who have a family member with cancer. We have used the terms “kids” and “children” interchangeably, and the term “teenagers” rather than “adolescents”.

You may like to share this booklet with grandparents, teachers, school counsellors, family friends and neighbours – anyone who talks with your children – to ensure your children hear a consistent message about cancer and how it may affect your family.

Some sections of this booklet may be difficult to read, such as the chapter on *Talking about advanced cancer* on pages 56–65. If you feel distressed reading this content, or if you need help with any cancer-related issues, call Cancer Council 13 11 20 or see *Finding support and information* at the end of this booklet.



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



Contents

Talking about cancer 4

Why talk to kids about cancer? 5

When you can't talk about cancer 8

How children understand cancer 9

Newborns, infants and toddlers 0–3 years 10

Preschoolers 3–5 years 10

Primary school children 5–12 years 11

Teenagers 12–18 years 12

Talking about the diagnosis 13

Who should tell my children? 14

When should I tell my children? 14

Where should I tell my children? 15

Should I tell my kids together? 16

How can I prepare? 16

The first conversation 17

If your child is diagnosed 21

When a sibling has cancer 22

When another child has cancer 24

Answering key questions 26

Involving others 32

Involving the school or preschool 32

Talking about treatment 35

What do children need to know? 36

Hospital visits 39

Answering key questions 40

Family life during treatment 41

After treatment 51

What do children need to know?	52
How children react	52
Family life after treatment	53
Answering key questions	55

Talking about advanced cancer 56

What do children need to know?	57
How children react	61
Answering key questions	62

How children understand death 66

Newborns, infants and toddlers 0–3 years	67
Preschoolers 3–5 years	67
Primary school children 5–12 years	68
Teenagers 12–18 years	68

Finding support and information 71

Getting support	71
Support from Cancer Council	73

Glossary 77

How you can help 80

Key to icons

Icons are used throughout this booklet to indicate:



More information



Personal story



Tips

Is this Cancer Council booklet helpful?

Please follow this QR code for a quick 3-minute survey, or call 13 11 20 to provide your feedback.



SCAN ME

Talking about cancer

Talking with kids about cancer can feel overwhelming. Your first reaction may be to keep the news of the diagnosis from children or to delay telling them. Or you may feel an urgent need to tell them straightaway. Research shows that being honest and willing to talk helps children cope with the cancer diagnosis of someone close to them.



Why talk to kids about cancer?

When someone is diagnosed with cancer, adults are sometimes hesitant to discuss the situation with children. Parents and other adults can feel overwhelmed by their own anxiety and fear, and their first reaction may be to protect children from those same uncomfortable emotions. However, there are many reasons why a straightforward and open discussion can help children.^{1,2} Children who are told about the illness of someone important to them tend to cope better than children who are left to find out through other ways.

You are the expert

As parents and carers, you are the experts on your children and what works for them. To help you discuss the subject of cancer with children, this book outlines evidence-based, practical strategies that can build upon your existing strengths and knowledge. Sometimes it may take a few attempts before you find an approach that suits your family. Use your understanding of your children's individual personalities and needs to guide you.

Secrecy can make things worse

Children are observant. No matter how hard you try to hide a cancer diagnosis, many children will suspect something is wrong. They may notice changes at home, such as your sadness, whispered conversations and voices behind closed doors. They may also see that their family member looks different or cannot do certain things. These signs may be more obvious to older children and teenagers, but even young children can pick up on change and will work out that a secret exists.

Not knowing the reason for the secret may leave them feeling powerless or left out of family matters. They may also feel that they

have done something that has caused this change in the family, or imagine that the situation is worse than it actually is.

How children hear about a diagnosis is important

Ideally, children should hear about a cancer diagnosis from their parents, guardian or a trusted family friend, particularly if it is their own parent or a close relative or friend who has cancer.

If you tell friends and relatives about cancer in the family, but don't tell your children, there is a chance your kids will learn about the cancer from someone else or overhear a conversation. Children often listen to adult conversations even when it seems like they are not paying attention.

They can feel hurt if they discover they have not been told something that affects their family. They may think they are not important enough to be included in family discussions or that the topic is too terrible for you to talk about. Sharing information shows you trust and value them, which can ease their concerns.

Children may make up their own explanation to fill in the gaps in their understanding. They may feel afraid to ask questions and worry in silence. Teenagers, and even younger children, may pick up on a few key words and search the internet for answers, which can lead them to unreliable information.

Kids can cope

When a family is affected by cancer, it can be an unsettling time for kids. You may wonder how they will get through it, but with good support and age-appropriate information, most children can cope with this difficult situation.

Kids have surprising abilities to respond to life's challenges. They learn about emotions and how to express them by watching others – especially their parents. Parents can role model how to recognise, talk about and manage a range of emotions. For example, you might say: “I’m feeling sad that Grandma is sick and I think I need to go for a walk.”

We can't stop kids from feeling sad or worried, but if we share our feelings and give them information about what's happening, we can support them as they experience a range of emotions.

Children need a chance to talk

Talking to your children about cancer gives them the chance to ask questions (see pages 26–28 for some suggested answers). Encourage your kids to share their thoughts and feelings, but don't be surprised if they don't want to talk when you do. Younger children may like to draw a picture, while older children may find it helpful to keep a journal to write down questions or thoughts as they come up.

Sometimes, kids, particularly teenagers, may feel guilty about burdening a sick parent with their worries or taking up a carer's time. Reassure them that their concerns are not a burden. They may also like to speak to a trusted adult who is not their parent (e.g. a grandparent, aunt or uncle) or perhaps another trusted person in their lives, such as a school teacher, counsellor or coach.

“Sooner or later, they were going to find out. Why not tell them straightaway? I tell them frankly what is happening. I think they find it much easier to cope because they are ready for things.”

SUSIE, MOTHER OF THREE CHILDREN AGED 12, 13 AND 16

Cancer in different cultures

There are a wide range of beliefs and ideas about cancer. People may believe that cancer is caused by bad luck, that it is contagious or always fatal. Others may believe that the cancer has been sent to test them. It is important to respect different ways of coping with a cancer diagnosis.

You may be reading this booklet because you work with children who have been affected by a

cancer diagnosis. Before talking to someone else's child about cancer, it's essential that you understand and respect the wishes of the parents.

If a family wants to keep a diagnosis private, organisations such as Cancer Council 13 11 20 or Cancer Hub (see page 23) may be able to suggest ways for children and other family members to discuss their feelings and concerns in a confidential setting.

When you can't talk about cancer

Some parents don't want to tell their children about the diagnosis at all and try to keep it secret. People have their own reasons for not sharing the diagnosis with their children, including cultural beliefs (see above) or a previous death of a relative from cancer. Sometimes you may want to wait to find out more about the diagnosis before telling your kids.

If you want to share the diagnosis with your children but your fear of saying or doing the wrong thing is keeping you from having this difficult conversation, it may be helpful to talk with a psychologist or social worker about how to approach the conversation.

How children understand cancer

Children's understanding of illness and their reactions to news of a cancer diagnosis will vary depending on their age, personality and family experiences. You may find that siblings, even of similar ages, respond differently. As children grow up, their understanding of the world will also develop. As they mature, they may become ready for more in-depth conversations.



Newborns, infants and toddlers 0–3 years

Very small children have little understanding of illness but may pick up on their parents' anxiety and other feelings. They are aware of periods of separation from their parents and can get upset when a parent is not there. They may become clingy or unsettled, especially if they need to be weaned from breastfeeding suddenly.

Toddlers may react to physical changes in their parent or relative (such as hair loss) or noticeable side effects (such as vomiting). They may react with more frequent thumb sucking, bedwetting or baby talk.

You can help them cope by:

- maintaining usual routines as much as possible
- giving them plenty of physical comfort
- playing age-appropriate relaxation podcasts or calming music.

Preschoolers 3–5 years

By the age of 3, children have a basic understanding of illness. Younger children may believe that they caused the illness (e.g. by being naughty or thinking bad thoughts). They may also think they can catch cancer. It is natural for young children to think everything is related to them: Did I cause it? Can I catch it? Who will look after me? They may also express their concerns or feelings through imaginative play.

Young children might become aggressive, or return to behaviour that is developmentally younger than their age, such as thumb sucking, bedwetting or baby talk. They may seek comfort by using security blankets or a special toy, or they might have trouble falling asleep or being separated from their parents. These behaviours are how some kids will communicate their worries and fears if they don't have the words.

You can help them cope by:

- explaining what they can expect and how schedules may change
- arranging daily opportunities for kids to use up excess energy, anxiety or aggression through sports, the park or using playdough
- using picture books, puppets, dolls or toy medical kits to talk about cancer and provide short explanations about what is happening
- reassuring them that their behaviour or thoughts have not caused the illness, and that they will always be taken care of.

Primary school children 5–12 years

In the early primary school years, children have a basic understanding of sickness, and by later primary years, they are usually ready for more details about cancer. They may use simple cause-and-effect logic to fill gaps in their knowledge. For example, they sometimes feel that their bad behaviour might have caused the disease. They may understand that people, including parents, can die.

Primary school children may feel a range of emotions such as irritability, guilt, envy or sadness. They may lose interest in school and refuse to go, become distant or quiet, or feel separation anxiety at the thought of leaving a parent. They may return to behaviour that is developmentally younger than their age (such as bedwetting or thumb sucking), and be extra concerned about the health of others.

You can help them cope by:

- informing their school about the diagnosis
- regularly asking the child how they feel
- talking about cancer and treatment using age-appropriate material such as books, apps and videos
- discussing dying if kids bring up the issue

- keeping children connected to friends and community through maintaining regular routines and after-school activities
- using sport, art or music to help them express their feelings
- updating them about progress and treatment
- giving them age-appropriate tasks to do around the house (see page 49).

Teenagers 12–18 years

During the teen years, young people start to think more like adults. They are able to understand complex cause-and-effect relationships, such as illness and symptoms. With increasing maturity, teenagers understand that people get sick, but they may avoid talking about difficult issues and are more likely to deny feeling scared or worried.

Teenagers may also worry about being different and not fitting in. They may not want to tell anyone at school because they want to stay “normal”. There are a range of responses your teenager might have, and these may change over time – from hiding their feelings and withdrawal, to “lashing out” in anger and rebellion. Some may want to help more around the house; others may take risks (e.g. with drugs and alcohol), or stay out late. As teenagers, they are still working out how to respond to strong emotions and big changes.

You can help them cope by:

- encouraging them to talk about their feelings with you or other people they trust (e.g. school counsellors)
- reassuring them with words and acts of kindness to let them know you love them
- chatting about things other than cancer, like school, sport and friends
- providing privacy as needed.

Talking about the diagnosis

When you first learn of a cancer diagnosis, you may feel shocked and overwhelmed. Among the many decisions you need to make will be when, where and how to talk to the children and young people in your life. Try to think of this as a series of conversations that evolve over time, rather than a one-off discussion.



Who should tell my children?

In most cases, it is easier if the information comes from someone who is close to your children. Ideally, that will be the parent who has cancer, with the support of a partner or other close family member.

However, this is not always possible. Another trusted adult close to your children, such as a grandparent, aunt, uncle or friend, may be able to tell them or be present when you tell them. This may be particularly important if you're a single parent. You may decide to share the news with the support of a member of your health care team, such as your general practitioner (GP) or hospital social worker.

When should I tell my children?

It's common to feel unsure about the best time to tell your children. Often there is no right time. You may wonder if you should tell them soon after you've found out, or wait until you have more details about test results and treatment. Although it is tempting to delay talking to your kids, try to tell them as soon as you feel you can.

It's also a good idea to tell children if:

- you think they may have overheard a conversation
- they are scared after seeing adults crying
- they are shocked or confused by physical or emotional changes in the person who has cancer, especially if the person has symptoms such as frequent vomiting, weight loss, hair loss, or is admitted to hospital for immediate treatment
- you notice changes in their behaviour.

It may be hard to know how much information to share, particularly if you are waiting on test results. Your children don't need to hear

everything all at once. If you don't know what treatment is needed, just say so – but also assure your children that as soon as you have more information, you will tell them. For example, “Dad is in hospital having tests. We're not sure what's wrong, but we'll tell you as soon as we know.”

Let children know it's okay to have questions at any time, such as during treatment, and to talk about how they feel whenever they need.

Where should I tell my children?

Many people find that bringing up the topic of cancer while doing something else – like walking the dog or washing dishes – can help reduce the tension. This approach may be less intimidating than sitting down for a formal discussion.

Find a time when you won't be interrupted and can answer all your children's questions without rushing. Ideally, you should tell them when and where they feel able to listen and take in the news. For example, you may have the discussion on a weekend, so kids have the time to process the information.

It's important you choose a place where children feel safe and comfortable to express emotions such as sadness or anger.

“The most important thing is honesty. Tell the truth, don't sugar-coat, don't be too over the top. Admit that it's not going to be a walk in the park, but you're not going to die tomorrow. The main thing is to be real.” IZZY, AGED 15

Should I tell my kids together?

If you have more than one child, you may wonder whether you should tell them individually or together. This will depend on the ages and temperaments of your children. You may need to use different language because of their ages. If you decide to tell them separately, try to tell them on the same day so no-one has to keep secrets.

How can I prepare?

Parents often doubt their ability to find the right words and to answer the questions their children may ask. It's not a matter of "getting it right", rather it's doing the best that you can at a challenging time. Take the time to plan what you'll say. Be honest about how you are feeling - it can help children share their feelings too.

You may find it helpful to say certain phrases out loud before talking to your children. For example, you might practise saying "I have cancer" or "Grandma has cancer". This means you've spoken the words and perhaps dealt with some of the anxiety attached to those words before you talk with your kids. You can also practise the conversation in front of a mirror. This helps set the words in your mind.

Even if you practise what to say and you think you know how your kids will respond, be prepared for questions and a wide range of reactions.

Before talking to your children, think about how the conversation might end. You could organise an activity, such as playing a game or going to the park, to help your children settle again. Older children may prefer some time alone, or you may suggest watching a TV show or movie together. Let your kids know that they can talk to you or another trusted adult any time they have questions or concerns.

The first conversation

The following is a guide to your initial conversation about cancer. The suggestions on pages 30–31 can help you adapt the information to the ages and reactions of your children.

Use words they can understand

You can share the news with a few short sentences explaining what you know so far and what is likely to happen next. Be clear about the name of the cancer, the part of the body affected and how the cancer will be treated.

To help explain cancer terms, you can:

- use the glossary (see pages 77–79)
- get hints from websites (see pages 74–76)
- download Camp Quality’s Kids’ Guide to Cancer app – it provides information about cancer for kids.

For younger children, accept that they may ask the same question several times. Each time you answer, they will absorb a little more information. Older children may be distant and quiet while they process what you’ve told them.

Find out what they already know

Once you have explained the basics, ask your kids what else they want to know, and only answer questions that they ask. Don’t assume children will have the same concerns as you; you can give them more details later if needed.

Ask your children what they know about cancer and clear up any misinformation or myths (e.g. they might think that they can catch cancer or that everyone dies from cancer). Children get information

from various sources, such as school friends and social media, and they may have their own ideas of what having cancer means. Parents can guide their children towards accurate online information (see page 75).

It's okay to say “I don't know”

If you don't know the answer to a question, it's fine to say so. Tell your children that you'll try to find out the answer from the doctor and let them know as soon as possible. Make sure you follow this through.

Tell them what to expect

Your children are likely to want to know what treatment will mean for their day-to-day lives. If you are in hospital, who will drop them to school, make them dinner, take them to after-school activities? To normalise the process and make sure everyone knows what to expect, you could have a physical calendar with treatment days and other events marked out.

Ask them if they want to tell anyone

Children may want to tell their close friends, their teacher, the whole class – or nobody. Explain that it's helpful to share the diagnosis with a few key people, such as their main teacher and the school principal, as well as other important people in their life, such as a music tutor or sports coach. See pages 32–34 for ideas about talking to the school.

“After Dad told us, the six of us sat around crying and hugging one another. Despite the sadness of the occasion, we actually had a pleasant dinner with lots of laughter. Our lives changed from that day.” LILY, AGED 17

When things don't go to plan

There is no “right” way to tell your children about a cancer diagnosis. If you end up blurting out the news or your child reacts differently to how you expected, don't worry. There will be many conversations over time, and this is just one of them. Don't worry if a conversation doesn't go exactly as planned – children benefit from your care and honesty over time.

Your child may even react in a way that causes hurt or offence. If this

happens, remember that children may not react with feelings of sadness straightaway. They may need time to understand what is being said, and what it means. Remind your child that they can ask questions or talk to you about their concerns at any time.

If you are feeling hurt or offended, try to deal with these feelings away from your child. Talking to friends, family or a health professional can help you make sense of your feelings.

Offer realistic hope

Tell kids that although cancer can be serious and going through treatment can be challenging, there will be good days, not-so-good days and relatively “normal” days. Explain that with the help of the treatment teams and doctors, you (or the person with cancer) will be doing everything possible to get well.

Show your love and emotion

Tell your children that you love them. You may show your love through hugging them, comforting them, or other ways of making them feel valuable. Some parents worry about crying in front of their children. It can be helpful for kids to know that strong feelings such as anger and sadness are normal and expressing them can make people feel better. Being open with each other about feelings can help your children cope.

Coping with kids' reactions

It's normal for children to have lots of different reactions to a cancer diagnosis. Talking with them about their reactions gives you a chance to discuss ways of managing how they're feeling. You will likely have several conversations about cancer as your children's understanding grows. If you are concerned that your children may need extra support, see *Getting support* on pages 71–73.



Crying

If your children cry, reassure them that feeling sad is a natural reaction. Holding them will help some children feel secure.



Fear

Fear is a natural response to something unknown. Some children may worry that they're going to be abandoned if something happens to the sick parent. Ask them what is their biggest worry and reassure them they will always be loved and looked after.



Anger

Children and young people may feel angry about the diagnosis as it means their lives could be disrupted (e.g. they might have to miss a party, help out around the house more, or a planned holiday may have to be cancelled.)



No reaction

Sometimes, children will appear not to have heard the news or do not react. You may be confused or hurt by this, but a lack of reaction isn't unusual – often the children are protecting themselves and need some time to process the information. Remind them that they can talk to you or another trusted adult about it anytime.

If your child is diagnosed

Families often describe the days and weeks after their child's cancer diagnosis as overwhelming. Among the many confronting decisions they face is how to talk to the child about their illness.

Although the focus of this booklet is children affected by someone else's diagnosis, much of the advice will still be relevant. Children with cancer tend to feel more secure when the adults around them are open – hiding the truth to protect a child may lead to greater anxiety.

How much information you share with your child will depend on their age and maturity. Keep your initial explanations simple and take your cue from your child as to whether they want to know more. The first conversation will be followed by many others, so you will have the opportunity to give more detail as the need arises. Include your child in discussions about their treatment and encourage them to ask questions.

Someone from the paediatric oncology team will be able to provide guidance and assist you with these discussions. For younger children, many hospitals have therapists (called child life therapists) who teach children strategies to manage their illness and can help explain the diagnosis and treatment. If you have a child with cancer, get in touch with Cancer Hub (see page 23).

Children and teenagers will respond to their cancer diagnosis in different ways. Fear, anger or sadness are all common reactions.

Remember that your child's hospital team is there to support the family as well. The social worker or cancer nurse specialist can let you know what support services are available, particularly if you need to travel long distances for treatment.

Some organisations have developed resources for parents of children diagnosed with cancer, including:

- Paediatric Integrated Cancer Service (vics.org.au/pics)
- Cancer Australia (childrenscancer.canceraustralia.gov.au).

Older children and teenagers may want to seek out information themselves (see *Support from Cancer Hub* on opposite page).

When a sibling has cancer

The siblings of children with cancer sometimes feel forgotten in the midst of a diagnosis. Parental attention is suddenly shifted, and daily routines, family roles and family responsibilities change.

Along with sadness, fear and anxiety, siblings may struggle with more complex emotions such as guilt, jealousy, resentment and anger. With so much focus on their brother or sister, they may feel that their needs do not deserve to be met and that they are not allowed to complain. Many children take on caring roles, whether they are asked to or not.

Some kids may feel self-conscious about their family being different from others. Some may be reluctant to tell their friends and teachers about the situation at home. If cancer changes how their brother or sister looks, they may feel embarrassed and shy away from being seen with their sibling.

“We wanted all the kids to feel involved with Leo’s treatment – we said, ‘You are part of the team, you are part of this.’ The hospital became part of our family life.” GENEVIEVE, MOTHER OF FOUR CHILDREN AGED 3, 5, 10 AND 14

You can help your children adjust to the changes in your family by talking openly. The tips on the next page under *When another child has cancer* will help, but your kids may also be reassured to know the following:

- It's not their fault.
- They can support their brother or sister by visiting the hospital and having regular contact.
- It's okay to have fun.
- Feeling cross is normal.
- They are loved and will always be looked after.

Support from Cancer Hub

Cancer Hub is a digital one-stop shop to help families (with children aged up to 25 years) access practical and emotional support. Call 1800 431 312 or visit cancerhub.org.au to connect with support from Camp Quality, Canteen and Redkite.

Camp Quality

Supports children living with cancer and their families, as well as children who have a parent or carer with cancer. The Camp Quality Kids' Guide to Cancer website and app is aimed at children aged up to 15 years. Camp Quality also offers free school programs, recreation programs, camps and family experiences, as well as a 5-part web series explaining the cancer journey.

Canteen

Helps young people aged 12-25 who are dealing with their own or a close family member's cancer. Young people can connect with others through the Canteen Connect app; get face-to-face, phone or online counselling; get specialist, in-hospital treatment; and attend programs, camps and gatherings.

Redkite

Provides practical, emotional and financial support for families who have a child aged 0-18 years diagnosed with cancer. Many services are delivered online through the myRedkite portal or by Redkite's team of specialised paediatric oncology social workers.

When another child has cancer

In most cases, children will first learn about cancer when an adult in their life has been affected (e.g. a grandparent, aunt or teacher). So it can be confusing and frightening for them if a child (e.g. a friend, sibling or cousin) is diagnosed with cancer.

Causes of cancer – Let your child know that there's nothing anyone did to cause the cancer, nor does a child get cancer because of behaviour or a minor accident like a bump on the head. Nobody did anything to cause the cancer.

It's not contagious – Children need to feel safe around the child with cancer. Tell them that cancer can't be passed on to other people. If the sick child is in isolation or unable to share food with other children, explain that this is to protect the child from infection, not to protect everyone else from the cancer.

Most children get better – Like adults, children may worry that cancer means their friend will die. Reassure children that although cancer is a serious disease, the overall survival rate for children is high (about 87%).³ This can vary depending on the diagnosis.

Expect change – If it's a child's friend, explain that things might change. For example, their friend may feel too unwell to play, may be away from school a lot or may have physical changes (e.g. lose hair or need to use a wheelchair). Encourage your child to focus on what hasn't changed – their friend's personality and their friendship.

Visit the hospital if possible – It can be confusing for your child if the person with cancer disappears from their life after diagnosis. They may imagine the worst. It may be helpful to take your child to visit

their friend in hospital, but first check with the friend’s parents and with the hospital.

Keep in touch – If a hospital visit is not possible, there are other ways for your child to maintain the relationship with their friend. Younger children might like to make a card or a decoration for the hospital room, or you could phone, text or make video calls.

Encourage expression of feelings – Let your child know that it’s okay to have lots of different emotions and that you have them too.

Busting the myths

There are many common fears and misconceptions around talking with children about cancer. Listed below are a few myths (and why they are incorrect):

- *“I have to get it right”*: There is no “right” time or way to talk to your children about cancer; every family will find their own way to have these conversations.
 - *“Finding out I have cancer will traumatise my children”*: Some children may have strong reactions to hearing that their parent has cancer, but this does not necessarily mean they are not coping (see page 20).
 - *“As a parent, I have to appear to know what I am doing at all times, and be in control”*: It’s okay to be sad in front of your children, and to not know all the answers.
 - *“Coping with cancer means that my children will always be happy and look on the bright side”*: Sadness, anger and fear are all normal reactions. See pages 71–72 for warning signs that your child may need some extra support.
 - *“There will be one big conversation where I break the news of cancer”*: While the first discussion is likely to be difficult, this will be the first of a series of conversations where your children can ask questions and explore their feelings and responses to the news.
-

Answering key questions

Q: What is cancer?

For younger children: *“Cancer is a disease that happens when bad cells stop the good cells from doing their job. These bad cells can grow into a lump and can spread to other parts of the body.”*

For older children and teenagers: *“Cancer is the name for more than 200 diseases when abnormal cells grow and rapidly divide. These cells usually develop into a lump called a tumour or they may spread through the blood. Cancer may spread to other parts of the body.”*

Q: Are you going to die?

This is the question that most parents fear, but often it doesn't mean what you think. For example, younger children may really mean “Who is going to look after me?” Older children may be wondering, “Can we still go away during the school holidays?”

You can explain that the treatment you are receiving is the result of many years of research and that treatments are improving all the time. If your child knows someone who has died of cancer, let them know that there are many different types of cancer and everyone responds differently.

Children and teenagers often have many questions about death and dying. Cancer commonly prompts them to reflect on their own life and the lives of those they care about.

“We don't expect that to happen, but I will probably be sick for a while. I am doing everything I can to be well. Sometimes it makes me sad, and I wonder if you get sad too.”

For ways to approach end-of-life discussions, see pages 58–60.



The Redkite Book Club has more than 80 books about childhood cancer suitable for a range of readers, from young children to teenagers. You can order these books for free via the myRedkite portal. Redkite also has a podcast series called Kids Cancer Conversations. For details, see redkite.org.au/kids-cancer-conversations.

Q: Was it my fault?

Some children may ask you directly if they caused the cancer, while others worry in silence, so it's best to discuss the issue.

“It’s no-one’s fault I have cancer. Scientists don’t know exactly why some people get cancer, but they do know that it isn’t anything you did or said that made me sick.”

Q: Do I have to tell other people about it?

If you're planning to inform teachers, the school counsellor or principal, talk to your kids first. Teenagers and even younger children may not want the school to know, so explain the benefits of telling the school and then chat about the best way to approach the discussion. Ask if your teenagers want to be involved in these conversations.

“You can tell your friends if you want to, but you don’t have to. People we know may talk about the diagnosis, so your friends might hear even if you don’t tell them. Many people find it helps to talk about the things that are on their mind.”

“Sometimes people talk about illness but they don’t know the full story. If the kids at school are talking about the cancer, let me know so we can discuss any things that they have got wrong.”

Q: Can I catch cancer?

“You can’t catch cancer like you can catch a cold by being around someone who has it, so it’s okay to hug or kiss me even though I’m sick.”

“Cancer can spread through the body of a person with cancer, but it can’t spread to another person.”

Q: Who will look after me?

“We will try to keep things as normal as possible, but sometimes I may have to ask Dad/Mum/Grandpa to help out.”

Q: Is there anything I can do to help?

Letting kids know that they can help may make them feel useful, but it’s important that they don’t feel overwhelmed with responsibility. Some parents may feel hurt if their children don’t ask how they can help, but it’s common for children not to think to offer.

“Yes, there are lots of things you can do to help. We will work out what those things can be, and what will make things easier for everyone. Is there something in particular you would like to do?”

“Some help around the house would be good, but it’s important that you keep up with your schoolwork and you have some time for fun and for seeing your friends.”

“It is often helpful to talk to other parents who have or have had kids at a similar age to yours when diagnosed. Talking to another parent who has travelled the same road can be reassuring.”

MIRA, MOTHER OF TWO CHILDREN AGED 3 AND 12



Suzanne's story

My children were only 5 and 6 years old when I was diagnosed with breast cancer.

When it was confirmed that I needed to have one breast removed, we knew we had to explain this to the kids. They thought that it was hilarious.

We asked the boys if they had any questions, reassuring them that they could ask me anything. The 2 little boys just sat there staring at us for a while, until the older one said: "I have a question."

Expecting a question about dying or something else that frightened him, we were surprised by his query. "Did the doctor use scissors or a knife?"

My younger son later said to me: "Don't worry, Mummy, it's just like Nemo's lucky fin."

So that was the depth of our conversations. The relief that I felt after talking to them was enormous. They are very simple at that

age; they don't need too much information. Sometimes we can be guilty of imposing our own fears on our children.

During the 8 weeks or so before telling the boys about my diagnosis, I didn't realise how much stress that was creating for me.

During treatment, along with the support of my mother and friends, we were able to keep the boys' routine as normal as possible. Aside from school, we kept them busy with sport and enrolled them in art classes.

The boys didn't ask many questions about the cancer until many years later, when they were about 14 and 15. It changed into a more mature conversation. They wanted to know if the cancer was ever going to come back. You can't say definitively that it is never going to come back.

And my youngest was right about my lucky fin. I am still here all these years later.

What words should I use?

It's often hard to find the words to start or continue a conversation. The suggestions below may help you work out what you want to say. Although these are grouped by age,

Infants, toddlers and preschoolers

About cancer

"I am sick with something called cancer. The doctor is giving me medicine to help me get better. The medicine might make me feel sick or tired some days, but I might feel fine on other days."

"Mummy is sick and needs to go to hospital to get better. You can visit her soon."

To check knowledge of cancer

"Sometimes children worry that they thought or did something to cause cancer. No-one can make people get cancer, and we can't wish it away either."

"We can still have lots of kisses and hugs – you cannot catch cancer from me."

To explain changes and offer assurance

"Mummy needs to go to the hospital every day for a few weeks, so Daddy will be taking you to preschool/ school instead."

"Grandpa is sick so we won't see him for a while. He loves your pictures, so maybe you can draw some for me to take to hospital."

"Mummy has to stay in bed a lot and isn't able to play, but she can still cuddle you and read with you. Aunty will be here to help us."

you may find that the ideas in a younger or older age bracket work for your child. See page 40, and also pages 26-28, for tips on how to answer specific questions.

Younger children

“You know that Mum has been sick a lot lately. The doctors told us today that the tests show she has cancer. The good news is that she has an excellent chance of getting better.”

“Do you know what cancer is? Cancer is a disease of the body that can be in different places for different people.”

“Even though your friends at school might say that cancer is really bad and I will get very sick, they don’t know everything about this cancer. I will tell you what I know about my cancer.”

“Even though things might change a bit at home, you’ll still be able to go to tennis lessons while Dad is having his treatment.”

“Mum is going to be busy helping Grandma after she comes out of hospital. There are ways we can all help out, but mostly things will stay the same for you.”

Older children and teenagers

“The doctors say Dad has a problem in his blood – it’s an illness called Hodgkin lymphoma. That’s why he’s been very tired lately. Dad will have treatment to help him get better.”

“Lots of people get cancer; we don’t usually know why. Most people with this type of cancer get better and we expect I will get better too.”

“There are many types of cancer and they’re all treated differently. Even though Uncle Bob had cancer, it might not be the same for me.”

“The doctor doesn’t know why I got cancer. It doesn’t mean that you’ll get cancer too.”

“Things will be different while Dad’s having treatment, and when I can’t drive you to soccer training, Annie will drive you instead.”

“After my operation, there are a few things I won’t be able to do for a while, like lifting things and driving. Our friends are going to help by dropping off meals.”

“If you have any questions or worries, you can come and talk to me. It’s okay if you want to talk to someone else too.”

Involving others

There are several ways to ensure kids hear a consistent message from people who are involved in their lives.

Tell key adults – Share the diagnosis with other people who talk with your kids (grandparents, friends, teachers, babysitters) and tell them what you plan to say to your children so that you all communicate the same message.

Talk to other people who have cancer – Often the best support and ideas come from people who've already been there. You'll realise you're not alone and you can ask them how they handled things (see *Finding support and information* on page 71).

Ask a professional – It may also be helpful to get some tips from a professional, such as an oncology nurse or social worker, psychologist or other health professionals at the hospital. They are used to a range of reactions and situations, and might have some tips for coping.

“Sometimes I felt alone when my dad was sick. None of my friends really understood what we were going through at home, or that the problem could go on for so long.” ADELE, AGED 16

Involving the school or preschool

Many parents wonder if they should tell the school when someone in the family has been diagnosed with cancer. If things are unsettled at home, school can be a place where kids can be themselves with their friends and carry on life as normal.

When the school is aware of the situation at home, staff may be more understanding of behaviour changes and can provide support. In fact, school staff are often the first to notice shifts in a child's behaviour that may indicate distress. Ask the school to let you know of any changes in behaviour or academic performance. Ideally, a particular staff member, such as the class teacher, student wellbeing coordinator or year adviser, can provide a regular point of contact with you and your children.

However, request that teachers don't probe – some well-meaning staff members might misinterpret your child's behaviour and unintentionally make them feel uncomfortable. For example, a teacher may ask if your child is okay when they're happily sitting on their own.

A cancer diagnosis in the family can also have an impact on academic performance, so the student may be entitled to special provisions. This can be particularly important in the final years of high school. Some states and territories have schemes to help a student enter tertiary study if they have experienced long-term educational disadvantage because of their or a family member's cancer diagnosis.

If you feel concerned about your child, ask your child's teacher or principal whether your child could see the school counsellor. Sometimes other children can be thoughtless in their comments. Talk to your child about how other children are reacting and encourage them to tell you if they have any concerns. You can raise these issues with teachers if needed.

Ask a parent of one of your child's friends to help you keep track of school notes, excursions, homework and other events. When life is disrupted at home, children may feel doubly hurt if they miss out on an event or activity at school because a note goes missing.

Support services for schools

You may want to let the school know about services that provide school visits and information about cancer. For primary school and preschool children, Camp Quality offers a cancer education program, featuring puppets, to help young students learn about cancer in an age-appropriate way. Camp Quality's new web series *Bloom* is also available online, and suitable for 12-16 year olds, with classroom resources attached. For more details, call 1300 662 267 or visit campquality.org.au.

“Dad just told us straight: ‘I have cancer.’ I just thought, ‘He’s going to die.’ Mum tried to sugar-coat it and said there were things they could do, but I was thinking the worst. I wanted to run. I wanted to do something. I thought if I could just do something, that would change it. I joined Canteen the next day.” IZZY, AGED 15

Talking about treatment

Cancer treatment can be challenging for the whole family, but children and young people often manage better when they know what to expect. How much detail you provide will depend on the child, your values and your cultural background. While you may not be able to say exactly what will happen, you can promise to follow up and keep your children updated.



What do children need to know?

Providing children and young people with information about the treatment, why and how it is done, and possible side effects can help them understand what to expect in the weeks and months ahead.

Outline the treatment plan

- Let the children be your guide as to how much they already know and how much they want to know about treatment.
- Start with questions such as “Have you heard the word chemotherapy?” or “Do you know what radiation therapy is?”. Then explain the basic facts using language they can understand (see the glossary on pages 77-79).
- Check if your kids want to know more, and let them know that they can ask questions throughout the treatment period if they have other queries or concerns.
- Talk to kids about how to search for trustworthy information online (see page 74 for a list of recommended websites).
- Keep children up to date with how long treatment will take and the length of the hospital stay.
- Explain who will be taking care of the person with cancer and the different ways the carers will help.

“I knew that my hair falling out might be very traumatic for the kids. I invited two girlfriends around to help shave my hair off and involved the children in a self-indulgence day. There was lots of laughter, the children got involved in the shaving, and then we all put on make-up and did our nails.”

ANNA, MOTHER OF TWO CHILDREN AGED 9 AND 13

Explain side effects

It's important to prepare children for treatment side effects, such as weight changes, fatigue, nausea, scars and hair loss. Explain that not everyone gets all side effects. People who have the same cancer and cancer treatment will not necessarily have the same side effects. Doctors can't be exactly sure what will happen to each person.

Tell your children what side effects to expect, based on what the doctor has said, and how these may change how you look or feel. Talk about ways your children can help you deal with the side effects (e.g. help shave your head or choose a wig). These actions make your children feel included and useful.

Children should know that side effects usually go away after treatment. Hair will grow back, scars will fade - but this often takes time. Reassure your children that they will get used to the changes. Point out that you're still the same person as before.

Explain that side effects do not mean that you're getting worse. It's common for kids to get upset when they see the effects of the drugs, which may include fatigue or vomiting. They may worry that the treatment is making the cancer worse or that the cancer has progressed.

If there are no side effects, reassure them that this doesn't mean the treatment is not working. If side effects mean you can't join in usual family activities, make sure your children understand that it doesn't mean you're not interested.

Explain to them what side effects are considered normal. This can be especially important for older teenagers who might worry about when they should call for help.

Creative ways to explain cancer and its treatment

A range of creative methods can help explain cancer treatment and explore feelings without talking. You can adapt these suggestions for different ages and interests.



Make up stories and play games

Blow some bubbles in the air to represent cancer cells and challenge your children to pop these cancer bubbles by jumping, slapping or stomping on them. You can explain to your children that the treatment is “popping” the cancer cells, just like they are popping the bubbles.



Visualise it

Draw a flow chart, map or timeline to show the different stages of the treatment plan. Throughout treatment, you can look at the chart together to see where you are up to.



Say it with music

Listening to different types of music together or getting kids to make up their own music could help kids imagine the impact of different treatments. (e.g. using percussion to represent destroying the cancer cells).



Keep a journal

Keeping a personal journal or diary can help older primary school children and teenagers to express their feelings. Some children may prefer to write stories or poems.



Draw feelings

Ask your kids to draw what they think cancer is or how different treatments work. Their artwork can show a lot about what they understand or are feeling.

Hospital visits

A visit to hospital can seem strange and confronting for a person of any age, but children's fears may be worse than the reality. Reassure them that hospitals are special places where people are given good care. Ask your kids if they want to go to the hospital or treatment centre. Some hospitals may offer a tour for families. If children would prefer not to go, don't insist on them visiting.

Preparing for a hospital visit

If children are keen to visit the hospital, tell them what to expect and what they may notice: the equipment; different smells and noises (e.g. beeping); how you may look (e.g. connected to tubes, a drip or catheter bag full of urine hanging on the side of the bed); doctors and nurses might keep coming in and out to check on patients.

Let your kids decide how long they want to stay. A friend or relative could take them out of the room if they feel overwhelmed. Your kids may want to help by getting you a drink or magazine from the hospital shop. Small children tend to get bored quickly and want to leave soon after arrival. Bring art materials, books or toys to keep them busy. Or you could simply watch TV or listen to music together. After the visit, talk to them about how they felt and answer any questions they have.

If you have to travel for treatment and your children are unable to visit, you could use video calling on a mobile phone to communicate.



Ask the doctor to explain anything that is confusing or unclear. The nurses and social workers at the hospital are good sources of information, as are Cancer Council's 13 11 20 information and support consultants. Once you have an understanding of the treatment, you may find it easier to explain it to your kids.

Answering key questions

Q: Does treatment hurt?

For younger children: *“Cancer doesn’t always hurt, but if I have pain, the doctors will give me medicine to help make it go away.”*

For older children and teenagers: *“The cancer treatment may cause me pain. The doctors can give me medicines for pain, but I might have good days and bad. I’ll let you know if I am having a bad day.”*

Q: Why do you look so sick when the doctors are meant to be making you better?

Often people who have cancer look perfectly well when diagnosed. It’s only when they have treatment and the side effects kick in that they start to look sick. This can be hard for children to understand.

“The doctors are using strong medicine to kill the cancer, but the medicine affects good cells as well as cancer cells. Some days I might feel and look sick, but this doesn’t mean the cancer is getting worse. I will start to feel better when treatment finishes.”

Q: Will your hair come back?

“The doctor says I may lose my hair because of the chemotherapy. If I want to, I can wear wigs, scarves or hats until it grows back.”

Q: Does radiation therapy make you radioactive?

A common fear among children is that they can become radioactive by touching you after radiation therapy. With most types of radiation therapy, this is not possible. Your doctor will tell you if you need to take any precautions.

“Radiation therapy is like an x-ray. It doesn’t hurt. It’s safe to touch me.”

Q: Why do you need to rest so much?

Children often can't understand the exhaustion you may feel after treatment. They may resent you not doing as much with them.

“The treatment I’m having has made me tired and I need to rest. Let’s make a plan for what we’ll do on a day I have more energy and perhaps today we can do something quiet like watch a movie.”

“My husband, Bruce, had a brain tumour and his personality changed because of it. At the dinner table one night, our 4-year-old, Emma, announced, ‘I wish Daddy was dead.’ I calmly asked Emma what she meant. She replied, ‘I don’t like the man who’s in my Daddy’s body. I want my real Daddy back.’ I could then explain why Bruce’s behaviour had changed.” DEBRA, MOTHER OF A 4-YEAR-OLD

Family life during treatment

If you are a parent with cancer, you may be keen to keep life as normal as possible for your kids during treatment. But this can be challenging when you are coping with treatment and recovery, because of frequent trips to the hospital, changes to your appearance or lower energy levels. You may feel guilty about not being able to do all the usual things with, and for, your kids.

There are no easy solutions to this problem, but you can make the most of your good days by doing fun things with the family. On the not-so-good days, let your kids know, rather than trying to protect them from the reality of how you’re feeling.

Acknowledging disappointment

It is normal for children to think mostly of themselves and how a situation affects them. Some older children and teenagers may seem annoyed about the diagnosis and act as if they don't care about their parent. You may find their reaction hurtful or frustrating, but it is common and age-appropriate.

It can be helpful to acknowledge your child's disappointment: "I know you're finding it frustrating that I can't watch you play soccer like I usually do, but I am not feeling well and I just need some quiet time right now."

You may like to tell younger children: "I know you feel upset that I can't play with you. I am sad too, but I am very tired. Let's think about what we can do tomorrow when I feel better."

It's also important that children and teenagers understand that how they behave won't affect your health and recovery. Children might assume they have to protect their parent, or act in a certain way or their parent won't get better.

If you are a parent caring for someone with cancer, such as your partner or your own parent, you may feel like you have little time and energy left for your children. Although asking for and accepting help can be difficult, it may relieve some pressure and allow you to spend more time together as a family.

Cancer Council's booklet *Caring for Someone with Cancer* discusses ways to look after yourself and how to take a break, and includes a list of support services for carers. Call 13 11 20 for a free copy, or download it from your local Cancer Council website.

Managing emotions

Anger, crying and withdrawal are some of the possible reactions in children. These can be protective responses that allow a child or young person time to deal with the information.

Some children may hide their feelings because they do not want to add to their parents' stress. Even if your child's behaviour doesn't suggest they are struggling, let them know you appreciate how hard this situation is for them.

Children will express their emotions differently depending on their age and nature. If your kids' reactions seem unusual, out of character or intense, consider getting some professional support (see page 71-72).



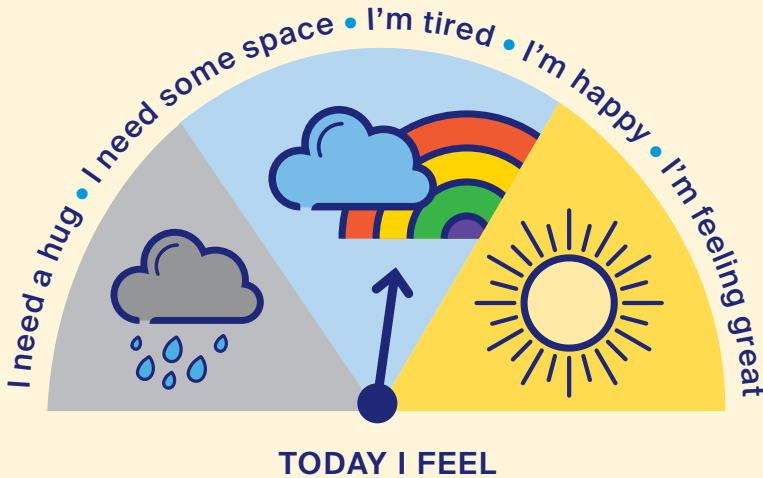
Tips to help children manage their emotions

- Encourage kids to identify and name feelings. For younger children, you may need to do this for them (e.g. "You seem like you might be angry" or "You seem really worried").
- Reassure them that there are no "right" or "wrong" feelings.
- Let them know that anger, guilt and sadness are normal feelings. You feel them too and it is okay to talk about them.
- Discuss ways to manage anxiety and stress.
- Make sure they have plenty of opportunities for physical activity and spending time with friends.
- Provide plenty of physical comfort, such as hugs.
- Offer creative ways for children to express their emotions.
- Create lots of opportunities for humour and fun. Let your children know that it is all right to joke and enjoy themselves. Laughter can often relieve tension and help everyone relax.

The emotions thermometer

The physical and emotional health of a person with cancer will vary during and after treatment. It can sometimes be hard to let your family know how you're feeling, and they might find it hard to ask.

An emotions thermometer may help. This simple tool allows you to show how you're feeling every day. You can make one yourself and ask the kids to help, or there are many versions available online. Just search for "emotions thermometer". Choose which feelings to include and add a pointer that moves to the different feelings.



Put the emotions thermometer up where everyone can see it, such as on the fridge or noticeboard.

Encouraging family time

Maintaining routines and family traditions as much as possible will help children and young people feel safe and secure. Sometimes you have to strike a balance between doing regular activities and coping with the effects of the cancer. During treatment, when life may be disrupted and unsettled, try to protect the time your family has together.

Camp Quality offers holiday accommodation and camps to families affected by cancer. This is often the first break a family has after a cancer diagnosis, and it gives them the chance to relax and reconnect. Call 1300 662 267 or visit campquality.org.au.



Tips to protect family time

- Some families may limit visitors and choose not to answer any phones at mealtimes. Others may welcome some visitors at this time.
- You may want to set some boundaries around when friends phone you, or you might ask them to send an email or keep in touch through social media platforms. There are many ways to keep family and friends updated on how you are doing. You may use a closed Facebook group, set up a chat group on a messaging app, or use caringbridge.org.
- Think of things to do together that don't require much energy. You could read a book aloud, watch a movie, or play a board game or a video game.
- Ask a close friend or relative to coordinate all offers from friends and family to help out with household chores. You could also use an app, such as gathermycrew.org.au or [KiteCrew \(redkite.org.au/how-we-help/kitecrew\)](http://KiteCrew(redkite.org.au/how-we-help/kitecrew)).
- Plan for “cancer-free” time with the family where you don't focus on the illness but do fun things that allow you to laugh, joke and relax.

Spending one-on-one time

When a family member is diagnosed with cancer, it can be difficult for parents to spend one-on-one time with their children. One way to focus your attention and care is to schedule a regular 30-minute session with your child or teenager. This may help them feel important, valued and understood.

Talk with your children about the type of activities and family time that are important to them. If you have more than one child, you may need to alternate weeks for one-on-one time depending on your energy levels.

Younger children may not have developed the thinking or language skills to describe how they're feeling, but a play session can help them to express feelings, make sense of events, and understand the world. Their play may reveal an inner world that you would never know about from what they say.

Teenagers may enjoy spending time with friends, but one-on-one time with you is important. You may like to visit a favourite cafe, go for a walk, watch a movie or listen to music with them.

Maintaining discipline

It can be hard enough to maintain family rules when you're fit and healthy, let alone when you're dealing with the emotional and physical effects of cancer treatment or caring for someone with cancer. Some parents say they feel guilty for putting the family through the stress of cancer, so they don't want to keep pushing their children to do homework and chores.

Maintaining the family's usual routines and boundaries during this time can strengthen your children's sense of security and their ability to cope.



For more information about all aspects of cancer, listen to Cancer Council NSW's podcast series, *The Thing About Cancer*. To listen, go to cancercouncil.com.au/podcasts or use any podcast app.

Keeping up children's chores, encouraging good study habits, calling out inappropriate behaviours, and sticking to regular bedtimes – all require continued and ongoing supervision from adults.

Although some flexibility may be reasonable at this time, a predictable set of boundaries and expectations can be reassuring for children and young people. Let teenagers know that the usual rules apply for curfews, drug and alcohol use, and sex.

Encouraging children to help

When a family is dealing with a cancer diagnosis, children may need to take on extra responsibilities. If children feel they are being useful, it can boost their self-esteem because it shows that you value and need them.

Young children can help with simple tasks like setting the table, vacuuming or feeding pets. With older children and teenagers, it's reasonable to want them to help more around the house and do tasks like making simple meals, cleaning the kitchen, and helping with laundry.

Try to share tasks fairly among all family members and avoid overloading teenagers with chores. Jobs that need to be done are not always obvious to older children, so discuss priorities and how tasks can be divided up.

When asking teenagers to help, keep in mind that it is normal for them to spend time with their friends as well.

This can be a time to reflect on priorities and what really matters for your family. You might choose to let go of or outsource some household tasks that you previously thought were essential.

Single-parent families

In any family, a cancer diagnosis can make it challenging to meet everyone's needs. If you are the only parent in your household, cancer may come on top of an already heavy domestic, financial and emotional load.

Your children will need to help but may end up taking on more responsibility than they are ready for. Ask your friends and extended family to support them. You can also find out what support services are available in your area by calling Cancer Council 13 11 20 or Cancer Hub on 1800 431 312.

You may want to get in touch with the Carers Australia Young Carers Network at youngcarersnetwork.com.au. This organisation runs activities and support groups for young people (aged up to 25 years) who care for a parent with a serious illness. Even young children may be considered young carers – for example, if they are helping with cooking or cleaning. Camp Quality and Canteen can also offer support to children when a parent has cancer (see page 23).

“I tried to get some rest during the day so that I was bright and more energetic when the family came home in the evening. I didn't want them to feel they had a sick mum all the time – I was only sick from the treatment, not from the disease itself.”

LIZ, MOTHER OF THREE CHILDREN AGED 10, 16 AND 18

Helping around the house

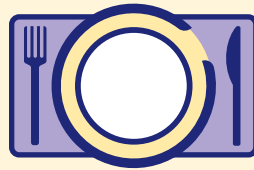
The internet is a good source of information about appropriate jobs around the house for children of all ages. Try searching for “age-appropriate chores”. Some possibilities include:

Ages 2–4



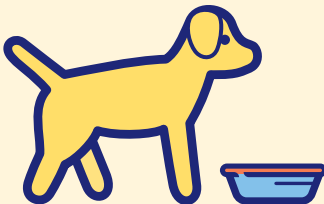
- put toys into toybox
- put books back on shelf
- put clothes into dirty washing basket

Ages 4–8



- set table
- match socks
- help make bed
- help dust
- help put away groceries

Ages 8–12



- make bed
- feed pets
- vacuum
- load and empty dishwasher
- rake leaves

Over 12



- make simple meals
- clean kitchen
- clean bathroom
- wash and hang out clothes
- wash dishes
- wash car

Staying in touch

If you need to travel for treatment, or if you have extended hospital stays, you may be away from your family for long periods. In some cases, both parents may need to travel to a major hospital and leave their children with family members or friends.

The following tips may help you stay in touch. They might also be useful if you don't need to leave home but want extra ways to communicate with your kids.



Tips for staying in touch

- Ask your kids to make artwork and send you photos of their day.
- Set a time to call home each night when you're away, then read a favourite story together over the phone or via video calling.
- Write an old-fashioned letter. Kids love finding mail addressed to them in the letterbox.
- Send an email or recorded message when you're feeling up to it.
- Connect through social media or play an online game together.
- Leave notes and surprises for kids to find, such as a note in a lunch box.
- Use private messenger apps for one-on-one chats with teenagers.
- If they're able to visit, children can bring cards or pictures from home, flowers picked from the garden, or a toy to "mind" you in hospital.

After treatment

For many people, the end of active treatment is a time of relief and celebration, but it can also be a time of mixed emotions. Children and teenagers may expect life to return to normal straightaway, but the person who has had treatment may be re-evaluating their priorities. Your family might need to find a “new normal”.



What do children need to know?

It may help children and young people to know that cancer can be a life-changing experience for many people. Once treatment has finished, some people want life to return to normal as soon as possible, while others feel they need to re-evaluate their life.

This process is often called “finding a new normal”, and it may take months or years. People may also worry about the cancer coming back. The person who has completed cancer treatment may continue to feel the physical impact of cancer and its treatment. For example, fatigue is a problem for most cancer survivors. They may make life changes such as choosing a new career, starting a new exercise program, reassessing relationships or improving their eating habits.

- ▶ See our *Living Well After Cancer* booklet for information about life after treatment.

How children react

Like many adults, children may find it hard to understand why things can't go back to the way they were before the cancer. They've had to deal with changes while their parent or other family member was sick, and now they probably want to get back to normal.

Your kids may:

- expect the person who had cancer to bounce back
- become clingy
- worry the cancer will return
- carry on as if the cancer never happened.

Expect good days and bad days – for both adults and children in the family. Focus on one day at a time.



Genevieve's story

Throughout my son Leo's treatment, it was so hard to plan. We just had to say, "Let's see what tomorrow brings". Two years of that. You think it's never going to end.

It was such a joyful day when the treatment finally finished. I had never allowed myself to look that far ahead. Leo had a "no more chemo" party at school. Leukaemia treatment is so socially isolating, and it was just wonderful to see people embrace the family and to see Leo so engaged with school and friends.

Now that treatment is over, each and every day matters. It may not be a good day, but all days are important. We've all learnt not to write off time – you don't put things off. It's a good life lesson.

I'm really proud of all 4 of my children. Despite all the hardship, there has been a lot of growth for them. They are more resilient and have developed strength and compassion. Leo's siblings pulled him through, and we all pulled through together as a family.

Family life after treatment

You may celebrate the end of cancer treatment and acknowledge that it has been a difficult period for everyone; this is particularly important for teenagers. Your children have lived with worry for months and may need your permission to relax and have fun again. Thank them for their role in keeping the family going and supporting you.

Let the family know how you're feeling emotionally and physically so they understand if you're not bouncing back as quickly as they expected. It may be helpful to remind your family that side effects are likely to last for a while after treatment finishes.

Keep using the emotions thermometer if you found it helpful (see page 44). Be open about your feelings, such as if you're feeling anxious before a check-up or disappointed that you couldn't attend something. This may encourage your kids to talk about their own emotions.

Do things at your own pace, and avoid any pressure to return to "normal" activities. You may want to ask yourself: Am I doing what fulfils me? Am I doing what I want to do? What is important to me?

Explain any changes to the family's lifestyle to your children and negotiate responsibility where possible.

During your recovery, you may be able to encourage your family to join you in making some healthy lifestyle changes – for example, you could do light exercise together, or make healthy changes to the kids' diets as well as your own.

Looking after yourself

If you are a parent who has finished cancer treatment, you may want to focus your attention on your children, but it is important to look after your own wellbeing as well. These strategies can help.

- Consider joining a support group. You may find it helpful to meet other people who have been through cancer and understand how you are feeling. Find out

about Cancer Council's Cancer Connect program by calling 13 11 20. They may be able to put you in touch with someone else in a similar situation.

- Read real-life stories of how other people have responded to a cancer diagnosis.
 - Take part in a survivorship program or event. To find out what is available in your area, contact Cancer Council 13 11 20.
-

Answering key questions

Q: Will the cancer come back?

This can be a chance to hear your children's concerns about “What if?”. Listening to their fears is important in helping them cope.

“The treatment is over and we all hope that will be the end of it. We hope that the cancer won’t come back, but the doctors will keep a careful eye on the cancer with check-ups every now and then. If the cancer does come back, I will have some more treatment, which we hope would make it go away again. We’ll let you know if that happens.”

Q: Why are you still tired?

“I’m feeling a lot better, but the doctor said it might take many months, even a year, to get all my energy back.”

“The treatment was worth it because now I’m better and the cancer has gone away, but it took a lot out of me and now my body needs time to recover. This is normal for people in my situation.”

Q: Can’t we get back to normal now?

You may need to take some time to process the ways that cancer has affected you, but this will probably be difficult for children, particularly younger ones, to understand.

“Life will start to get more like normal as I feel better, but we may change the way we do things, like ... [the way we eat/how much I go to work]. Maybe we can also find some new hobbies to do together.”

“We’ve all been through a lot and I know it’s been hard for you too. Things might not get back to exactly how they were before I got sick, but together we can find a new way that works for all of us.”

Talking about advanced cancer

This chapter is a starting point for talking to your children if someone they love has cancer that has come back or spread. The issues are complex, emotional and personal, so you may find reading parts of this chapter difficult. If you want more information or support, talk to hospital staff or contact the services listed on page 74.



What do children need to know?

For some people, the cancer may be advanced when they are first diagnosed. For others, the cancer may spread or come back (recur), even after the initial treatment seemed to work.

Living longer with advanced cancer

Many people with advanced disease are surviving for longer periods of time. Treatment can often keep the cancer under control and maintain quality of life for many months, and sometimes for years. When this happens, the cancer may be considered a chronic (long-term) illness.

If the cancer has advanced, it is important to keep talking with your children. Just as with the initial diagnosis, children may sense that something is happening, and not telling them can add to their anxiety and distress. Children may have similar feelings to adults after hearing the cancer has advanced. These include shock, denial, fear, sadness, anger, guilt or loneliness.

Uncertainty about what the future holds will be a challenge for both you and your children. You may be able to reassure children that, although the cancer cannot be cured, there are treatments that can help you feel better and you may be able to stay well for a long time. Remember that the concept of time can be different for younger children. While several years might seem a short time to you, it can seem like a long time for children.

Offering realistic hope

A diagnosis of advanced cancer does not necessarily mean giving up hope. Some people with advanced cancer can continue to enjoy many aspects of life, including spending time with their children and other people who are important to them, and doing things they enjoy.

If the disease progresses, the things that are hoped for may change. For example, a person may now focus on living comfortably for as long as possible or being able to celebrate a particular event. You can share these hopes with children while still acknowledging the reality of the situation and allowing them to prepare for loss.

Conversations about the end of life

While some people with advanced cancer live for years, for others, the outcome (prognosis) is fairly clear and they will know that they may have only weeks or months to live. If death is likely in the short term, it is best to be as open as possible while trying to make the subject of death less frightening. For example, avoid saying that death is always peaceful because this may not be the case.

If you need to talk about yourself or your partner, this can be an especially hard thing to do. Hospital social workers and other health professionals can support you and help you find ways to have these challenging conversations with your children.

You may ask children what they know about death and what they think it means. This can help you to clear up any misconceptions. Talking to children about death openly may help them feel more comfortable spending time with their family member who has cancer. Acknowledging that someone is likely to die also gives your family the chance to show and say how much you care for each other, and it allows families to work on any unresolved issues.

Wait for your children to ask

When you talk with your children about death, offer simple and short explanations. Give brief answers to questions they ask. Wait for the next question to emerge and respond to that.

It usually doesn't help to offer lengthy explanations if your children aren't ready to hear them. If they ask a question you don't know the answer to, say you'll find out and let them know.

Use words they can understand

Terms such as “passed away”, “passed on”, “lost”, “went to sleep” or “resting” can be confusing for children. It's best to use direct language. This includes using the words “dying” or “death”. See pages 67–68 for how to explain these concepts in an age-appropriate way.

Feeling overwhelmed

It's easy to feel overwhelmed when you or a family member has advanced cancer. An important part of supporting children is to ensure that you have support around you too. You may find some of the following suggestions helpful.

- Ask family and friends for help. Let them know what you need – they will probably be relieved to have something to do. Use an app like KiteCrew or Gather My Crew.
- Get practical assistance and information from Cancer Council and other organisations (see pages 73–74).
- Talk with your GP and consider getting a referral to a psychologist or psychiatrist, or speak with a counsellor. Depression and anxiety

are common after cancer but effective treatments are available.

- Consider using complementary therapies, such as massage, to manage stress. You could also try the relaxation and meditation exercises in Cancer Council's podcast *Finding Calm During Cancer* (cancercouncil.com.au/podcasts).
- Contact Cancer Hub on 1800 431 312 and ask Canteen, Camp Quality or Redkite for help. Lifeline and Kids Helpline both provide 24-hour phone counselling (see page 74).

For more details, see *Finding support and information* on pages 71–76.

Tell them what to expect

Prepare children by explaining how the illness might affect the person in the days ahead and what treatment they may have. For example, the person might be sleepy or need a lot of medicine. Young children tend to think in concrete terms, and it helps to talk about death as a change in function. For example, “When Grandma dies, her body will stop working. She will stop breathing, and she won’t feel anything either.”

What words should I use?

If you need to prepare a child for the death of someone they care about, it can be hard to find the words to use. See also pages 62–65 for tips on how to answer specific questions.

When advanced cancer is diagnosed

“Some people with this sort of cancer recover, but some don’t. I’m going to do everything I can to keep the cancer under control, and I will always let you know how the treatments are going.”

When end of life is near

“The doctors say the treatments have stopped working for me. There isn’t anything else they can do that can make me better. We think that means I am going to die soon. We will try to spend some special, quiet time together and make the most of the time I have left.”

To explain death

“I have some very sad news to tell you. Grandma died last night. Her body stopped working so she couldn’t breathe or move anymore. We won’t be able to see Grandma again, but we will always know she loved us. Is there anything you’d like to know about how Grandma died?”

How children react

When children find out that the cancer is advanced, they may have similar but more intense reactions than when they found out about the original diagnosis. Some studies of people with advanced cancer show that family members often feel more distressed than the person with cancer. This seems to be more common in families who have not spoken with their children about cancer.

Dealing with denial

Some people find it difficult to accept that their parent will never get better. This is a normal and understandable response to such a painful and difficult situation. Try to be gentle with young people who have this reaction. Pushing someone to accept that their parent is dying may be stressful for everyone. It's also unlikely to lead to acceptance.

While an impending death of a parent from cancer may mean that there isn't much time, try to stay calm and be available to listen to your children's fears and concerns.

When parents are separated or divorced

All families are different and sometimes family members may not be on good terms. This can affect the way they talk to each other and work through challenges, such as cancer.

In most cases, children of separated or divorced parents need to be given the chance to spend time with the parent with cancer. If the parent is likely to die, it's important that children are prepared for the loss, and that they have the opportunity to say goodbye. It's also important that a clear plan for the ongoing care of the children is agreed before the parent's death. If you need help with difficult family relationships at this time, it may help to talk to a hospital social worker.

“I was in my teens when my mother died of cancer. This was at a time when patients were not told the truth. In case she didn’t know, when I visited my mother I kept up the charade and didn’t mention death. She didn’t bring it up. This was a great loss to me and I’m sure to her too. A big hole in my life, to this day, is that I don’t know how she felt about her death’s effect on me, my sister and our father.” EVA, NOW A MOTHER HERSELF WITH TEENAGE DAUGHTERS

Answering key questions

How you answer questions depends on the nature of the cancer and the effects of treatment. It’s a good idea to work out in advance what your children might ask, and think about how you want to respond.

Asking the same question repeatedly is normal for children. By answering questions over and over again, you are helping to ease your children’s worries. Sometimes children may test you to see if your answers stay the same.

Q: Why is this happening?

At some stage, children are likely to ask why such a terrible thing is happening in their family. This may be a question that you are grappling with yourself. How you respond will depend on your culture and belief system, but there are no easy answers. The important thing is to let children know it is okay to talk about it.

“I don’t know. Life feels unfair sometimes and we don’t always know why sad things happen. Why do you think sad things happen?”

Q: Is it my fault?

“It’s no-one’s fault. Nothing you, or anyone else, did or said made me ill. And being kind and well-behaved can’t stop someone from dying either.”

Q: When will you/they die?

Time is a difficult concept for young children, so it may not help to give even vague time frames. For younger children, it may be helpful to talk about time in relation to upcoming events (e.g. school holidays, a birthday). Older children may want some idea of how long a parent is likely to live. It is still important to balance hope with reality.

“Nobody knows for sure when anyone will die. The doctors said I will probably live for X months/years. Whatever happens, we want to make the most of that time. I hope to be well enough to go to your kindy concert.”

When death is near, you may need to give a different answer.

“I honestly don’t know, but I will probably get a little weaker each day.”

“No-one can answer that, but we hope there will still be some good days.”

“Pop is very ill now because the treatment hasn’t made him better. He’s not having any more treatment and will probably die soon.”

Q: Who will look after me?

“It’s very important to me that you will always be safe and looked after. Dad will be there for you, and your aunty will help all of you.”

“You might be worried about what will happen if the treatment doesn’t work and I’m not around. I’ve already talked to Grandma and Grandpa, and they will be there for you and will look after you.”

For some children, the death of a parent from cancer will mean a big change in the child's living arrangements. For example, if they are living with only one parent and that parent dies, they may have to move to a different house to live with another parent, family member or guardian. In these situations, it's important to discuss this before the sick parent dies, and to include the other parent, family member or guardian in discussions.

Q: What happens if Mum/Dad dies too?

“When someone you love is very sick, it can make you feel very scared. But Mum/Dad is well and healthy now and they will be around to look after you. Whatever happens, we’ll make sure you are safe, loved and well cared for.”

Q: Am I going to die as well?

“You can’t catch cancer. When someone you love dies, it’s normal to think ‘Am I going to die too?’. It’s very unusual and unlikely for someone young like you to die or be so ill that the doctors can’t make you better.”

Q: What happens to people when they die?

How you answer this question depends on your personal or spiritual beliefs. You may need to probe further to work out what the child means by this question. Keep your explanations simple and straightforward, and follow the child's lead to work out how much information to give.

“The body goes to a funeral home until it’s time for the funeral. Then they will put the body in a big box called a coffin, which will be carried into the funeral service. After the funeral is over, the coffin is buried in the ground in the cemetery.” (This example can be adapted if a cremation is planned.)

Questions about what happens after death may also be prompted by more spiritual concerns, such as whether there is an afterlife. How you explain the spiritual aspects will vary depending on your own culture and belief system. You may want to explore what the child already believes before explaining your own view.

“People believe different things about whether a person’s soul lives on after death. What do you believe?”

Maintaining family life

When cancer is advanced and life is even more uncertain, many families find new ways to focus on the things they value most. Some ideas for maximising your time with your family and preparing them for the future include:

- accept offers of help
 - make a memory box, choosing keepsakes together
 - plan a special outing with your family
 - listen carefully to what your children say.
-

How children understand death

In preparing children for the loss of a parent or another significant person, it's helpful to understand how death is perceived at different ages. Children's grief may be expressed through their behaviour or how they play.



Newborns, infants and toddlers 0–3 years

Babies don't have any knowledge of death but can sense when their routine is disrupted and when their carers are absent. Toddlers often do not understand that death is permanent.

Newborns and infants may become unsettled and clingy, while toddlers may worry persistently about the well parent and think that they or their behaviour were responsible for the cancer.

You can provide comfort to children while maintaining usual routines and boundaries as best you can. Be prepared to patiently answer the same questions many times. Avoid explaining death as "sleeping" because this can cause distress about sleep.

Preschoolers 3–5 years

By the preschool years, children are starting to understand the concept of death but struggle with the idea that death is permanent (e.g. they may repeatedly ask about death, or ask when the dead parent is coming home). Young children don't have an adult concept of time and understand only what's happening now.

They may:

- get angry with their parent for not giving them enough attention
- have frightening dreams
- keep asking about death
- feel as if it is somehow their fault.

Watch your child play for clues to their feelings, and if they ask questions, try to answer in an open, honest way. Explain that the parent has died and they won't be coming back, which makes everyone sad.

Primary school children 5–12 years

By the primary school years, children may understand death but often don't have the emotional maturity to deal with it. Younger children may think death is reversible or that they are responsible, or blame someone else. They are likely to be openly sad, angry and distressed, and may ask confronting questions about what happens when somebody dies.

You can help young children cope by:

- encouraging them to tell you if they are feeling sad, tired, angry, or need help
- providing plenty of physical and verbal expressions of love
- explaining that it's okay to talk about the dead parent
- being sensitive but straightforward
- discussing how family roles might change.

Teenagers 12–18 years

Teenagers can understand death but may not have the emotional capacity to deal with its impact. They need as much preparation as possible for a parent's death. Like adults, teenagers' responses to death vary. Some may be more upset when their parent is unwell than following the death, others become distressed after the death.

They might react in a range of ways, including:

- denying or hiding their feelings to protect you
- trying to handle the loss alone or distance themselves from family
- worrying about not being able to do their normal activities, or struggle to reconnect with friends or sport after a loss
- struggling with and questioning their own mortality
- engaging in risk-taking behaviour such as skipping classes, self-harming, or experimenting with drugs and alcohol.



Izzy's story

We were sitting in my sister's lounge room when Mum told me Dad was dying. I was like, "Are you serious? This can't be true."

From when Dad was first diagnosed with lung cancer to when he died was only 4 months. It was just so quick. The prognosis kept getting worse – first they said it was 12–18 months, then 3–4 months, then 48 hours.

I wasn't there when he died. I went to a netball dinner. I didn't want to be

around it – that's not how I wanted to remember him, it's not what he was like. Dad told me, "Do what makes you feel comfortable. Do the things you need to do to cope."

When your parent dies, it's like a snow globe has fallen off a bench and cracked and snow is going everywhere. But the cracks get mended, maybe with sticky tape, and the snow slowly calms down.

You can help teens by encouraging them to talk about their feelings with you or friends or another trusted adult. They may also want to express their feelings in other ways such as listening to music, playing sports or writing in a journal. Ask if they want to help plan the funeral or memorial service, and try to maintain routines and house rules around behaviour as much as possible.

Issues with going to school

It can be difficult to know whether to send your children to school each day if you think someone in the family may die soon. You may feel like you need to let them spend as much time as possible with their loved one. Maintaining routine in a child's life can help them

to feel more stable and safe. With things changing at home, it can be helpful to go to school and see that normal life can continue. However, there may also be days when keeping your children home feels like the right thing to do.

You may want to talk to your children's teachers about what is going on at home. It's helpful for the school to know about any major concerns in a student's life so they can make a plan with the family and respond appropriately to any changes in behaviour or academic performance.

How to support grieving children

Each child will react to loss in their own way. Do not underestimate the impact of a bereavement, even if a child is very young or does not seem sad. Their grief may be expressed through play or other behaviour.

Children often work through feelings slowly, facing them in bearable doses. Allow children space to grieve – you do not need to “fix” their sorrow. Let them know

that it is natural for people to show sadness in various ways, just like other emotions.

Call Cancer Council 13 11 20 for bereavement information and support, or contact Grief Australia at grief.org.au, Griefline on 1300 845 745 or at grieffline.org.au and Cancer Hub on 1800 431 312 or cancerhub.org.au.

Finding support and information

Talking to children about cancer can be daunting, but you are not alone. Cancer Council can provide information and support, and can point you in the right direction for specialised assistance. This chapter explains when to seek professional help for a child and lists many support organisations.

Getting support

Many professionals and organisations can help you communicate with your children throughout the cancer experience. You don't need to have a specific problem to contact these services. You can ask for support even before sharing the news with your children.

When to seek professional support for your child

Children and teenagers react to a cancer diagnosis in their family in a range of ways. It's hard to know when professional support may be needed, but you may consider it if your child:

- has a change in their usual behaviour (e.g. aggressive or regressive behaviour) that is ongoing
- is showing less mature ways of coping, such as regularly wetting the bed
- is refusing to go to school – they may have separation anxiety and think they need to stay home to look after their parent
- has a persistent change in eating habits
- shows noticeable concentration challenges (falling grades at school)
- is spending more time online
- is having trouble sleeping

- talks about wanting to die or is extremely preoccupied with dying
- acts sad and withdrawn
- demonstrates severe risk-taking behaviour, such as self-harm, alcohol or drug use
- is withdrawing from friends.

For children with autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) or other additional needs, you may need to seek professional help sooner.

Teachers and other school staff can be among the first people to notice that something is worrying a young person. Because they see children every weekday, they may see a change in behaviour, concentration levels, marks, eating habits and socialising with peers.

Health professionals who can help

If you're concerned about your child, you could see:

- **your GP and other specialists** – may be able to talk to your children, or help you decide whether to consult a psychologist
- **nurses** – may be the most regular contact you have with the treatment centre and are a source of information and support
- **social workers** – often part of the cancer care team, can link you with support services and help with emotional, practical or financial issues
- **school counsellors** – are trained in child development and can be a useful source of support and ideas
- **psychologists and counsellors** – can help you with communication and behavioural issues (visit [Australian Psychological Society at psychology.org.au](http://AustralianPsychologicalSociety.org.au) and scroll down to “Find a psychologist”)
- **psychiatrists** – will see children with more serious issues (you will need a referral from a GP).

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Council 13 11 20.

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancercouncil.com.au/OC.

Useful organisations

Support services

<p>Beyond Blue Supports young people dealing with depression, anxiety and other mental health problems.</p>	<p>1300 22 4636 beyondblue.org.au</p>
<p>Camp Quality (part of Cancer Hub) Provides programs and services for children aged 0–15 growing up with cancer.</p>	<p>1300 662 267 campquality.org.au</p>
<p>Cancer Council Provides a wide range of support and information services for people affected by cancer.</p>	<p>13 11 20 For your local Cancer Council website, see back cover</p>
<p>Cancer Hub A digital one-stop shop to help families (with children aged up to 25 years) more easily access practical and emotional support. Made up of Camp Quality, Canteen and Redkite working together.</p>	<p>1800 431 312 cancerhub.org.au</p>
<p>Canteen (part of Cancer Hub) Supports young people aged 12–25 affected by their own or a family member's cancer diagnosis.</p>	<p>1800 945 215 canteen.org.au</p>
<p>Griefline Offers phone and online counselling.</p>	<p>1300 845 745 griefline.org.au</p>
<p>headspace Run by the National Youth Mental Health Foundation, provides mental health services to people aged 12–25.</p>	<p>1800 650 890 headspace.org.au</p>
<p>Kids Helpline Offers 24-hour phone and online counselling for young people aged 5–25.</p>	<p>1800 55 1800 kidshelpline.com.au</p>
<p>Lifeline 24-hour general crisis support.</p>	<p>13 11 14 lifeline.org.au</p>

Support services – continued

ReachOut

Online support and general information about mental health and wellbeing for young people going through tough times.

au.reachout.com

Redkite (part of Cancer Hub)

Offers financial, emotional and educational support for people aged up to 18 with cancer, as well as their families and networks.

1800 733 548
redkite.org.au

Ronald McDonald Learning Program

Provides assessment, therapy and tuition for young people whose education has been disrupted by serious illness.

1300 307 642
rmhc.org.au

Online information for children

Kids' Guide to Cancer

Camp Quality's free app and information for children who have a parent, sibling or loved one with cancer – answers common questions kids have about cancer.

campquality.org.au/kids-guide-to-cancer

Online information for teenagers

Canteen Connect

Canteen's platform for young people aged 12–25 to access discussions, ad-hoc counselling, blogs, and peer support.

canteenconnect.org

Bloom web series

A 5-part web series for teenagers about the cancer journey. It includes teacher resources and was co-produced by Arterial Films, Camp Quality and Canteen, with support from Screen Australia.

campquality.org.au/how-we-help/help-understanding-cancer/bloom-web-series/

Stupid Cancer

US site for people aged 15–39 affected by cancer.

stupidcancer.org

General online information

Cancer Council

Trustworthy information about cancer by topic and by type; web content and PDFs of Understanding Cancer booklets and fact sheets; links to local programs and services.

For your local Cancer Council website, see back cover

Cancer Australia

Information about cancer, healthy living and clinical best practice from Australian Government cancer control agency.

canceraustralia.gov.au

Children's Cancer

Information about many aspects of children's cancer.

canceraustralia.gov.au/cancer-types/childrens-cancer

Paediatric Integrated Cancer Service (PICS)

Information for families when a child is diagnosed with cancer.

vics.org.au/pics

American Cancer Society

Detailed information about cancer types and topics from the largest voluntary health organisation in the US.

cancer.org

Cancer Research UK

Detailed information about the diagnosis and treatment of different cancer types.

cancerresearchuk.org

Macmillan Cancer Support

Information about cancer prevention, diagnosis and treatment from the leading UK cancer charity.

macmillan.org.uk

Glossary (in child-friendly language)

anaesthetic

A medicine that makes someone go into a special type of sleep so they don't feel pain when they have an operation. A local anaesthetic just numbs one part of the body.

benign

A lump on the body that isn't dangerous.

biopsy

A test to diagnose cancer. The doctor takes cells in the body and looks at them under a microscope to see if they're healthy or not.

blood count

A test that checks how healthy the blood is.

cancer

A disease that happens when bad cells stop the good cells from doing their job. These bad cells can grow into a lump and can spread to other parts of the body.

cells

The body is made up of billions of tiny things called cells, and each has a job to make your body work and stay healthy.

chemotherapy

Special medicine that kills the cancer cells.

child life therapist

A health professional who helps children manage the stress and anxiety of being in hospital using play and other strategies. May also be called a play therapist.

CT scan

A test that uses x-rays to create pictures of the body so doctors can see if there is cancer inside.

diagnosis

When the doctor works out what disease someone has.

dietitian

Someone who helps people work out the healthiest foods to eat.

donor

A person who gives blood or another part of their body to someone else.

haematologist

A doctor who knows how to help people whose blood or bones are affected by cancer.

hormone therapy

A medicine that's used when the cancer grows in response to the body's natural hormones.

hospice

A special hospital for people who may be coming to the end of their life.

immune system

The part of the body that helps defend the body against germs. It helps fight illness if somebody does get sick.

immunocompromised

When someone gets sick very easily.

immunotherapy

A treatment that helps the body fight cancer.

intravenous (IV)

Injected into a vein.

leukaemia

A type of cancer that starts in the blood.

lymph nodes

Filters that remove germs that could harm you. Sometimes, the germs can make some of the lymph nodes swell.

maintenance treatment

When someone is given medicine for a long time to help keep the cancer away.

malignant

Another word for cancer. Cells that are malignant can spread to other parts of the body.

medical oncologist

A special doctor who uses strong medicine to treat people with cancer.

metastasis (advanced cancer)

When the cancer cells have spread to another part of the body. Also known as secondary cancer.

MRI scan

A way to take pictures of the inside of a person's body using a large, noisy machine.

nausea

Feeling as if you're going to vomit. Nausea is a common side effect of chemotherapy.

occupational therapist

Someone who helps people work out how to do things for themselves again after they have been sick.

palliative treatment

Treatment that reduces or stops symptoms of cancer but doesn't try to cure the cancer.

PET scan

A way of taking pictures of the inside of a person's body. The person is given an injection with a special liquid that shows up in the pictures and helps the doctors find cancer.

physiotherapist

Someone who helps a person's body get stronger after they have been sick.

prognosis

What the doctors think might happen after cancer treatment, and someone's chance of getting better.

psychologist

Someone who helps people who are worried or sad with their thinking and feelings.

radiation oncologist

A doctor who uses x-rays to kill cancer cells and make the cancer smaller.

radiation therapy

Invisible beams called x-rays that go into the body to kill cancer cells and make the cancer smaller. This is different to when you get x-rayed to see inside your body (e.g. for a broken arm).

recurrence/relapse

When cancer comes back after a period of improvement.

remission

When cancer goes away after treatment. Remission may not mean that cancer is cured, but that it is now under control.

side effects

When a person has problems such as feeling tired or losing their hair after treatment. Some people might not feel like eating and may look different. Most side effects go away after some time. This is because treatment damages some healthy cells as well as the cancer cells.

stage

How large the cancer is and whether it has spread from the original site to other parts of the body.

stem cell transplant

Stem cells are cells that make new blood in our bodies. Having strong medicine can destroy stem cells. The person is given new stem cells from bone marrow or blood to make them healthy again.

surgery

An operation to remove the cancer. A doctor called a surgeon cuts out the cancer and sometimes large parts of the body, such as a breast or the bladder, will also be removed along with the cancer.

targeted therapy

Special medicine that damages or kills some cancer cells, but doesn't harm healthy cells.

tumour

A lump in the body that shouldn't be there. Tumours can be benign (not cancer) or malignant (cancer).

ultrasound

A test that uses soundwaves to create a picture of part of the body, and lets doctors look inside the body so they can work out if anything is wrong.

x-ray

A test that takes pictures of the inside of the body using high-energy waves.

Can't find a word here?

This is a simplified version of our glossary. For more cancer-related words, visit:

- cancercouncil.com.au/words
 - cancervic.org.au/glossary
-

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2. EM Park et al., "Talking with children about prognosis: The decisions and experiences of mothers with metastatic cancer," *JCO Oncology Practice*, vol. 17, iss. 6, e840–e847, 2021.
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How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. accesshub.gov.au

*Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

Visit your local Cancer Council website

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actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

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