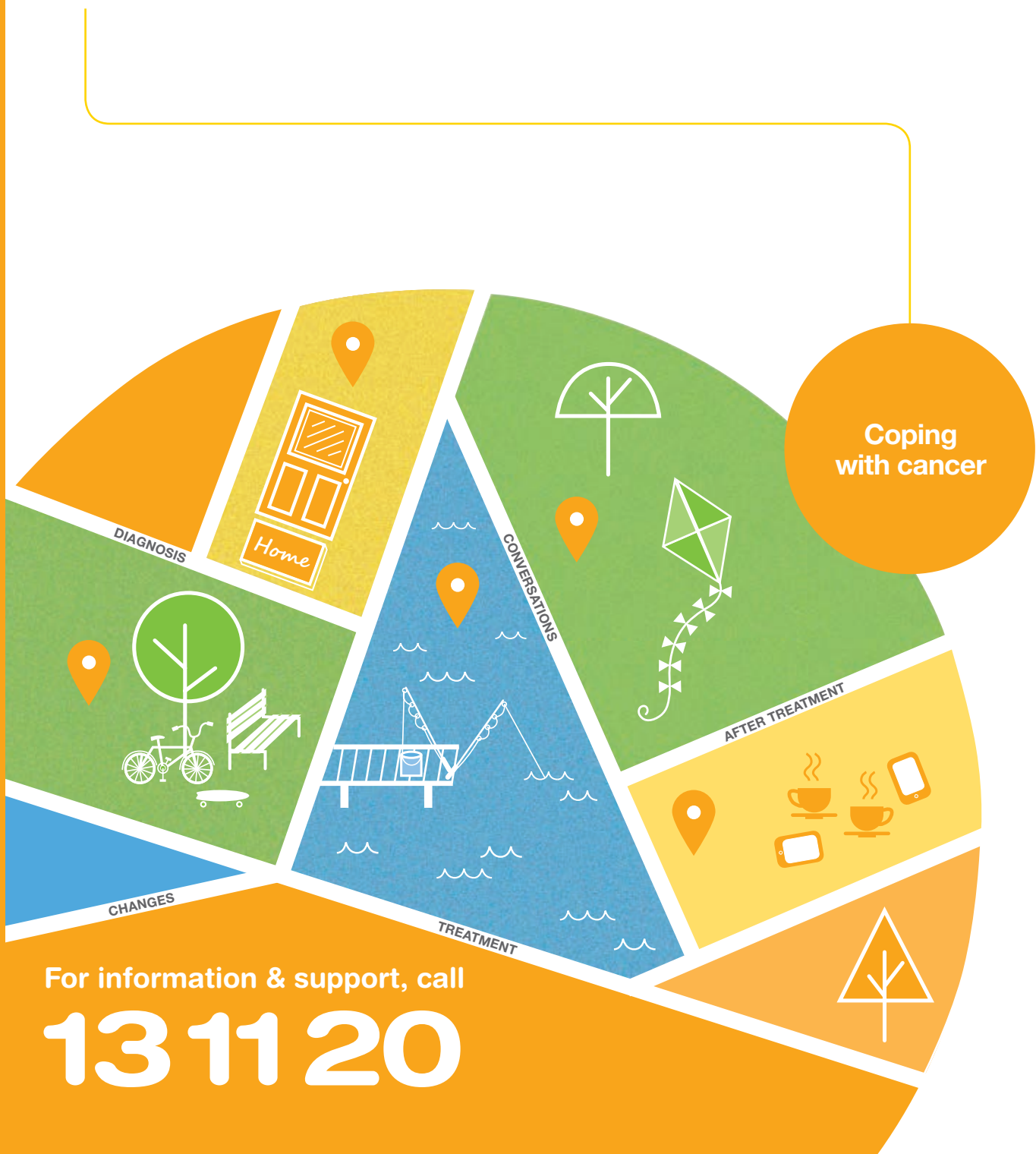


Talking to Kids About Cancer

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 book 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 book with them. All care is taken to ensure that the information in this book 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 Australia

Cancer Council Australia is Australia's peak non-government cancer control organisation. Through the eight 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.



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About this book

Explaining a diagnosis of cancer to children or teenagers can feel difficult and overwhelming. This book is designed as a starting point for having this conversation. Talking sensitively and honestly about the diagnosis can provide children with reassurance during a time of uncertainty and change.

Talking to Kids About Cancer focuses on when a parent has cancer, but much of the discussion will be relevant for anyone who needs to explain a cancer diagnosis to children or teenagers – for example, when a child’s sibling or friend has cancer, when their grandparent or another significant adult has cancer, or when a child has cancer.

Different chapters offer tips on talking to children throughout all stages of cancer, from breaking the news about a cancer diagnosis to coping with life after treatment. The book includes quotes and stories from people who have been affected by cancer (with some names changed for confidentiality), along with examples of what a parent or carer might want to say. These are just ideas and you will need to adapt what you say to suit your children’s ages and their individual personalities – you know your children best and can judge their ability to understand things.

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

If you need extra copies of this book or have any questions, simply call Cancer Council 13 11 20. You can also download a digital version from your local Cancer Council website (see back cover for details).

A note about the language in this book

To avoid gender-specific references, we have used third-person plural pronouns (they, their) in place of third-person singular pronouns (he or she, his or her) throughout this book. We have used the terms “kids” and “children” interchangeably and the term “teenagers” rather than “adolescents”, as this is how families tend to speak.



How to use this book

Each chapter of this book covers a particular aspect of discussing cancer with children – for example, talking about treatment. You can choose to read the entire book from cover to cover, but you may only need to refer to one or two chapters at a given time.

Please keep in mind that some sections of the book may be particularly difficult to read, such as Chapter 5: *Living with advanced cancer*. Many people do survive cancer, so this issue may not be relevant to your situation and you may prefer not to read this chapter. However, some readers will find it useful to have this information.

Families and children have generously shared their experiences with us. Their perspectives appear throughout the book as quotations and personal stories. The page margins feature colour-coded boxes that highlight particular types of information:



Tips



More information



Personal story



Key points

If you need help with any cancer-related issue, call Cancer Council 13 11 20 or see Chapter 6: *Finding support and information* at the end of this book.

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Talking about cancer

Talking to kids about cancer can feel overwhelming. Your first reaction may be to keep the news from children or to delay telling them. Even though it can be difficult, research shows that being open and honest 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 strong emotions. They may be concerned about their children's reactions or worry the diagnosis will disrupt their children's school performance or friendships.

However, there are many reasons why a straightforward and honest discussion can help children.

You are the expert

To help you discuss the difficult subject of cancer with children, this book offers 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 who are told about the illness of someone important to them tend to cope better than children who are kept in the dark. Trying to keep the diagnosis secret can be difficult. It can add to your stress – you may worry about whether you should tell, or feel guilty if you don't say something. You may need to change your daily routine without your children knowing why, which can be confusing for them.

Keeping secrets teaches children that it is okay for family members to lie to each other if a good reason exists. In turn, children may keep information from their parents if they think it will upset them.

You can't fool kids

Children are observant. No matter how hard you try to hide a cancer diagnosis, most children will suspect something is wrong. Even if it's not a parent who has cancer but a close relative, such as an aunt or grandparent, this can cause stress that kids will usually pick up on.

They will notice changes at home, such as your sadness, whispered conversations, closed doors, an increase in the number of phone calls or visitors, and possibly changes to family schedules. These signs may be more obvious to older children and teenagers, but even young children can pick up on change. They will work out that a secret exists, but that it should not be discussed. Not knowing the reason for the secret may leave them feeling powerless or disconnected from everyone else, without knowing why.



Cancer in different cultures

You may be reading this book because you work with children who have been affected by a cancer diagnosis. Before talking to someone else's child about cancer, it is important to understand and respect the wishes of the parents.

Cancer can have a range of meanings for different groups of people. Some cultures believe that cancer is caused by bad luck or 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. If a family wants to keep a diagnosis private, organisations such as Cancer Council **13 11 20** or CanTeen (see page 17 for contact details) may be able to provide a way for children and other family members to discuss their feelings and concerns in a confidential setting.

Honesty can build trust with your child

Children can feel hurt if they suspect or discover they have not been told something important that affects their family. Sharing information shows you trust and value them, which can boost their self-esteem and ease their concerns. Hearing bad news is better than the worry they feel when they don't know what's happening.

The diagnosis may also be a chance for children to learn from their parents how to deal with complex feelings. Together you can all find ways to bounce back from difficult situations (resilience).

They might find out from someone else

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

If you tell friends and relatives about cancer in the family, but you 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 busy with their own activity and not paying attention. They may also look for a way to listen without being noticed.

Overhearing the news can make your children feel upset and confused. They may think the topic is too terrible for you to talk about, or that they are not important enough to be included in family discussions.

Children may also misunderstand information and think a situation is much worse than it is or make up their own explanation to fill in what they don't understand. They may feel afraid to ask questions. They might worry in silence or spread incorrect information to other children in the family. Teenagers, and even young children, may pick up on a few key words and search the internet for answers, which can lead them to unreliable websites.

“ 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



Kids can cope

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

Children and young people learn about emotions and how to express them by watching others – especially their parents. A key factor in helping kids get through difficult times is to role model how to recognise, talk about and manage a range of emotions, e.g. “I’m feeling sad about Grandma’s diagnosis and I think I need to go for a walk”.

It is okay to admit to your child that what you are telling them is upsetting – let them know it’s natural to have strong feelings. We can’t stop kids from feeling sad, but if we share our feelings and give them information about what’s happening, we can support them in their sadness.

Children need a chance to talk

Talking to your children about cancer gives them the chance to ask questions (see pages 8–11 for some suggested approaches). Encourage your kids to share their thoughts and feelings, but don’t be surprised if they don’t want to talk when you do, and don’t push if your kids prefer not to talk. Suggest that children keep a journal to write down questions or thoughts that come up.

Sometimes kids, particularly teenagers, may feel guilty about burdening a sick parent or taking up a healthy parent’s time. So they will open up to an adult who is not their parent. That person may be a grandparent, an aunt or uncle, a family friend or their best friend’s parent.

When you can’t talk about cancer

Some parents don’t want to tell their children at all and try hard to keep the diagnosis secret. People have their own reasons for not sharing the diagnosis with their children, including cultural differences (see box, page 5), family circumstances, or an earlier death of a close relative from cancer. Sometimes you may want to wait to find out more about what the diagnosis means 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, talk with a psychologist or social worker, who may be able to help you develop a strategy. Keep in mind that talking about cancer often becomes easier over time.

Key points

- Start with questions to check what your kids know about cancer.
- Offer basic information and provide more details if they ask.
- Practise your response to potential questions before talking to kids.
- Explain that the cancer is not their fault and is not contagious.
- Assure them they will always be looked after, even if you can’t always do it yourself.
- Stop and listen to your children so you know how they really feel.
- Share your own feelings to help show children that it is okay to feel strong emotions about the situation.
- Children may react with different emotions. They may feel angry, sad or guilty. Reactions can also be physical, such as bedwetting or a change in sleeping patterns.
- Teenagers may find it hard to talk to you or show how they feel.
- Continue daily routines as much as you can. Talk about your children’s own activities as well, and let them know that it’s still okay to have fun.

Different views of cancer

Children’s understanding of illness and their reactions to bad news will vary depending on their age, temperament and family experiences. You may find that siblings, even of similar ages, respond differently. These tables give an overview of children’s possible reactions at different ages, which might help you work out how best to support them.



Newborns, infants and toddlers

Infants 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. Toddlers may react to physical changes in their parent or relative (such as hair loss) or noticeable side effects (such as vomiting).

Possible reactions	Suggested approaches
<ul style="list-style-type: none"> • newborns and infants: becoming unsettled, especially if they need to be weaned suddenly • newborns and infants: wanting to breastfeed more frequently for emotional comfort • becoming fussy and cranky • becoming clingy • change in sleeping or eating habits • colic • toddlers: tantrums, more negativity (saying “no”) • return to, or more frequent, thumb sucking, bedwetting, baby talk, etc. 	<ul style="list-style-type: none"> • maintain routines: ask any carers to follow the established schedules for your baby or toddler as much as possible • give plenty of physical contact (e.g. hugging, holding, extra breastfeeds) to help them feel secure • watch play for clues to how a child is coping • use relaxation tapes, calming music or baby massage



3-5
years

Preschoolers

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?

Possible reactions

- return to behaviour that is developmentally younger, e.g. sucking their thumb
- comfort-seeking behaviours, such as using a security blanket or special toy
- fear of the dark, monsters, animals, strangers and the unknown
- trouble falling asleep or sleeping through the night, refusal to sleep
- nightmares, sleepwalking or sleeptalking
- bedwetting
- stuttering or baby talk
- hyperactivity or apathy
- fear of separation from parents or other significant people, especially at bedtime and when going to preschool
- aggression (e.g. hitting or biting), saying hurtful things or rejecting the parent with the cancer diagnosis
- repeated questions about the same topic, even if it has been discussed several times

Suggested approaches

- provide brief and simple explanations about cancer; repeat or paraphrase when necessary
- use picture books, dolls or stuffed animals to talk about cancer
- read a story about issues such as nightmares or separation anxiety
- assure them that they have not caused the illness by their behaviour or thoughts, nor will they catch cancer
- explain what they can expect; describe how schedules may change
- reassure them that they will be taken care of and will not be forgotten
- encourage them to have fun
- listen and be alert to their feelings, which they may express through speech or play
- arrange opportunities for children to be physically active every day to use up excess energy, anxiety or aggression
- continue usual discipline and limit-setting



5-12
years

Primary schoolchildren

In the early primary school years, children have a basic understanding of sickness, and by later primary years, they are ready for more details about cancer cells. 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.

Possible reactions

- irritability, anxiety, guilt, envy
- sadness, crying
- physical complaints, e.g. headaches, stomach-aches
- trouble sleeping
- sudden worry about the well parent's health
- school refusal
- separation anxiety when going to school or away to camp
- returning to behaviours that may be developmentally younger
- hostile reactions, e.g. yelling or fighting, including towards the sick parent
- poor concentration, daydreaming, lack of attention
- unexplained change in school marks
- withdrawal from family and friends
- difficulty adapting to changes
- fear of new situations
- sensitivity to shame and embarrassment
- trying to be extra good
- nailbiting

Suggested approaches

- look for clues in their stories and play for how they feel, and let them know you care
- talk about cancer and treatment using books
- use sport, art or music to help children express and manage their feelings
- assure them that they did not cause the cancer by their behaviour or thoughts, and that they cannot catch it
- reassure them that they will be taken care of and tell them that it's okay to have fun
- let them know their other parent and relatives are healthy
- give them age-appropriate tasks to do around the house
- tell them you won't keep secrets and will always let them know what is happening
- suggest letting school know
- help them understand that what their schoolfriends say may not always be right – encourage them to check with you
- try to continue after-school activities to maintain routine and to encourage fun
- discuss the issue of dying if your kids bring up the topic (see pages 52–53)
- see also ideas for preschoolers (page 9)



Teenagers

During adolescence, young people start to think more like adults. As their ability for abstract thought develops, 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 are more likely to deny fear and worry to avoid discussion.

Possible reactions

- wanting to be more independent and treated like an adult
- becoming very insecure and dependent on parents, or lapsing into previous behaviours, such as watching children's TV shows
- criticising support offered by adults
- preferring to confide in friends, and acting as if friends are more important than family
- depression or anxiety
- worry about being different and not fitting in
- anger and rebellion
- poor judgement and risk-taking behaviour, e.g. binge drinking, smoking, staying out late, unsafe sex
- withdrawal
- apathy
- physical symptoms caused by stress, e.g. stomach-aches, headaches
- hiding feelings – adults are less likely to see true reactions
- changes in academic performance
- worrying they will also get cancer (e.g. daughter of a woman with breast cancer or son of a man with prostate cancer)

Suggested approaches

- notice any changes in their behaviour and ask them about it – this can lead to a conversation about their concerns
- encourage them to talk about their feelings, but realise they may prefer to talk to friends or other trusted people
- use words and gentle touches to the arm or back to let them know you love them
- talk about role changes in the family
- provide privacy, as needed; highlight the importance of respecting privacy and using social media appropriately
- encourage them to keep up activities and friendships; talk about finding a balance between going out and staying at home
- set appropriate boundaries
- arrange opportunities for counselling
- don't expect them to take on too many extra responsibilities
- let them know of resources for learning more about cancer and getting support
- reassure them that you don't always need to talk about cancer – you still want to chat about things like homework, sport and friends
- see also ideas for younger children (opposite)



2

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. However you decide to approach the conversation, try to be open and honest and leave kids with a feeling of hope.



When should I tell my children?

It's common to feel unsure of the best time to tell your children; often there may be no right time. You may wonder if you should tell them soon after you've been told yourself, 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 able. Keeping the diagnosis a secret can be stressful, and your children will probably sense that something is wrong.

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

- you think they may have overheard a conversation
- they are scared by 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 or hair loss, or is admitted to hospital for immediate treatment
- you notice changes in their behaviour.

It may be hard to decide 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 required, 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 to have some tests. We're not sure yet what's wrong, but when we do know we will tell you."

Let children and young people know it's okay to have questions at different times, such as during treatment, when you are managing side effects and later during recovery, and to talk about how they feel at anytime.

Where should I tell my children?

Try to find some time when you won't be interrupted or have to rush off without answering all their questions.

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

Talking to children before bedtime or before an important event may not be a good idea. Ideally, you should tell them at a time and in a place where they are more likely to listen and take in the news.

Looking after yourself

Telling children and young people about a cancer diagnosis can be confronting and difficult. You may have trouble helping your kids deal with the news if you're struggling yourself. You may be facing both emotional and physical challenges and you will have to make many decisions, but you don't have to do this alone.

- Wait until your initial feeling of shock has eased before attempting the conversation.
- Talk to a few trusted adults beforehand – this will allow you to express your own feelings and start getting used to the news yourself.
- Make a list of things that other people can do for you. Family and friends are often keen to help out, but usually need guidance on what to do.
- Ask a friend to coordinate offers of help.

See pages 26–27 for more information about involving others. There are also many support services for people who are newly diagnosed with cancer – see contact details on pages 59–60.



Hearing the news

Mum was driving us over to McDonald's when she asked me about cancer and what I knew about it. Then she told me about Dad's leukaemia – what it meant, what it was doing and how it would affect him. I was sitting in the car park feeling pretty overwhelmed.

James, aged 12

Should I tell them together?

Depending on the ages and temperaments of your children, you may decide to tell them individually or together. You may need to use different language because of their age. If you decide to tell them separately, try to tell them on the same day. Asking older children to keep the diagnosis a secret from younger siblings can add to their stress.

Who should tell my children?

Deciding on the person to tell the children is another thing to consider. 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, the other parent or both of you together.

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

How can I prepare?

Parents often doubt their ability to find the right words and to answer the tricky questions their children ask. Take the time to plan what you'll say. Role-playing the conversation with your partner, friend, relative or the oncology social worker at the hospital can help you. It 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 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. You may not have all the answers, but it's okay to say you don't know or that you'll find out.

Work out beforehand how you might end the conversation. 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. Also let your kids know that they can talk to you anytime they have questions or concerns.

If you end up blurting out the bad news or your child reacts differently to how you expected, don't worry. You'll have opportunities to talk about the diagnosis further as time goes on. Your children are unlikely to be affected by one discussion that doesn't go exactly to plan.

What do children need to know?

The following is a guide to what to cover in your initial conversation about cancer. The suggestions on pages 22–23 can help you adapt the information to the ages and reactions of your children.

Tell them the basics in words they can understand

You can break the news with a few short sentences explaining what you know so far and what will happen next.

Be clear about the name of the cancer, the part of the body that has the cancer and how it will be treated. To help explain cancer terms, you can:

- use the glossary (see pages 62–64)
- get hints from websites (see page 60)
- read books about cancer written for children (see page 61)
- download the *Kids' Guide to Cancer* app developed by Camp Quality for children aged 8–13 from the App Store (Apple phones) or Google Play (Android phones).

Start with small amounts of information. Ask them what 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 they are interested. 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 the diagnosis.

Find out what they already know

Ask your children what they know about cancer and clear up any misinformation or myths (e.g. they might think that you can catch cancer, that their naughty behaviour caused the cancer or that everyone dies from cancer). Children get information from various sources, such as school, TV programs and the internet, and they may have their own ideas of what having cancer means. Parents can help guide their children towards accurate online information (see page 60).

“ 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

“ 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

Be honest and open

Let them know if you don't know the answer to a question. Say 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 them. If you are in hospital, who will drop them to school, make them dinner, take them to after-school activities? Reassure them that there will be a plan and you will let them know what it is.

Ask them if they want to tell anyone

Your children may want to tell their close friends, all the teachers, 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 figures in their life, such as a music tutor or sports coach. Discuss ways to approach these conversations. See pages 26–27 for ideas about talking to the school.

Balance hope with reality

Tell kids that although cancer can be serious and going through treatment can be challenging, most people get better. Explain that with the help of the doctors and treatment teams, 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, and show your love by hugging them, comforting them and making them feel valuable.

Some parents worry about crying in front of their children, but this is okay as long as you are not out of control. 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 honest with each other about feelings can help your children cope.

Coping with kids' reactions

It's natural for children and young people to have lots of different reactions to a cancer diagnosis. Talking with them about their reaction gives you a chance to discuss ways of managing their emotions.



Crying – If your children cry, let them know it's a natural reaction. Holding them will help them feel secure. Let them know that they don't have to "be strong", and that feeling sad after a cancer diagnosis is common.



Fear – Some children will worry endlessly. It can be hurtful if they start to avoid or ignore the person who has cancer. Explain that the person with cancer is still the same person, despite any changes in appearance.

Children may also worry that they're going to be abandoned by their sick parent or by their well parent. Reassure them that they will always be cared for. Help your child deal with their concerns by giving them a chance to talk about their fears.



Anger – It is natural for children and young people to feel angry about the diagnosis as it means their lives could be disrupted.

Younger children may be annoyed if asked to play quietly. Older children may seem angry and uncooperative if asked to help out more. Both may be disappointed or upset if a planned holiday has to be postponed or 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, especially if it took some planning and courage to share the diagnosis.

A lack of reaction isn't unusual – often the children are protecting themselves and need some time to digest the information. Or they may want to protect you from seeing how they are feeling. Remind them that they can talk to you about it anytime.

You may need to talk again if the situation or their behaviour has changed since you first talked. Sometimes, despite your efforts to help your children cope, they may struggle with the diagnosis. See the other box on this page for services that can help children whose family members have cancer.



Support for children and young adults

Camp Quality

Camp Quality supports children living with cancer and their families, and children who have a parent with cancer. Their *Kids' Guide to Cancer* app is aimed at children aged 8–13 who have a parent, sibling or friend with cancer. It answers the big questions about cancer and includes stories from other children. Camp Quality also offers a free educational puppet show for schools and organises recreation programs, camps and family experiences. Call **1300 662 267** or visit **campquality.org.au**.

CanTeen

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 online; access counselling face-to-face, by phone, email or online; get specialist, in-hospital treatment; and take part in programs, camps and recreation days – all to help them cope with the impact of cancer. To find out more about CanTeen, call **1800 835 932** or visit **canteen.org.au**.

When another child has cancer

Your child may have a friend or cousin who has been diagnosed with cancer. While children may know someone with cancer, usually it's an adult in their life who is affected (e.g. a grandparent or teacher). It can be confusing and frightening for a child to learn that children can have cancer too.

Causes of cancer – Let your child know that childhood cancers are not lifestyle-related (e.g. caused by sun exposure or smoking), nor does a child get cancer because of naughty behaviour or a minor accident like a bump on the head. There's nothing anyone did 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, 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, life-threatening disease, the overall survival rate for children is now more than 80%.² This can vary depending on the diagnosis, but most children will survive cancer.

Expect change – Explain that things will change for the friend. They may feel too tired to play or may be away from school a lot. They may have physical changes (e.g. hair loss, wheelchair). Encourage your child to focus on what hasn't changed – their friend's personality and their friendship.

Visit the hospital – Take your child to visit their friend in hospital if you can. It is confusing for your child if the person with cancer disappears from their life after diagnosis. They may imagine the worst. Let them know it's natural to wonder how to act and what to say, and that the more time they spend with their friend, the more they'll relax.

Keep in touch – Help your child maintain the relationship with their friend. They may not see each other as often and might not interact in the same way, but there are other ways to keep in touch. For younger children, this could mean making a get well card or a decoration for the hospital room. Older children may prefer to communicate by phone, email or social media.

Encourage feelings – Let your child know that it's okay to have lots of different emotions and that you have them too. They need to feel that they can approach you when they want to discuss what they're going through. It's also a good chance to discuss ways of coping with difficult emotions.



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 can change for a while.

Along with feelings of sadness, fear and anxiety, siblings may be struggling with more complicated emotions such as guilt, jealousy, resentment and anger. Because so much focus is on their brother or sister, they may feel that their needs do not deserve to be met and that they have no right to complain.

For many children and teenagers, fitting in with their peers is very important. This means they may feel embarrassed or self-conscious about their family now being different to other families. 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.

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

It's not their fault – Check that siblings realise that they did not cause their brother or sister's cancer – even if they had been fighting with them or thinking mean thoughts about them.

What they can do – Explain that they can help support their brother or sister, and let them think about how they would like to do that. The sibling relationship is still important, so try to offer plenty of opportunities to maintain it. This may involve regular visits to the hospital and/or regular contact via phone, email or social media.

It is okay to have fun – Even though the child with cancer has to have a lot of attention at the moment, the needs of their siblings matter too. As far as possible, they should keep doing their own activities and have time for fun.

They are still just as loved – Explain to siblings that you may need to spend a lot of time and energy focused on the child with cancer, but this is out of necessity rather than feeling any less love for your other children. Naming the challenges and acknowledging the impact can really help.

They will always be looked after – Let them know that you will make sure someone is always there to look after them. Talk to them about who they would like that person to be if you can't be there yourself.

Family conversations

My third child, Leo, was diagnosed with leukaemia when he was five years old. We didn't tell the kids straightaway – we needed time to digest the news ourselves. I couldn't even tell my parents.

Leo knew he was sick because he felt so sick. We told him he was in the best place and that the doctors and nurses would help to make him better. That was enough at first.

Because Leo's siblings were such different ages, I told them individually, but the key messages were the same: Leo hadn't done anything to cause the leukaemia, it's not contagious, and he would get well – it was important to offer hope. I told them that Leo would look different because of the treatment and that it would take a long while.

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

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 the illness.

Although the focus of this book 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 and honest – hiding the truth to protect a child may just 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.

The paediatric oncologist, clinical nurse consultant and social worker at your child's hospital will be able to provide further guidance and assist you with these discussions. For younger children, some hospitals have child life therapists who teach children strategies to manage their illness and can help you explain the diagnosis and the treatment. If you have an older child with cancer, get in touch with one of the Youth Cancer Services. These are hospital-based services that offer specialised treatment and support to young people aged 15–25. Visit canteen.org.au/youth-cancer for more information.

““ We let Leo lead the way with what he wanted to know, and over time he wanted to know everything.””

Genevieve, mother of four children aged 3, 5, 10 and 14

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

Several organisations have developed resources for parents of children diagnosed with cancer. Visit the Victorian Paediatric Integrated Cancer Service at pics.org.au/families/written-resources, or Cancer Australia at childrenscancer.canceraustralia.gov.au.

As much as possible, include your child in discussions about their treatment and recovery, and encourage them to ask questions. Older children and teenagers may want to seek out information themselves. You can let them know about reliable, age-appropriate resources such as CanTeen and Redkite (see page 59 for contact details and other support services).

Karen's story*

Karen's lung cancer was a bolt from the blue. She had never smoked, had no family history and was simply unlucky. Dr Ranjana Srivastava shares her patient's experience of talking to her children about her diagnosis. Karen wanted to tell the children and overcame her husband Jim's early hesitation.

**Adapted with permission from "How do you tell your children you have cancer?", The Guardian, November 2015.*

She sat them down one evening and told them that she had been diagnosed with an illness called lung cancer. She deliberately chose to use the correct terminology rather than Jim's suggestion of calling it a lump. We had discussed the fact that children fell down in the playground and got lumps and bumps. She didn't want the children to think that all lumps were sinister. Their eldest, Alyssa, had seen the ads depicting cancer on cigarette packets and her first question was if her mother had been smoking cigarettes. Karen assured her daughter that she had never smoked and that sometimes people developed cancer for unknown reasons. Robbie, their middle son, wanted to know if she was going to die. He had a classmate who had just lost her grandfather to lung cancer. "I'm not dying right now, darling," Karen told him. "I hope to get better with treatment." The youngest child, Emily, at four years old, didn't understand any of the conversation. She jumped on her mother's back and chirped: "Can we play hide-and-seek now?"

As she began chemotherapy, Karen set about consolidating a support system for the children. She did this by

calling upon a small group of parents whose children were friendly with hers. Over the next few weeks, they worked out a system that meant each child had one or two additional adults to rely on if Jim and Karen were both busy. When Karen felt well, which was almost always in the initial months, the extra help was not needed, but having a roster in place meant that the other adults were not surprised at being rung at short notice.

A practical thing Karen discussed early with her children was rearranging after-school activities that required prolonged parental involvement. She explained to the children that while she was keen to maintain their activities, her illness meant that they all had to make adjustments. For Alyssa this meant finding a French class closer to home. For Emily it meant moving a gymnastics class. Robbie offered to reduce the frequency of his painting lessons.

Karen spoke to her children's school early in the piece, too, letting them know about her diagnosis and the changes in their lives. The counsellor agreed to keep a close eye on all three and periodically provide updates to Karen and Jim.

One day Robbie came home, upset that a boy in his class had said he would catch cancer from his mum. On hearing this, Alyssa complained that she was sick of being asked if she was all right. Little Emily, meanwhile, carried on, seemingly oblivious to anything being out of the ordinary. Karen used the occasion to discuss her cancer with them further. She reassured Robbie that cancer was not contagious and explained to Alyssa how much her friends and their parents cared about her. Karen also told them that her being sick was not the children's fault and that people sometimes said awkward things because they didn't know how to express their true feelings. Karen felt that this gave the children permission to discuss any other concerns they might have about her and bring home any comments they had heard on the playground.

Continued on page 47



What words should I use?

It's often hard to find the right 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 & preschoolers

About cancer

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

"I have an illness 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."

To clear up misinformation about cancer

"Sometimes girls and boys 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."

"How do you think people get cancer?"

"We can still have lots of kisses and cuddles – you cannot catch cancer from me or from anyone who has it."

To explain changes and offer reassurance

"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 me some to take to hospital."

"Mummy has to stay in bed a lot and isn't able to play, but she can still cuddle you."

you may find that the ideas in a younger or older age bracket work for your child.
See pages 24–25 for tips on how to answer specific questions.



Younger children



Older children & teenagers

“We’ve had some bad news. I’ve got cancer. We don’t know what we’re dealing with yet, but I’m going to have surgery so that the doctors can have a look and find out.”

“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.”

“We can still have lots of kisses and cuddles – you cannot catch cancer from me or from anyone who has it.”

“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.”

“The doctors will take good care of me. I will have treatment soon, which I’ll tell you about when it starts.”

“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 won’t change for you.”

“The doctors say Dad has a problem with his blood. That’s why he’s been very tired lately. The illness is called Hodgkin lymphoma. Dad will have treatment to make him well again.”

“Lots of people get cancer. We don’t know why it happens. Most people get better and we expect I will get better too.”

“There are lots of different 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. It’s not contagious (you can’t catch it) and the cancer I have doesn’t run in families.”

“Even though Grandma has cancer, the doctors say she’ll probably be okay because she was diagnosed early.”

“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.”

“What things would you like to help with at home?”

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

Answering key questions

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?"

Try to explore the question by asking, "Do you have something in particular you're worried about?" or "What were you thinking about?" You can explain that treatments are improving constantly. If your child knows someone who has died, let them know that there are many different types of cancer and everyone responds differently.

A: *"We don't expect that to happen, but I will probably be sick for a while. Sometimes it makes me sad, and I wonder if you get sad too."*

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.

A: *"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."*

"You did not cause this cancer. There is nothing you could have said or done that would cause someone to have this illness."

Q: Can I catch cancer?

A common misconception for many children (and some adults) is that cancer can spread from person to person (contagious). This belief may be reinforced because when patients have chemotherapy they need to avoid contact with people who are sick. This is to protect the person with cancer from picking up infections, not to protect everyone else.

A: *"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?

When family routines change, it's important for children to know how it will affect their lives: who will look after them, who will pick them

up from school, and how roles will change. Try to give them as much detail as possible about changes so they know what to expect. For older children, it's worth asking them what arrangements they'd prefer.

A: *"We will try to keep things as normal as possible, but sometimes I may have to ask Dad/Mum/Grandpa to help out."*

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

Your children may not know who to tell about the cancer or what to say. They may not want to say anything at all. It helps to explore their feelings about talking to others.

If you're planning to inform teachers, or the school counsellor or principal, talk to your kids first. Teenagers and even younger children may be reluctant for 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 talking to key teachers or the principal with you – this way they are part of the agreement made with the school.

A: *"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."*

"Do you worry about how your friends will react or treat you?"

"I need to let your teachers know so they understand what's happening at home. We can talk about who to tell and how much we should say."

Q: Is there anything I can do to help?

Answering this question can be a delicate balance. 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.

A: *"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."



Thinking the worst

When I was 14, Dad developed a bad cough. I remember sitting in my older sister's lounge room on a Sunday afternoon. Dad was coughing. I knew they were going to tell us something because they were sitting down.

Dad just told us straight: "I have cancer." Mum tried to sugar-coat it and said there were things they could do, but I was thinking the worst. It's the great fear – death and dying – and I just thought, "He's going to die." 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.

Right from the start, Dad said, "I might be the one with cancer, but you are going to be affected by it, so we will make decisions as a family. We're going to fight this – one in, all in."

Izzy, 15-year-old whose father had cancer

“ 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. ”

Genevieve, mother of four children aged 3, 5, 10 and 14

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, the nanny, 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 *Support services*, page 59).

Ask a professional – Get some tips from the oncology nurse or social worker, psychologist or other health professionals at the hospital (see pages 56–57).

Involving the school or preschool

Many parents or carers wonder if they should tell the school. 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 will 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. A cancer diagnosis in the family can also affect academic performance, so the student may be entitled to special provisions, which can be particularly important in the final years of high school.

Ways to involve the school include:

- Tell the principal, the school counsellor and your child's teachers. They may know of other people in the school community affected by cancer and this may influence your child's understanding of the disease (e.g. a parent or a child at the school may have died of cancer).



- Let relevant staff know what your child has been told about the cancer and what they understand cancer to mean, so staff can respond consistently.
- 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 the student. However, request that teachers don't probe – some well-meaning members of staff might misinterpret your kid's behaviour and unintentionally make them feel uncomfortable (e.g. the teacher may ask if they're okay when they're happily sitting on their own).
- If you feel concerned about how your child is coping, ask the principal whether your child could see the school counsellor.
- Sometimes other children can be thoughtless in their comments. Check with the teachers and your child to see how other children are reacting so that negative behaviour can be addressed appropriately.
- 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 something at school because a note goes missing.
- Ask the principal whether the school could organise for services that support students to visit the school. For primary schoolchildren, Camp Quality has developed an educational puppet show to help young students learn about cancer in a safe, age-appropriate way. For more details, call 1300 662 267 or visit campquality.org.au. For older children, CanTeen has a cancer awareness program called *When Cancer Comes Along*. To find out more, contact CanTeen on 1800 234 007.
- Explore what special provisions might be available for exams or admission into university.

For more ideas about how your child's school can help, see Cancer Council's book *Cancer in the School Community: A guide for staff members*, which explains how school staff can provide support when a student, parent or staff member has cancer.

Key points

- Discuss the diagnosis with trusted adults first if you need to.
- Ask for practical and emotional support from relatives, friends or colleagues.
- Work out the best time to talk to your children.
- Decide who you want to be there with you.
- Tell your children what has happened.
- Explain what is going to happen next.
- Assure them they will continue to be loved and cared for.
- Approach the initial conversation as the first of many.
- Let them know it's okay to feel scared or worried, and talking can help.
- End the discussion with expressions of hope.



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; in general, kids like to know what the treatment involves, how it works, and why there are side effects. While you may not be able to say exactly what will happen, you can promise to 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 prepare them for what to expect and help them adjust.

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 62–64).
- 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 accurate information online (see page 60 for a list of recommended websites), to avoid incorrect or unhelpful information.
- Keep them 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 they will help.

Explain side effects

It's important to prepare children for treatment side effects, such as physical changes after surgery, weight changes, fatigue, nausea and hair loss.

- Explain that not everyone gets all side effects. People who have the same cancer and treatment will not necessarily have the same side effects. Doctors know what happens to most people having a particular treatment but can't be exactly sure what will happen to individuals.
- Tell your children what side effects to expect, based on what the doctor has said, and how these may change how the person with cancer looks or feels. Say you'll let them know if the person does start to experience these side effects.
- Talk about ways your children can help the person with cancer deal with the side effects (e.g. help shave the person's head, help choose a wig). Such actions can be empowering and make your children feel like they're useful.

Understanding treatment

It can help to understand the treatments and their side effects. Don't be afraid to ask the doctor to explain anything that is confusing or unclear. The nurses and social workers at the hospital are also good sources of information, as are Cancer Council's **13 11 20** Information and Support consultants.

You can request copies of Cancer Council's booklets on different aspects of cancer treatment by calling **13 11 20**, or find this information on your local Cancer Council website (see back cover). You can also listen to *The Thing About Cancer* podcast at **cancercouncil.com.au/podcasts**. Once you have a good understanding of the treatment, you will probably find it easier to explain it to your kids and answer their questions.



Making a day of it

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

It was a great afternoon. There was no trauma. The children were happy to see I was happy and that I could still look wonderful with make-up on.

Anna, mother of two children aged 9 and 13

- Let them know that the doctors will try to make sure treatment causes as few side effects as possible. They should know that side effects usually go away after the treatment is over, but this often takes time – hair will grow back, scars will fade.
- Reassure your children that they will get used to the changes. Point out that the person having treatment is still the same person as before.
- Side effects do not mean the person is getting worse. It's common for kids to get upset on chemotherapy days when they see the effects of the drug, such as fatigue or vomiting. They may worry that the treatment is making the person worse or that the cancer has progressed. Let them know that the side effects are separate to the cancer symptoms. If there are no side effects, reassure them that this doesn't mean the treatment is not working.
- Assure them that even if some side effects mean the person with cancer can't participate in activities or appears drowsy, it doesn't mean they're not interested.
- Explain to them how much of the side effect is considered normal. This can be especially important for older teenagers who might worry about when they should call for help.

Prepare for hospital and treatment centre visits

Cancer treatment can involve short but frequent visits to the hospital as an outpatient (day treatment) or a longer stint as an inpatient (staying overnight). A visit to hospital can seem strange and confronting for a person of any age, but especially for children. You might worry that your children will get anxious if they see people with cancer in hospital or having treatment. If you are a parent with cancer, however, you may worry about your kids being separated from you.

Ask your kids if they want to go to the hospital or treatment centre. If they would prefer not to, don't insist on them coming in.

If they are keen to visit, the following may help prepare them.

- Before children enter the hospital room, tell them what to expect and what they may notice: the equipment; different smells and noises (e.g. buzzers, beeps); how the patients may look (e.g. tubes, bandages, 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 the patients.



- You may be able to arrange with the nursing staff for children to look at pictures or see some of the equipment in an empty room before visiting the person with cancer.
- If your kids are reluctant to go to the hospital, their first visit could just be to the ward lounge room. Reassure them that this is okay and that they can send a card or call, if they prefer.
- Let your kids decide how long they want to stay. Small children tend to get bored quickly and want to leave soon after arrival. They may want to help by getting you a drink or magazine from the hospital shop.
- Have a friend or relative come along. They can take the kids out of the room if they feel overwhelmed and then take them home when they're ready to leave.
- Bring art materials, books or toys to keep them occupied. Older children may want to play cards or board games with you. Or you could simply watch TV or listen to music together.
- If you have to travel for treatment and your children are unable to visit, use video calling on a mobile phone to communicate. See page 40 for more tips on staying connected with your kids.
- If the hospital stay will be longer, ask the kids to make the room cosy with a framed photo or artwork they've made.
- After the visit, talk to them about how they felt and answer any questions they may have.
- Ask the staff for support. Nursing staff and hospital social workers are sensitive to children's needs during this difficult time and could talk to your children if necessary.

How to play with a child in hospital

If your child is visiting a sibling or friend in hospital, explain beforehand that the other child may not feel well enough to play or talk much, but will be happy that you care enough to visit. If the child with cancer is interested in playing, here are some activities you could try:

- card games
- board games
- drawing games, such as folding a sheet of paper in three then the children take turns to draw the head, middle and legs of a character
- charades
- shared imaginary play with toys
- simple craft
- using your laptop or tablet to watch a favourite movie or program together.

“When my ex-wife got breast cancer, I talked to my little girl about how the treatment caused changes, like Mummy would get very tired and her hair would fall out, but we expected her to be okay.”

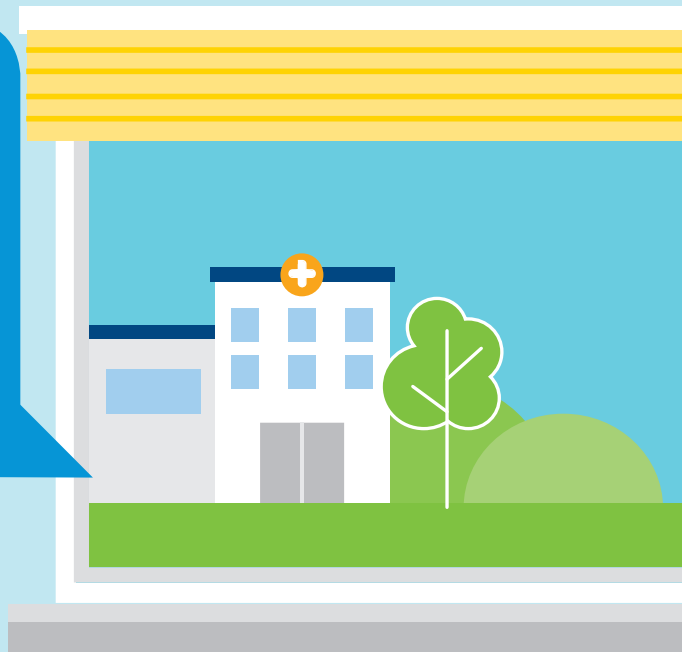
Simon, father of a four-year-old

Creative ways to explain cancer

Sometimes talking isn't the best way to communicate with children and teenagers. A range of creative methods can help explain cancer treatment and explore feelings. You can adapt these suggestions for different ages and interests.

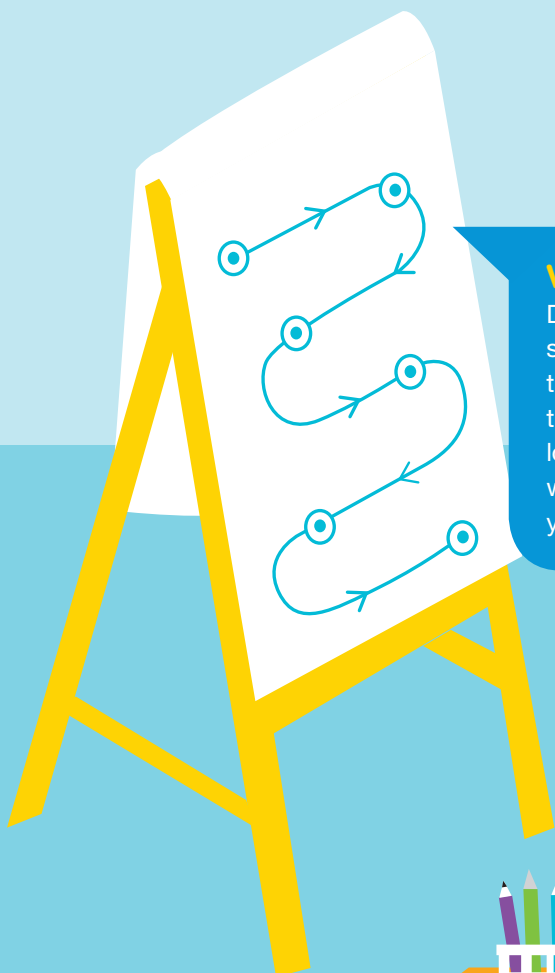
Offer them a tour

Before treatment starts, give your children a tour of the treatment centre or hospital ward. Check with staff whether this can be arranged. This experience will give your children a clearer idea about what happens during treatment. They can picture where the person with cancer will be and meet the medical team. Older children are often particularly interested in how the treatment technology works.



Visualise it

Draw a flow chart or timeline to show the different stages of the treatment plan. At different times throughout treatment, you can look at the chart together to see where you are up to and how far you have come.



Keep a journal

Keeping a personal journal or diary can help older primary schoolchildren and teenagers to express their feelings. Some may prefer to write a short story that is based on the cancer diagnosis and treatment.



Make up stories and play games

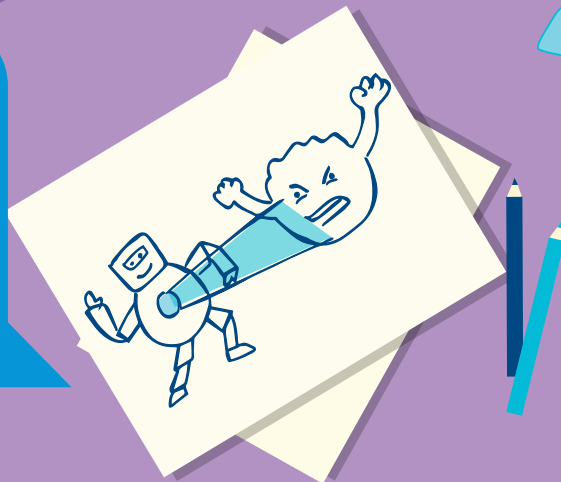
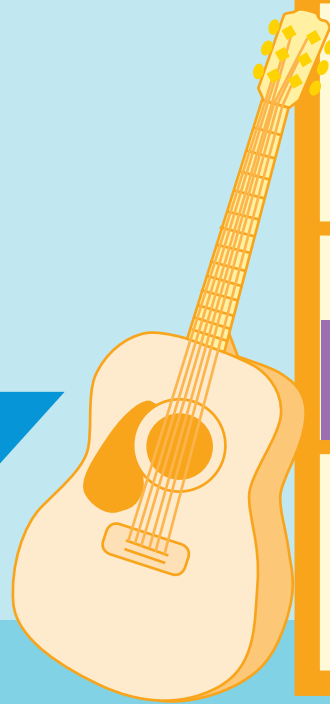
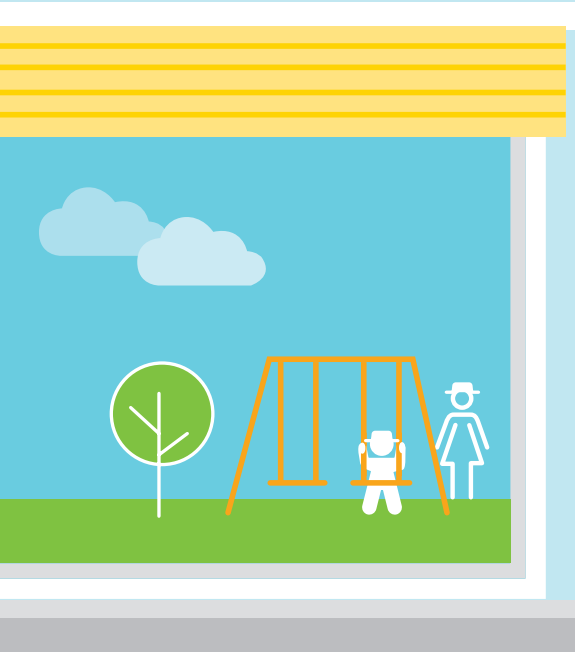
Try explaining cancer treatment using stories they know, or by playing games. You could make up a story about the battle of the good cells and the bad cells, using surgery, radiation therapy, chemotherapy and other treatments as the weapons. You could build a Lego game to show how, in the battle to defeat the bad cells, some good cells get hurt too (causing side effects). Kids who love video games will get the idea about chemotherapy zapping the bad cells. Once you get your kids started, their imagination will do the rest.

Say it with music

Listening to different types of music together or getting kids to make up their own music could help with their understanding of the different treatments (e.g. using percussion to represent destroying the cancer cells, or listening to a lullaby to represent falling asleep before having an operation).

Draw out feelings

Use art as a way to talk about cancer treatment. 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.





Chemo days

I turned my yuck chemo days into “treat” time for the kids and me. We’d pick out some movies the day before chemo. After school, the kids would come into my room and we’d watch the videos.

I didn’t take much in and often dozed, but at least we were all together. It made the times very special and something positive in the midst of all the awful treatment.

Anna, mother of two children aged 9 and 13

Answering key questions

Q: Is it going to hurt?

Many children – and adults – worry about cancer pain. Cancer doesn’t always cause pain, and if it does, the pain can be relieved or reduced.

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

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

A: 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 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 will 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?

Hair loss can be upsetting for you and your children, so it can help if the family knows what to expect and what you might do about it.

A: *“The doctor says I may lose my hair because of the chemotherapy. It will come back but probably will look a bit different, especially at first. 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.

A: *“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.

A: *“The operation/treatment I’m having has made me tired and I need to rest a lot so my body can recover and get better. Why don’t we make a plan for where we’ll go or what we’ll do on a day I have more energy? Perhaps today we can do something quiet together like watch a movie.”*

Living with uncertainty

One of the challenges of a cancer diagnosis is dealing with uncertainty.

When first diagnosed, many people want to know what's going to happen and when it will be over. But living with uncertainty is part of having cancer. There are some questions you will not be able to answer. Learning as much as you can about the cancer may make you feel more in control.

You may find you need to give your family regular updates on the progress of treatment.

Talk about any uncertainty with your children by saying something like, "The doctor is confident that this is the best treatment for me, but if that changes, we'll let you know, and we may have to look at another type of treatment."

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. You may try to push yourself to keep going, but some days this may not feel possible.

There are no easy answers to this problem, but you can make the most of your good days by forgetting the housework and 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.

It is normal for children to think mostly of themselves and how a situation affects them. You may find their reaction hurtful or frustrating, but it is age-appropriate. It can be helpful to acknowledge your child's disappointment: "I know you're finding it frustrating to keep the noise down because I don't feel well, but I just need a bit of quiet time right now."

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 book *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.



Changed behaviour

My husband, Bruce, had a brain tumour and his personality changed because of it. At the dinner table one night, our four-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 four-year-old

Managing emotions

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

If your kids' reactions seem unusual or extreme, consider getting some professional support (see page 56). However, 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.

Ways to help them to understand and manage these emotions, include:

- Encourage, but don't push, kids to identify and name feelings. For younger children, you may need to recognise and identify the emotion for them (e.g. "you look angry" or "you seem really worried").
- Reassure them that there are no right or wrong feelings. Everyone reacts in their own way.
- Let them know that anger, guilt and sadness are normal feelings. You feel them too and it is okay to talk about them.
- Remind them that they can talk to you anytime about how they're feeling.
- 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 and cuddles.
- Offer creative ways for children to express their emotions.
- Create everyday opportunities for humour and fun. Let your children know that it is alright to joke and have fun. 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. 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.

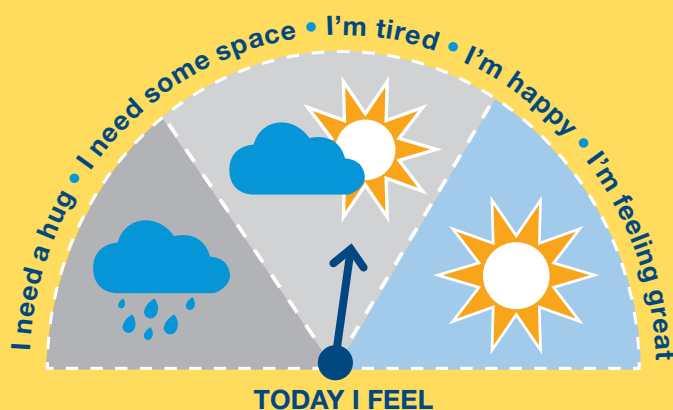
Encouraging family time

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.

If you have to adjust a regular routine during treatment, tell children what the change will be, why it's occurring and how it will affect them. They will probably want to know who will look after them, such as who will take them to school or sport or do the cooking. Tell your children where you'll be, such as at the hospital or resting at home. If you or your partner can't get them to their after-school activities, arrange for a friend or relative to help out. If that's not possible, you may have to cut back on the activities for a while, but involve your children in the decision.

During treatment, when life may be disrupted and unsettled, try to protect the time your family has together. Here are some tips you could try:

- Limit visitors and don't answer any phones at mealtimes.
- Ask your friends to send an email rather than call. For phone calls, ask them to ring when the children are at school or after their bedtime.
- Think of things to do together that don't require much energy. You could share reading a book aloud, watching a movie, or playing a board game.
- Ask a close friend or relative to coordinate all offers from friends and family to help out with household chores. This will give you more time with your family.
- 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.
- Use an invite-only blog, such as caringbridge.org, to update family and friends on how you're doing, or put a message on your voicemail.





Family time

I tried to get some rest during the day so that I was bright and more energetic when the family came home from school and work 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.

It was important to spend time together as a family. Special times together often opened up questions for the kids.

Talking is not the only way of communicating about feelings – in fact, it often goes over the head of a young child. When my kids were younger, it worked better to use dolls or stuffed animals to play out being sick, having treatment and getting well again.

Liz, mother of three children aged 10, 16 and 18

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 weekly 30-minute session with your child or teenager. This will help them feel important, valued and understood.

If you have more than one child, you may need to alternate weeks depending on your energy levels.

A younger child may not have developed the thinking or language skills to describe how they're feeling, but a play session can help the child to express feelings, make sense of events, and understand the world. They may:

- act out a story with toys or puppets
- use fantasy and dress-up
- draw or paint
- play games
- talk about their experience.

During a play session, comment on what they're doing using empathy or observation, which will let them know that you are interested in what they are doing, saying and feeling. They may play on their own or invite you to play with them. Avoid asking questions or correcting your child. This time is for them to lead the way. Their play may reveal an inner world that you may never have known about from what they say.

It's common for teenagers to prefer spending more time with friends, but they may like to visit a favourite cafe, go for a walk, watch a movie or listen to music with you.

Maintaining discipline

The issue of discipline is a common concern for families dealing with cancer. Maintaining the family's usual boundaries and discipline during this time can strengthen your children's sense of security and their ability to cope.

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.

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.



Some children may misbehave to get the attention they feel they are missing. It's okay to bend the rules occasionally, but try to keep to your family's boundaries as best as you can. Let teenagers know that the usual rules apply for curfews, drug and alcohol use, and unsafe sex.

Although some flexibility may be reasonable at this time, a predictable set of boundaries and expectations can help to maintain a sense of normal life and will be reassuring for children and young people.

Encouraging children to help

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

Young children can help with simple tasks (see box on this page for ideas). With older children and teenagers, it's reasonable to want them to help more around the house, but talk to them about it first. It's important to negotiate tasks with teenagers – avoid overloading them and try to share tasks fairly among all family members. Jobs that need to be done are not necessarily obvious to them, so discuss priorities and how tasks can be divided up.

When asking teenagers to help, keep in mind that it is age-appropriate for them to spend time with their friends. Missing the opportunity to socialise with their peers can make them feel resentful at a difficult time and affect their self-esteem.

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 out, 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.

You may want to get in touch with Carers Australia Young Carers Network at youngcarersnetwork.com.au. This organisation runs activities and support groups for children and young people up to 25 years of age 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 59).

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 beds
- 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
- clean out fridge
- wash and hang out clothes
- wash dishes
- wash car



Key points

- Explain treatment to children as simply as possible.
- Don't be afraid to be creative or have fun with your explanations.
- Let kids know how treatment works and how side effects may change the person with cancer.
- Encourage your kids to ask questions and express any fears or worries about the cancer treatment.
- Try to keep home life as stable as possible and allow kids to continue their normal activities.
- Realise that children and adults alike may become emotional or overreact occasionally.
- Maintain boundaries as much as possible.
- Let all children help out around the house.
- Reassure your family if you expect there to be better days ahead.
- Enjoy time just with the family.

Staying in touch

If you live in the country and 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.

- Ask your kids to do drawings and take photos to send to you.
- 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 (e.g. Skype, FaceTime).
- Write an old-fashioned letter. Kids love finding mail addressed to them in the letterbox.
- Send an email or recorded message.
- Leave notes and surprises for kids to find, such as a note in a lunchbox.
- Connect through social media or personal blogs.
- Use private messenger phone 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.

The Thing About Cancer podcast

For more information about all things cancer, listen to Cancer Council NSW's audio podcast series, *The Thing About Cancer*. The episodes cover a wide range of topics, including:

- *Coping with a Cancer Diagnosis*
- *Making Treatment Decisions*
- *Managing Cancer Fatigue*
- *Sleep and Cancer*
- *How to Help Someone with Cancer*
- *Cancer Affects the Carer Too*
- *Explaining Cancer to Kids*
- *Family Dynamics and Cancer*



To listen, go to cancercouncil.com.au/podcasts.



4

After treatment

For many people, the end of 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”.



Important days

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, 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 four 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.

Genevieve, mother of four children aged 3, 5, 10 and 14

What do children need to know?

Children and young people may need to know that cancer is 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 reflect on what's happened and re-evaluate their life. This process is commonly called finding a new normal, and it may take months or years. The person who has completed cancer treatment may:

Make changes – This period can be unsettling and lead to big changes, such as making lifestyle or dietary adjustments, choosing a new career or reassessing relationships.

Continue to feel the physical impact – The physical effects of cancer sometimes last long after the treatment is over. Fatigue is a problem for most cancer survivors and can interfere with daily activities. Many people have to deal with temporary or permanent side effects, such as physical scars, early menopause, or fertility and sexuality problems.

Worry about recurrence – One of the major fears for survivors is that the cancer might come back. This is an understandable fear, which can be triggered by regular check-ups and even minor aches and pains.

Call Cancer Council 13 11 20 for a free copy of our *Living Well After Cancer* booklet, or download it from your local Cancer Council website.

How children react

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

Expect the person who had cancer to bounce back – Often children don't understand that fatigue can continue after cancer treatment is over. This can lead to disappointment and frustration.

Become clingy – Separation anxiety that started during treatment may continue well after treatment is over.

Worry the cancer will return – Like the person with cancer, recurrence is a big fear for children and young people. You may need to reassure your children that regular check-ups will help monitor the cancer.

Family life after treatment

Celebrate the end of cancer treatment, and acknowledge that it has been a difficult period for everyone; this is particularly important for teenagers. Encourage kids to have fun. They have lived with worry for months and may need your permission to relax again.

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 let the family know that treatment effects are likely to last for a while after treatment finishes. Keep using the emotions thermometer if you have one (see pages 36–37). Be open about your fears, such as if you're feeling anxious before a check-up. This may encourage your kids to talk about their own fears.

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 and negotiate where possible. During your recovery, you may be able to incorporate healthy lifestyle changes into family life or activities – for example, you could do light exercise together, or make healthy changes to the kids' diets as well as your own.

Focus on each day, and expect good days and bad days – for both the adults and the children in the family.

Survivorship

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. These strategies can help.

- Consider joining a support group. Many cancer survivors join a group to meet people who understand what they have been through and how they're feeling. Talking with other survivors can help you cope and will therefore benefit your kids. See page 58 for more information.
- Read cancer survivors' stories. Learning how other people have made meaning of a cancer diagnosis may help.
- Take part in a survivors' event or attend a survivorship program, such as *Healthy Living After Cancer*, if there is one in your area. To find out what is available, contact Cancer Council **13 11 20**.
- 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 who has had cancer treatment.



Key points

- People who have had cancer treatment often have mixed emotions.
- It may be difficult to settle back into how life was before cancer.
- Kids and young people might continue to have their own fears and worries about the cancer.
- Children may find it hard to understand why life can't go back to normal. It could help to explain that the family will have a new normal.
- Give your children permission to have fun and to re-establish their own new normal along with you.
- Keep communicating and sharing your feelings with each other.

Answering key questions

Q: Will the cancer come back?

You probably wish you could tell your children that everything will be fine now, but the uncertainty of cancer lasts long after treatment is over. As well as giving a positive message, this may be a chance to listen to your child's concerns about "What if?" Allowing a child to talk about their fears and concerns is important in helping them cope.

A: *"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?

Cancer survivors often feel tired for many months after treatment. This can be hard for kids who want their energetic parent, grandparent or friend back.

A: *"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?

The person with cancer may need to take some time to process the ways that cancer has affected them, but this will probably be difficult for children, particularly younger ones, to understand. It may be helpful to explain that not everything will be the same as it was before, but that doesn't have to be a bad thing. The new normal could actually offer some benefits. Many people who've had cancer can see positive outcomes from the experience, and it may help to highlight these to the kids.

A: *"Day-to-day life will start to get more like normal as I feel better, but there may be some changes to the way we do things, like ... [the way we eat/how much I go to work/how much time we spend together as a family]. 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."



5

Living with **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 this chapter difficult. If you want more information or support, talk to hospital staff or contact the services listed on page 51.



A big hole

I was in my teens when my mother died of cancer. These were the days 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

What do children need to know?

Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may spread or come back (recur) after initial treatment. If the cancer has advanced, it is important to keep talking with your children. Again, 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, anxiety, sadness, anger, guilt, or loneliness.

Preparing children and young people for the loss of a family member is a daunting and challenging thing to do. The following is a guide to what to cover in the initial conversation. The suggestions on page 49 can help you use words they will understand.

Be honest and open

Once children know the cancer has advanced, they will need to be given some idea about what this may mean in terms of the outcome (prognosis). With some cancers, the prognosis is fairly clear and people will know that they may have only months to live. However, more and more people with advanced disease are surviving for a longer time, sometimes for many years.

If death is likely in the short term, it is best to be as honest and truthful as you can while trying to make the subject of death less frightening. For example, avoid saying that death is always peaceful as 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. You don't need to do it on your own: social workers and other health professionals at the cancer treatment centre or the palliative care service can help you to tell your children.

Being open about death gives you and your family the chance to show and say how much you care for each other, as well as the opportunity to work on any unresolved issues. The chance to talk through old arguments and make amends seems to be particularly important for older children.

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, they 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."

Karen's story*

Things went smoothly for nearly nine months and everyone fell into a comfortable pattern. One day, Karen came in for a quick visit with all three children, whom she left in the waiting room to watch TV. Dr Srivastava won't forget that day, because it was when she had to tell Karen that after more than a year of stability, the cancer had begun to spread.

**Adapted with permission from "How do you tell your children you have cancer?", The Guardian, November 2015. For the first part of this story, see page 21.*

We talked about changing treatments and hoping for the best while expecting that treatments down the line would not work as well as the initial one. She listened worriedly and then burst into tears. "Oh, what a bad day to bring the kids," she said in a woeful understatement. Then I watched in admiration as she rose and washed her face in the sink, reapplied her lipstick, and said: "We will handle it. I will talk to them."

Some weeks later, when we met again, I reluctantly asked how her talk had gone with her children. She said that directly after her consultation, she took them out for ice cream and enjoyed the occasion while suspending her fears. Later, with Jim present, she told the family that the cancer was becoming active again. Karen talked seriously but kindly and slowly, telling the children that she wanted them to know the truth from her rather than hear snatches of conversations elsewhere that left them wondering what was going on. She told them that she would always be honest with them. This is when Alyssa asked if her mother was going to die.

"I will probably die one day from this cancer, but the doctor says it's not happening yet. So I plan to take the new treatment, and I promise to let you know if things are not working out." Karen said that this was the question she had been most dreading, but tackling it honestly had been far easier than offering excuses. Robbie had always been deeply perceptive. "But Angie's grandma died in her sleep. What if that happens to you?" To this she replied: "I suppose this could happen, but if I die in my sleep, you know that Daddy is healthy and perfectly able to look after you with the help of all our wonderful friends and family." Karen said that since she could not reassure him about how or when she would die, she wanted to emphasise that they had a support structure in place that they had experienced and trusted. They would not be left alone.

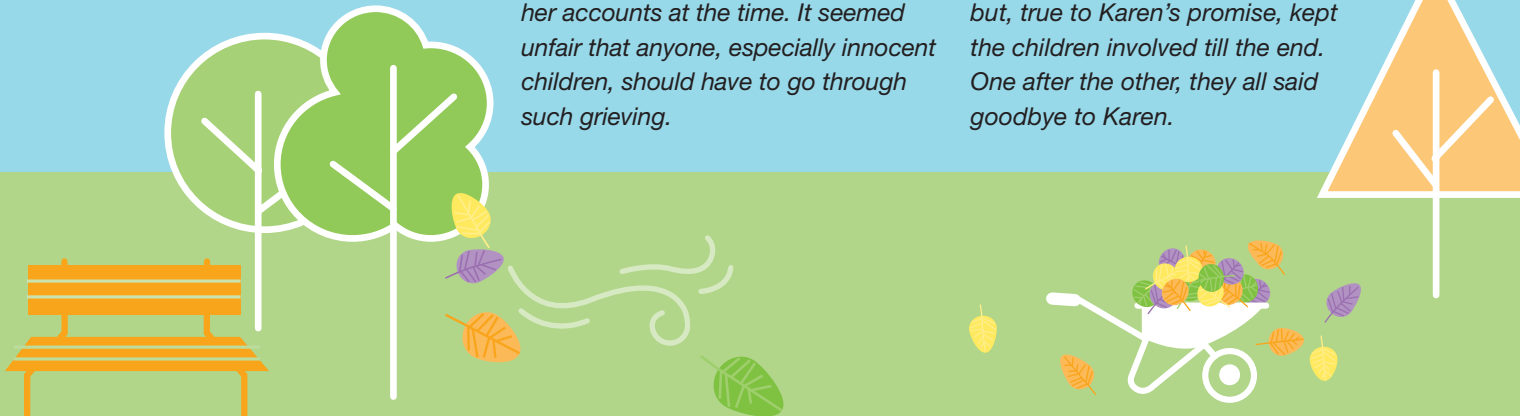
As Karen began her new treatment, the children again settled into their routine and accepted a slightly different normality. Although it's easy to relate Karen's experiences here, I found it heart-wrenching to hear her accounts at the time. It seemed unfair that anyone, especially innocent children, should have to go through such grieving.

But when I brought this up with Karen, she said with typical perspective: "Doctor, it is what it is. I just want to prepare them for life without me and know that I have done my very best."

The next big change came when she became very breathless and had to be hospitalised. Emily visited her in hospital but her older children decided to wait for her at home. Karen sent them a message but didn't insist on their coming in, believing this was their way of coping and perhaps slowly coming to terms with her dying.

Soon after this, Karen was admitted to hospice. That evening the children visited her in hospice. Jim had explained where she was and what to expect. He told Emily that her mum was sick and was going to meet God. Robbie asked if it was going to be quick and Jim said the doctor expected it to be, but it would relieve Mum of more suffering because the cancer could not be cured.

Four days later, Karen became unconscious. She was sedated and looked peaceful. Jim was devastated but, true to Karen's promise, kept the children involved till the end. One after the other, they all said goodbye to Karen.



Balance hope with reality

A diagnosis of advanced cancer does not mean giving up hope. Some people live for years with cancer that has advanced, and sometimes receive palliative treatment alongside active treatment. They can continue to enjoy many aspects of life, including spending time with their children and other people who are important to them.

As the disease progresses, the things that are hoped for may change. You can still be honest and offer hope. 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 the loss.

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 lots of 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", "gone away" or "resting" can be confusing for children. It's best to use straightforward language. This includes using the words "dying" or "death". See box opposite for some examples of how to explain these concepts.

How children react

How you react to a diagnosis of advanced cancer can affect how the whole family responds. If you are anxious and depressed, the family may be too. 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 if family members don't communicate well.

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. They are likely to feel insecure, although teenagers may not want you to see this. Depending on their age, kids usually have different immediate concerns when they hear the news. See pages 52–53 for typical reactions from children and young people.

Children of separated or divorced parents need to be given the opportunity to see their ill parent, to prepare for the loss, and to say goodbye.

What words should I use?

If you need to prepare a child for the death of someone they care about, it can be confronting to find the right words to use. See also pages 50–51 for tips on answering specific questions.



Infants, toddlers & preschoolers



Younger children



Older children & teenagers

	Infants, toddlers & preschoolers	Younger children	Older children & teenagers
When advanced cancer is diagnosed	<p><i>“Some people with this sort of cancer get better, but some don’t. I am going to do everything I can to get better.”</i></p>	<p><i>“Some people with this sort of cancer get better, but some don’t. I’m trying to do everything I can to treat the cancer, and I will always let you know how I’m feeling.”</i></p>	<p><i>“Some people with this sort of cancer recover, but some don’t. I’m planning to do everything I can to keep the cancer under control, and I will always let you know how the treatments are going.”</i></p>
When end of life is near	<p><i>“Daddy is very sick now. The doctors say there isn’t any medicine that can make him better. We think that means he is going to die soon. We will try to spend some special quiet time together.”</i></p>	<p><i>“The doctors say that the treatments have stopped working for Dad. There isn’t anything else they can do to treat the cancer. We think that means Dad will die soon. We want to make the most of the time he has left.”</i></p>	<p><i>“The doctors say that the treatments haven’t worked for Dad. There isn’t anything else they can do to treat the cancer. We think that means Dad will die soon. We want to make the most of the time he has left.”</i></p>
To explain death	<p><i>“When Grandma died, her body stopped working – she can’t breathe or move or cuddle you anymore. A dead body can’t come back to life. We won’t be able to see Grandma again, but we will always know she loved us.”</i></p>	<p><i>“I have some very sad news to tell you. Grandma died last night. She can’t breathe or move anymore. Is there anything you’d like to know about how Grandma died?”</i></p>	<p><i>“I have some very sad news. Grandma died last night ... Is there anything you’d like to know about how Grandma died?”</i></p>



48 hours

We were sitting in my sister's lounge room again 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 four 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.

Izzy, 15-year-old whose father had cancer

Answering key questions

How you answer these questions depends on the nature of the cancer and the effects of treatment. 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 your children's questions over and over again, you are helping to ease their worries. Sometimes children may test you to see if your answers stay the same.

Q: Why?

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

A: *"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?

A: *"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. Older children may want some idea. It is still important to balance hope with reality.

A: *"Nobody knows for sure when anyone will die. The doctors have said I will probably live for at least X months/years. Whatever happens, we want to make the most of that time. I will be trying to live for as long as possible."*

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

A: *"I honestly don't know, but I will probably get a little weaker each day now."*

"No-one can answer that, but we are hoping that 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?

Many children will still be worried about who will look after them, so it's best to tackle the question early on.

A: *"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."

Q: What happens if Mum/Dad dies too?

A: *"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 and loved."*

Q: Am I going to die as well?

A: *"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 check what the child means by this question. Responding with an open-ended question such as "What do you think happens?" can help you work out what the child really wants to know. They may be asking what the physical process of dying involves or what happens to the body after death. Keep your explanations simple, concrete and honest. If there will be a cremation, adapt the following example – follow the child's lead to work out how much detail to give.

A: *"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."*

(However, the question may 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.)

A: *"People believe different things about whether a person's soul lives on after death. What do you believe?"*

Supporting 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 express sadness in various ways, just as they express other emotions.

For bereavement information and support, call Cancer Council **13 11 20** or contact one of these organisations:

Australian Centre for Grief and Bereavement
1800 642 066
grief.org.au

GriefLine
1300 845 745
griefline.org.au

CanTeen
1800 835 932
canteen.org.au

Redkite
1800 733 548
redkite.org.au

Different views of 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 play or behaviour.

0-3 years



Newborns, infants and toddlers

Babies don't have any knowledge of death, but can sense when their routine is disrupted and when their carers are absent. Toddlers often confuse death with sleep and do not understand its permanence.

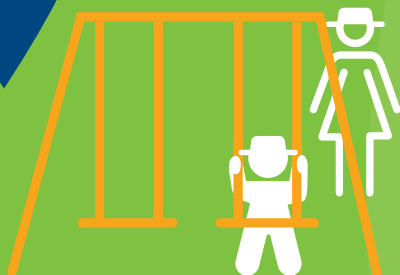
Possible reactions

- babies: unsettled and clingy
- toddlers: may worry persistently about the well parent and think that they or their behaviour caused the advanced cancer
- may also be angry with parents for not being able to give them more attention

Suggested approaches

- avoid explaining death as "sleeping", because that can cause distress about sleep
- provide comfort
- be prepared to patiently answer the same questions many times
- maintain routines and boundaries

3-5 years



Preschoolers

By the preschool years, children are starting to understand the concept of death but struggle with its permanence (e.g. they may 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.

Possible reactions

- may feel it is somehow their fault
- may be angry with their parent for not giving them enough attention
- can react as if they were much younger when under stress
- may have frightening dreams
- may keep asking about death

Suggested approaches

- watch their play for clues to their feelings
- offer comfort
- answer questions in an open, honest way
- maintain routines and boundaries



5-12 years



Primary schoolchildren

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 and that they are responsible.

Possible reactions

- may be openly sad or distressed
- may express anger
- may worry about being responsible for the death, but also might blame someone else
- may ask confronting questions about what happens when somebody dies
- may be more able to talk about their feelings and act sympathetically

Suggested approaches

- encourage them to talk, but realise they may find it easier to confide in friends, teachers or other trusted people
- provide plenty of physical and verbal expressions of love
- be sensitive but straightforward
- discuss changes to family roles
- provide privacy as needed
- maintain routines and boundaries

12-18 years



Teenagers

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.

Possible reactions

- may deny their feelings or hide them in order to protect you
- may think they can handle it alone and not look for support, or may distance themselves from family and talk to friends instead
- may react in a self-centred way and worry about not being able to do their normal activities
- may express distress through risk-taking behaviours (e.g. skipping classes, experimenting with drugs and alcohol, acting recklessly)
- worry that death is frightening or painful, and struggle with their own mortality

Suggested approaches

- encourage them to talk about their feelings with friends or another trusted adult
- support them to express their feelings in positive ways (e.g. listening to music, playing sports, writing in a journal)
- negotiate role changes in the family
- maintain routines and boundaries
- let them know that support and counselling are available (see page 51 for some options)
- offer them the opportunity to participate in a public or private memorial service



Key points

- Children and adults can react very strongly to the news that cancer is advanced.
- It is important for people to be able to express their emotions and to grieve in their own way.
- Children should be given some idea about the person's prognosis.
- Be open about death. Let your kids ask questions and express their fears.
- Reassure your kids about the future.
- Let your children spend time with the person who has cancer so they can create meaningful memories together.
- Give kids realistic hope, e.g. that the family can still enjoy time together or that the person with cancer will have some good days.

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. Here are some ideas for maximising your time with your family and preparing them for the future:

- Accept offers of help. It not only frees up your time and energy for the family, it also allows friends to feel that they are contributing.
- Make a memory box, choosing keepsakes together. These will be personal choices, but could include: treasured photos; a DVD of a family event; special birthday cards; a favourite cap, tie, scarf or another item of clothing; a list of shared memories; tickets from special outings; a family recipe; a pressed flower from your garden; a bottle of perfume or aftershave; and a lock of hair.
- Plan a special outing with your family. You might have always wanted to take your kids to the beach, the ballet or the football grand final. You might want to show your kids where you grew up, or maybe there is somewhere special that your children would like to take you.
- Listen carefully to what your children want to say. Allow your children to express any regrets that they have.

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. It might help them to go to school and see that normal life can continue, even though things are changing at home. 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 understand and respond appropriately to any changes in behaviour or academic performance.

If you have older children, it's important to ask them what they want you to do. Teenage children might choose to tell their teachers themselves. They may not want their teachers to know at all because they don't want the attention or to be thought of as different from the other students. Reassure your teenager that their teacher can help and won't tell anyone else without their permission.



6

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. It includes a reading list and glossary to help you explain cancer to younger and older children.

Getting support

Many professionals and organisations can help you communicate with your children throughout your experience with cancer. You don't need to have a specific problem to make contact with these services. You can ask for help even before breaking the news to your children. A health professional could practise the conversations with you so that you feel better prepared.

You can also ask health professionals and organisations for help if you are worried about your children's behaviour. You may choose to see or call the professional yourself, and to use their advice to sort out the problem. Most parents, with the right advice, can support their children through difficult situations. Occasionally, a child may need to attend a consultation, and parents might be asked to come too.

When to seek professional support for your child

While it's difficult to know if your child's reaction is typical or something more serious, sometimes extra support can help. Some warning signs that you should see a professional are 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 wetting the bed every night for a month
- refuses to go to school – they may say they are too sick for school, but actually have separation anxiety and think they need to stay home to look after their parent
- has a persistent change in eating habits
- has noticeable concentration challenges (dropping grades)
- is spending more time online
- talks about wanting to die or is extremely preoccupied with dying
- is having trouble sleeping
- acts sad and withdrawn
- demonstrates severe behaviour, such as self-harm
- has increased risk-taking behaviours, such as alcohol or drug use
- is withdrawing from friends.

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 for many weeks in a row, they may see a change in behaviour, concentration levels, grades, eating habits and socialising with peers. This is one of the reasons it is valuable to let the school know what is going on at home and to ask them to contact you if they have any concerns about how your child is coping.



Health professionals who can help

Professionals to see if you are concerned about your child include:

Your GP and 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 – link you to support services and help with emotional, practical or financial issues.

Psychologists and counsellors – can help you with communication and behavioural issues (visit Australian Psychological Society at psychology.org.au and scroll down to “Find a Psychologist”).

School counsellors – are trained in child development and can be a useful source of support and ideas.

Psychiatrists – will see children with more serious issues (you will need a referral from a GP if your child is treated privately).

Practical and financial help

A cancer diagnosis can affect every aspect of your life, and it often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment, such as help with the cost of prescription medicines, transport costs, utility bills or basic legal advice
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances to make life easier at home
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost. To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, get in touch with Cancer Council 13 11 20 or see our booklets *Cancer and Your Finances* and *Cancer, Work & You*.

If you feel overwhelmed

A child's ability to cope is often closely linked to how their parents are coping. Kids often copy their parents' behaviour, so if Mum or Dad is depressed and anxious, they are more likely to be too. It is important to seek support if you feel overwhelmed.

- Ask family and friends for help. Let them know what you need – they will probably be relieved that you can give them something to do.
- Get practical assistance and information from Cancer Council and other organisations to help ease your worries (see details at left and on the next page).
- Use complementary therapies, such as massage, hypnotherapy or relaxation techniques to manage stress.
- Contact CanTeen, Camp Quality or Redkite about programs that may help you and your children cope with cancer. Lifeline and Kids Helpline both provide 24-hour telephone counselling. See page 59 for a list of support services.



Related resources

You might also find the following free Cancer Council booklets and other resources useful:

- *Cancer in the School Community: A guide for staff members*
- *Explaining Cancer to Kids* (podcast episode)
- *How Can I Help? Supporting Someone with Cancer* (brochure)
- *Emotions and Cancer*
- *Relaxation and Meditation CDs**
- *Caring for Someone with Cancer*
- *Cancer and Your Finances*
- *Living with Advanced Cancer*
- *Understanding Palliative Care*
- *Facing End of Life*
- *Understanding Grief*
- *Living Well After Cancer*

* May not be available in all states and territories.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20 – Trained professionals will answer any questions you have about the situation in your family and link you to services in your area (see the inside back cover). A translator service is available for languages other than English. Call 13 14 50.

Information resources – Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery (see box on this page). For a copy or to download a digital version, call 13 11 20 or visit your local Cancer Council website (see back cover). You can also listen to Cancer Council's audio podcast series, *The Thing About Cancer*, at cancercouncil.com.au/podcasts.

Practical help – Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include transport to treatment, affordable accommodation near treatment centres, and help with household tasks from trained volunteers. Call 13 11 20 to find out what services are available in your state or territory.

Legal and financial support – If you need advice on legal, financial, small business or workplace issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. The Cancer Council team will ask several questions to determine whether you are eligible for assistance. Call Cancer Council 13 11 20 to ask if you are eligible. If you don't qualify for free assistance, we can put you in touch with a professional who can help on a paid basis.

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.

“My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain.”

Sam

Support and information directory

Support services

<p>Camp Quality provides programs and services to strengthen the wellbeing of children aged 0–13 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 (see opposite page for more details)</p>	<p>13 11 20 For your local Cancer Council website, see back cover</p>
<p>CanTeen supports young people aged 12–25 affected by their own or a close family member’s cancer diagnosis</p>	<p>1800 835 932 canteen.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 telephone and online counselling for young people aged 5–25</p>	<p>1800 55 1800 kidshelpline.com.au</p>
<p>Lifeline offers 24-hour general crisis support</p>	<p>13 11 14 lifeline.org.au</p>
<p>ReachOut general information about mental health and wellbeing for young people going through tough times</p>	<p>au.reachout.com</p>
<p>Redkite offers financial, emotional and educational support for people aged 0–24 with cancer, as well as their families and networks</p>	<p>1800 REDKITE (1800 733 548) redkite.org.au</p>
<p>Ronald McDonald Learning Program provides assessment, therapy and tuition for young people whose education has been disrupted by serious illness</p>	<p>1300 307 642 rmhc.org.au/our-programs/learning-program</p>
<p>Young Carers Network provides information and support for people under 25 who care for someone with an illness, disability or mental health issue</p>	<p>youngcarersnetwork.com.au</p>
<p>youthbeyondblue supports young people aged 12–25 dealing with depression, anxiety and other mental health problems</p>	<p>1300 22 4636 youthbeyondblue.com</p>
<p>Griefline offers phone and online counselling</p>	<p>1800 642 066 grief.org.au</p>

Online information for children aged 3–13 years

Bearing Up Club

internet club for kids dealing with bereavement – once a child is registered, they can join an online chat room

bereavementcare.com.au

Kids' Guide to Cancer

Camp Quality's free educational app for children aged 8–13 who have a parent, sibling or other loved one with cancer – answers the common questions kids have about cancer

campquality.org.au/kidsguidetocancer

Online information for teenagers aged 12–18 years

CanTeen

aimed at young people aged 12–25 who are dealing with their own or a close family member's cancer diagnosis; peer community and discussions as well as access to counselling

canteen.org.au/cancer-information

riprap

UK site for teenagers who have a parent with cancer

riprap.org.uk

Stupid Cancer

US site for people aged 15–39 who are affected by cancer

stupidcancer.org

General online information

Cancer Council

reliable information about cancer by topic and by type; PDFs and ebooks 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

childrenscancer.canceraustralia.gov.au

Victorian Paediatric Integrated Cancer Service (PICS)

information for families when a child is diagnosed with cancer

pics.org.au

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

Picture books

Butterfly Kisses and Wishes on Wings
Ellen McVicker & Nanci Hersh, S.N., 2006
butterflykissesbook.com

Nowhere Hair
Sue Glader & Edith Buenen,
Thousand Words Press, 2010
nowherehair.com

In the Rainbow
Tracey Newnham, 2017
intherainbow.com.au

Safina and the Hat Tree
Cynthia Hartman & Hayley O'Brien, Nomota, 2004
talesforkids.com.au

For younger readers

Because...Someone I Love Has Cancer.
Kids' Activity Book, Terri Ades, American
Cancer Society, 2006

I'm a Kid Living with Cancer
Jenevieve Fisher & Casey Huie, Isaiah 11:6
Publishing, 2010

*Beginnings and Endings with Lifetimes
in Between*
Bryan Mellonie & Robert Ingpen, Penguin, 2005

I Miss You: A first look at death
Pat Thomas, Barron's Educational Series, 2001

Big Tree is Sick
Nathalie Slosse & Rocio Del Moral,
Jessica Kingsley Publishers, 2017

The Memory Tree
Britta Teckentrup, Hachette, 2014

I Know Someone with Cancer series, 2018
bupa.co.uk/bupa-cancer-promise/i-know-someone-with-cancer

My Mum's Got Cancer
Dr Lucy Blunt, Jane Curry Publishing, 2012

For teenagers

Allie McGregor's True Colours
Sue Lawson, Black Dog Books, 2006

The Honest Truth
Dan Gemeinhart, Scholastic Press, 2015

The Fault in Our Stars
John Green, Penguin Books, 2014

My Parent Has Cancer and It Really Sucks
Maya Silva & Marc Silva, Sourcebooks, 2013

For adults

*Cancer in Our Family: Helping children cope
with a parent's illness (2nd ed.)*
Sue P. Heiney & Joan F. Hermann
American Cancer Society, 2013

*Raising an Emotionally Healthy Child
When a Parent Is Sick*
Paula K. Rauch & Anna C. Muriel,
McGraw-Hill Education, 2006

Glossary

Word	For younger children	For older children and teenagers
anaesthetic	A medicine that makes someone go to sleep so they don't feel anything when they have an operation.	A drug that stops people feeling pain during a procedure such as surgery. A general anaesthetic puts someone to sleep. A local anaesthetic just numbs one area of the body.
benign	A bump or lump on the body that isn't dangerous.	Not cancerous or malignant. Benign tumours are not able to spread to other parts of the body.
biopsy	When the doctor looks at cells in the body to see if they're healthy or not.	A test to diagnose cancer. The doctor takes small bits of tissue from the body and looks at them under a microscope to see if the cells have changed.
blood count	A test that checks how healthy the blood is.	A test that counts how many red blood cells, white blood cells and platelets there are in the blood.
cancer	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.	Cancer is the name for over 200 diseases in which abnormal cells grow and rapidly divide. These cells usually develop into a lump called a tumour. Cancer may 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.	Cells are the building blocks of the body. Our bodies constantly make new cells to help us grow, to replace worn-out cells, or to heal damaged cells after an injury.
chemotherapy	Special medicine that kills the bad cancer cells.	A cancer treatment that uses drugs to kill cancer cells or slow their growth.
child life therapist	Someone who helps kids understand what is going on and how to have fun when they are in hospital.	A health professional who helps children manage the stress and anxiety of being in hospital through play and other coping strategies.
CT scan	A test that makes pictures so doctors can see what's happening inside the body.	A procedure that uses x-rays to create detailed, cross-sectional pictures of the body that show if cancer is present.
diagnosis	When the doctor works out what is making someone sick.	Working out what kind of disease someone has.
dietitian	Someone who helps people work out the healthiest foods to eat.	A health professional who supports and educates people about nutrition and diet.
donor	A person who gives blood or another part of their body to someone else.	The person who gives blood, tissue or an organ to another person for transplantation.
haematologist	A doctor who treats people whose blood makes them sick.	A specialist doctor who diagnoses and treats diseases of the bone marrow, blood and lymphatic system.
hormone therapy	A treatment that helps stop cancer cells growing.	A treatment that blocks the body's natural hormones, which sometimes help cancer cells grow. It is used when the cancer is growing in response to hormones.
immune system	The part of the body that helps someone stay well by getting rid of germs inside the body. It fights illness if somebody does get sick.	A network of cells and organs that defends the body against attacks by foreign invaders, such as bacteria and viruses, which can make people sick.

Word	For younger children	For older children and teenagers
immunocompromised	When someone gets sick very easily.	Weakening of the immune system, often caused by disease or treatment.
immunotherapy	A treatment that helps the body fight cancer.	Treatment that uses the body's own immune system to fight cancer.
intravenous (IV)	Putting a needle into a vein (where blood flows in the body).	Injected into a vein.
leukaemia	A type of cancer that starts in the blood.	A form of cancer where the cells that make blood start reproducing damaged cells at a fast rate.
lymph nodes	Lymph nodes are like filters that remove germs that could harm you. Sometimes, the germs can make some of the lymph nodes swell.	Small, bean-shaped structures that form part of the lymphatic system and help fight infection.
maintenance treatment	When someone is given medicine for a long time to help keep the cancer away.	Treatment given for months or years as part of the treatment plan. Often used for acute lymphoblastic leukaemia.
malignant	Another word for cancer.	Cancerous. 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.	A specialist doctor who treats cancer with chemotherapy.
metastasis (advanced cancer)	When the bad cells have travelled to another part of the body.	When cancer has spread from one part of the body to another. Also known as secondary cancer.
MRI scan	A way to take pictures of the inside of a person's body.	A medical scan that uses magnetism and radio waves to take detailed, cross-sectional, pictures of the body. MRI stands for "magnetic resonance imaging".
nausea	Feeling sick in the tummy.	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.	A health professional who helps people solve physical and practical problems after illness, so they can lead independent lives.
palliative treatment	Sometimes the doctors and nurses can't stop the cancer from growing, and they will give someone medicine to make them feel better and get rid of any pain.	Treatment that reduces or stops symptoms 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.	A scan in which a person is injected with a small amount of radioactive glucose solution. Cancerous areas show up brighter in the scan because they take up more of the glucose. PET stands for "positron emission tomography".
physiotherapist	Someone who helps a person's body get stronger after they have been sick.	A health professional who helps people recover their physical abilities after illness and surgery.
prognosis	What the doctors think might happen after treatment, and someone's chance of getting better.	The expected outcome of a disease. This helps doctors decide on treatment options.

Word	For younger children	For older children and teenagers
psychologist	Someone who helps people keep their minds healthy.	A health professional who helps people with their thoughts, feelings and behaviours.
radiation oncologist	A special doctor who uses x-rays that go into the body to kill cancer cells and make the cancer smaller.	A specialist doctor who treats cancer by prescribing and coordinating a course of radiation therapy.
radiation therapy (also called radiotherapy)	Invisible beams called x-rays that go into the body to kill cancer cells and make the cancer smaller.	The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. This is different to when you get x-rayed to see inside you (e.g. for a broken leg).
recurrence/relapse	When cancer comes back and the person feels sick again.	When cancer comes back after a period of improvement.
remission	When cancer goes away after treatment.	When cancer cells and symptoms reduce or disappear because of 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 gain or lose weight, or have other changes. Most side effects go away after some time.	The unwanted effects of treatment, such as nausea, hair loss or fatigue. This is because treatment damages some healthy cells as well as the cancer cells. The healthy cells usually recover after a while (e.g. hair grows back).
stage	When the doctor tells the person how sick they are.	The extent of the cancer and whether it has spread from an original site to other parts of the body.
stem cell transplant	Stem cells are cells that make new blood in our bodies. Sometimes a person's cancer has to be treated with such strong medicine that their stem cells are destroyed. The person is given new stem cells to make them healthy again.	A treatment in which diseased blood cells are destroyed by high-dose chemotherapy or radiation therapy, then replaced with healthy stem cells. Stem cells are obtained from either the bone marrow or blood of the patient or a donor.
surgery	When someone has an operation and a doctor called a surgeon cuts out the cancer.	An operation to remove the cancer. Sometimes large parts of the body, such as a breast or the bladder, will be removed with the cancer.
targeted therapy	Special medicine that damages or kills cancer cells, but doesn't harm healthy cells.	Drugs that attack specific features of cancer cells while minimising harm to healthy cells.
tumour	A lump in the body that shouldn't be there. The lump may or may not be cancer.	A new or abnormal growth of tissue on or in the body. Tumours can be benign (not cancer) or malignant (cancer).
ultrasound	A test that allows doctors to look inside the body so they can work out if anything is wrong.	A scan that uses soundwaves to create a picture of part of the body. It helps show where and how big a tumour is.
x-ray	A test that takes pictures of the inside of the body.	A test that takes pictures of the inside of the body using high-energy waves.

References

1. SJ Ellis, CE Wakefield, G Antill, M Burns & P Patterson, "Supporting children facing a parent's cancer diagnosis: A systematic review of children's psychological needs and existing interventions", *European Journal of Cancer Care*, vol. 26, iss 1, 2017.
2. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2017*, Canberra, 2017.



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 cancer nurses 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.

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



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

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



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.

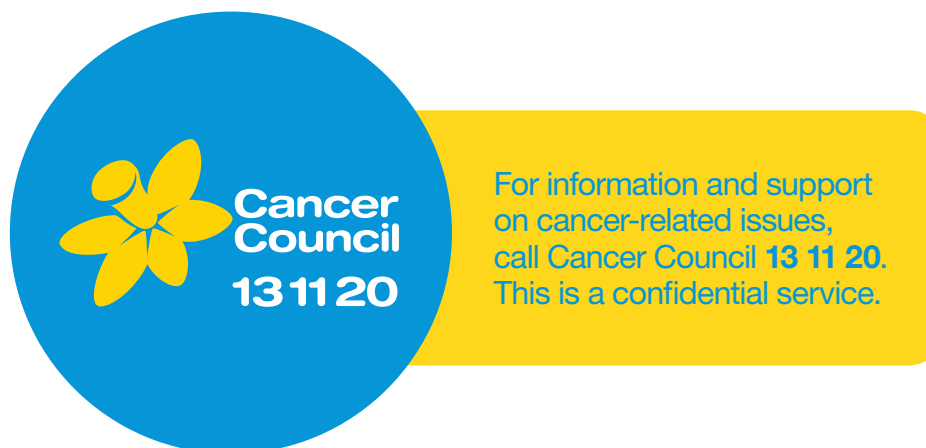
Make a donation: Any gift, large or small, makes a meaningful contribution to our work supporting people with cancer and their families now and in the future.

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 (see back cover).



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

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nt.cancer.org.au

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