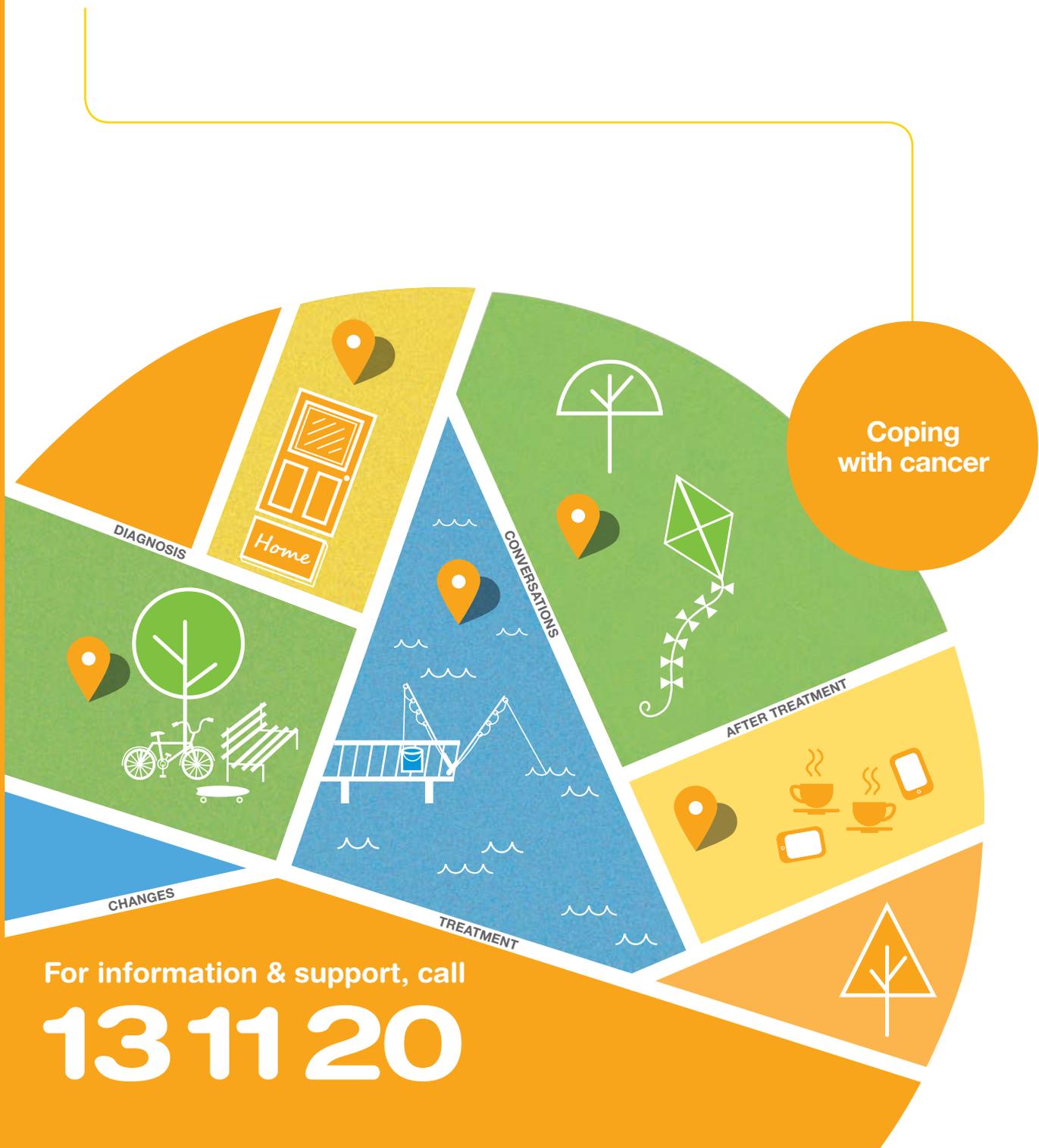


# Talking to Kids About Cancer

A guide for people with cancer,  
their families and friends



For information & support, call

**13 11 20**

## Talking to Kids About Cancer

A guide for people with cancer, their families and friends

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## 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 publication. We have used the terms 'kids' and 'children' interchangeably and the term 'teenagers' rather than 'adolescents', as this is how families tend to speak.

## 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](http://cancer.org.au) or call your local Cancer Council.



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# Talking to Kids About Cancer

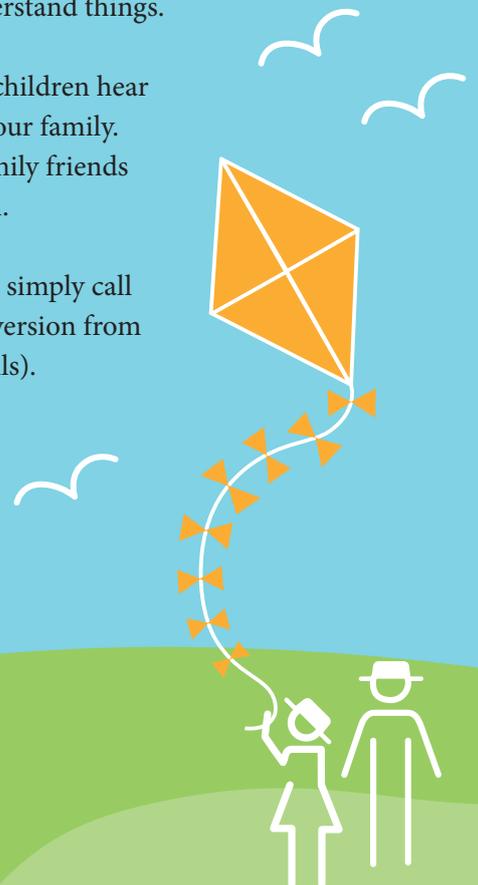
Explaining a diagnosis of cancer to children or teenagers can feel difficult and overwhelming. This book isn't designed to tell you exactly what to say, but we hope it gives you a starting point. Talking sensitively and honestly about the diagnosis can provide reassurance during a time of uncertainty 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 diagnosis of cancer to children – for example, when a child's sibling or friend has cancer, when their grandparent or another significant adult has cancer, or when the 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 resource 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 vary what you say according to the children's ages and their individual characteristics – you know your children best and can judge their ability to understand things.

You may like to use this book as a resource to ensure your children hear a consistent message about cancer and how it is affecting your family. Pass it on to grandparents, teachers, school counsellors, family friends and neighbours – anyone who is talking with your children.

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).



## How to use this book

Each chapter of this book explores 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: *When cancer won't go away*. Many people do survive cancer, so this issue won't be relevant to everyone and you may prefer not to read this chapter. However, some readers will find it useful to have this information.

Throughout the book, the page margins feature colour-coded boxes that highlight particular kinds of content:



**Tips**



**Information**



**Personal story**



**Key points**

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

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# Cancer **conversations**

Talking about cancer can seem overwhelming. Your first reaction may be to keep the news from children or to delay telling them. Research shows that being open and honest is one of the best ways to help 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 unsure about discussing the situation with children. Parents and other adults can feel overwhelmed by their own anxiety and fears, and their first impulse may be to protect children from feeling those same strong emotions.

However, there are many reasons that a straightforward and honest discussion can actually make children feel more secure.

### 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 the best way for your family. Remember that you are the expert on your children, and your understanding of their individual personalities and needs can 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. Secrets can be difficult to keep. 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 routine without your children knowing why, which can be confusing for them and tricky for you.

### 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 a 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 less attention being shown to them. These signs may be more obvious to older children and teenagers, but even young children can sense a change.

A lack of information can lead to increased distress in young people who have a parent with cancer.<sup>1</sup> If your kids suspect there's a serious problem and you haven't told them about it, they may make up their own explanation. They will then spend a lot of their coping energy on adjusting to this imagined situation, which will often be worse than the reality.

### 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 family.

Cancer can have different 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 be respectful of different ways of coping. If a family wants to keep a diagnosis private, organisations such as Cancer Council or CanTeen (see page 59 for contact details) may be able to provide a way for family members to discuss their feelings and concerns in a confidential setting.

### **They have a right to know**

Children can feel hurt if they suspect or discover they have been excluded from something important to them and their family. Sharing information shows you trust and value them, which can enhance their self-esteem.

The diagnosis may also be a chance for your kids to develop emotionally. They may learn about living with uncertainty and how to cope when life doesn't go to plan. This helps build their resilience, the ability to bounce back from difficult situations.

### **They might find out from someone else**

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

If, as a parent, you tell friends and relatives about cancer in the family, but you don't tell your children, there is a chance your kids will hear about the cancer from someone else or overhear a conversation. Children often pick up on adult conversations even when it seems like they are busy with their own activity and not paying attention. They may even look for a way to listen without being noticed.

Overhearing the news can give your children the wrong idea. 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. It can also affect their sense of trust that their parents will tell them the truth.

**“ 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*

Children may also misunderstand information and think a situation is much worse than it is. They may feel afraid to ask questions. They might worry in silence or spread incorrect information to other children in the family. Many children will pick up on a few key words and turn to the internet for answers, which can lead them to unreliable websites. In the complex world of cancer and online resources, parents are often the best pathway to truthful, specific and accurate information.



## Kids can cope

When kids are in a family affected by cancer, it can be a challenging time for them. You may wonder how they will get through it, but with good support, most children can cope and will display resilience.

A key factor in helping kids get through difficult times is a close relationship with an adult who values and supports them, and accepts them for who they are. That adult can be a parent, a grandparent, a favourite aunt or uncle, or a family friend. Whatever the connection, an adult who provides support can help a child through tough times.

## Children need a chance to talk

Talking to your children about cancer gives them the chance to tell you how they feel and lets them know it is okay to ask questions. Don't be afraid to express your own feelings or cry. As long as you are not out of control, it can be helpful for young people to know that emotions such as anger and sadness are normal reactions and that adults feel them too.

Sometimes kids will open up to adults who are not their parents. They may feel guilty about burdening a sick parent or taking up a healthy parent's time, so they will confide in someone else like a teacher or step-parent.

As a parent, it is important to encourage your kids to talk about their thoughts and feelings with you or someone else who is trustworthy. A strategy that might be helpful is to ask them to write down five trusted adults outside the immediate family. These are the people your children can turn to if for any reason they feel like they can't talk to you about something.

## When you can't talk about cancer

While some people are able to be open about cancer, others find it hard to discuss the illness, particularly with their own children. Some parents don't want to tell their children at all and try hard to hide the diagnosis.

People have their own reasons for not telling children, including cultural differences (see box, page 5), family circumstances and an earlier death of a close relative from cancer. Sometimes you may not know how serious the cancer is and you want to wait to find out more before telling your kids.

Most people find that when the time comes to tell their children, they do find the strength for the conversation. After the initial conversation, the talks about cancer become easier.

## Key points

- Start with questions to check what the child knows about cancer.
- Try not to overload kids with too many details.
- 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. Explain that the parent with cancer may seem distant but still loves them.
- Stop and listen to your children so you know how they really feel.
- Share your own feelings to help show kids 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 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, have quite different responses. These charts give an overview of children's needs at different ages and might help you work out how best to support them.



0-3 years



## Newborns, infants and toddlers

Infants have little awareness of illness, but are aware of their parents' anxiety and other feelings. They are also aware of periods of separation from their parents and can get upset when the physical presence of a loving parent is missing. Toddlers may react to physical changes in their parent or relative or the presence of side effects (such as vomiting).

### Possible reactions

- 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.

### Suggested approaches

- 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
- ask family members and friends to help with household tasks and care
- observe play for clues to how a child is coping
- use relaxation tapes, calming music or baby massage
- share your feelings and fears with others



3-6  
years

### Preschoolers

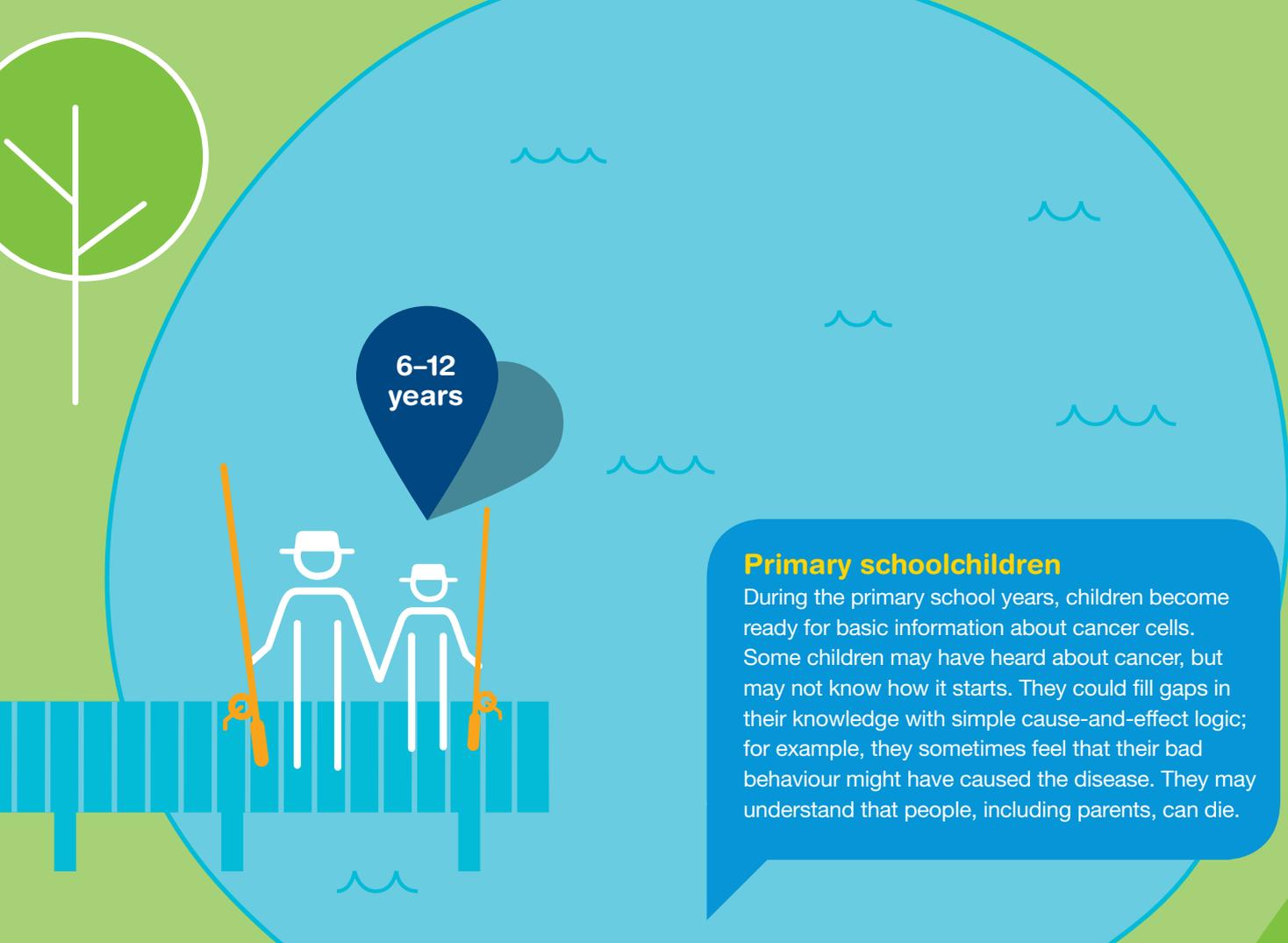
By the age of 3, children have a basic understanding of illness. Younger children may believe that they caused the illness (e.g. by being naughty or thinking bad thoughts); this is called magical thinking. They may also think cancer is contagious. It is natural for young children to be egocentric and think everything is related to them – Did I cause it? Can I catch it? Who will look after me?

#### Possible reactions

- regression, e.g. starting to suck their thumb again
- 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
- talk about cancer using picture books, dolls or stuffed animals
- 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 children 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
- let children get physical activity every day to use up excess energy and provide an outlet for any anxiety or aggression
- continue usual discipline and limit-setting



6-12 years

### Primary schoolchildren

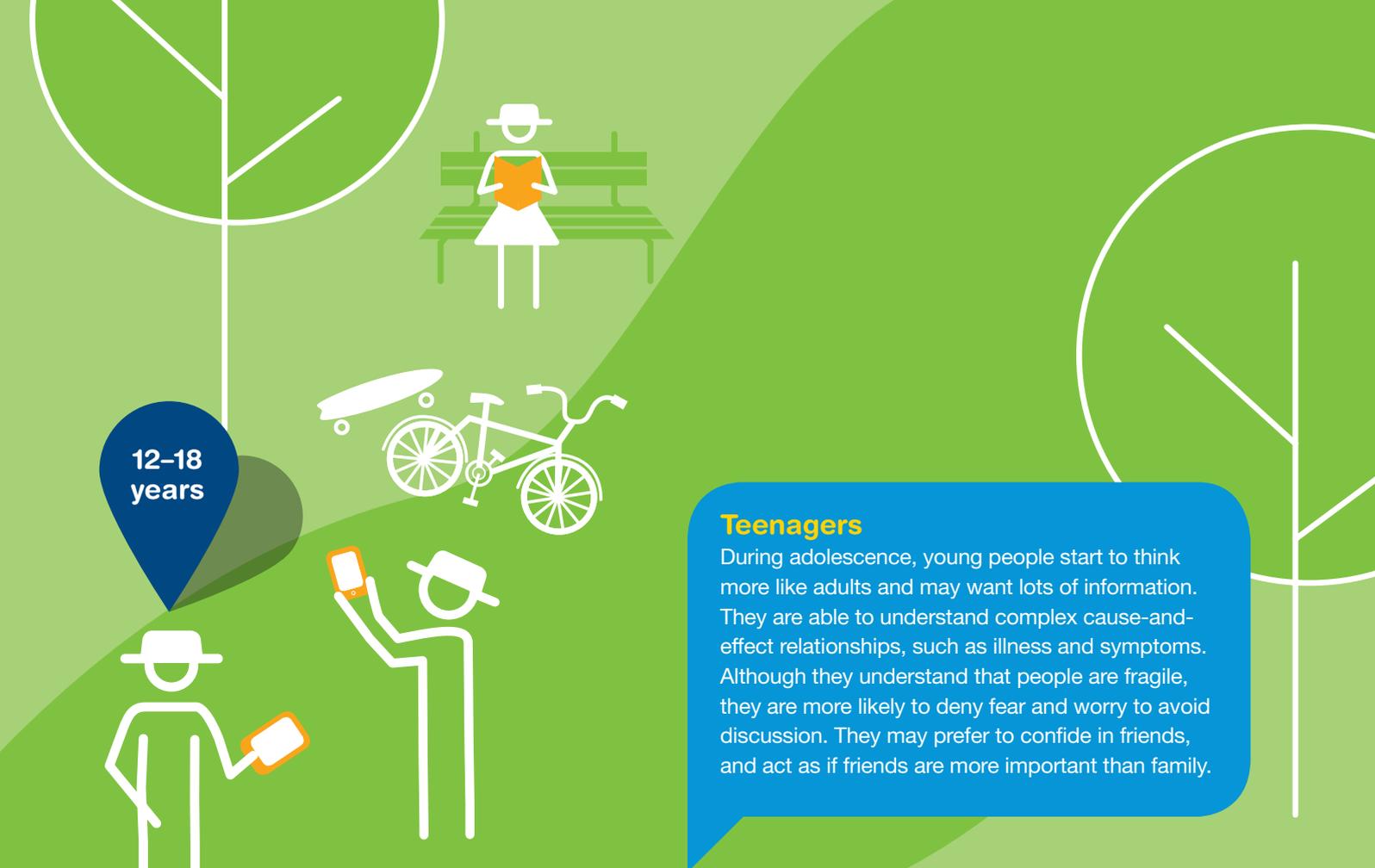
During the primary school years, children become ready for basic information about cancer cells. Some children may have heard about cancer, but may not know how it starts. They could fill gaps in their knowledge with simple cause-and-effect logic; for example, they sometimes feel that their bad behaviour might have caused the disease. They may understand that people, including parents, can die.

#### Possible reactions

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

#### Suggested approaches

- be alert to their feelings (expressed through speech or play) and let them know you care
- use books to explain cancer and treatment
- 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 it is not contagious
- reassure them about their care and schedule and tell them that it's okay to have fun
- let them know that their other parent and relatives are healthy
- give them age-appropriate tasks to do around the house
- tell them that you won't keep secrets and will always tell them what is happening
- help them understand that what their schoolmates say may not always be right – encourage them to check with you
- discuss the issue of dying if your kids bring up the topic
- see also ideas for preschoolers (page 9)



12-18  
years

### Teenagers

During adolescence, young people start to think more like adults and may want lots of information. They are able to understand complex cause-and-effect relationships, such as illness and symptoms. Although they understand that people are fragile, they are more likely to deny fear and worry to avoid discussion. They may prefer to confide in friends, and act as if friends are more important than family.

#### Possible reactions

- wanting to be more independent and treated like an adult
- regression – wanting more nurturing, becoming very insecure and dependent on parents, or lapsing into previous behaviours, such as watching children’s TV shows
- critical view of how adults react to or handle the situation
- depression or anxiety
- worry about being different
- anger and rebellion
- poor judgement and risk-taking behaviour (e.g. binge drinking, smoking, staying out late, unsafe sex)
- withdrawal
- apathy
- physical symptoms from stress (e.g. stomach-aches, headaches)
- more likely to turn feelings inward, which means adults are less likely to see reactions
- worry that they will also get cancer, particularly if they’re a daughter of a woman with breast cancer

#### Suggested approaches

- notice any differences in their behaviour and ask them about it – this can open the door to a conversation about their concerns
- encourage them to talk about their feelings, 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
- talk about role changes in the family
- provide privacy as needed
- encourage them to maintain activities and friendships; talk about finding a balance between going out and staying at home
- set appropriate limits
- provide opportunities for counselling
- don’t rely on them to take on too many extra responsibilities
- provide resources for learning more about cancer and getting support
- let them know that you don’t always want to talk about cancer – you still want to chat about things like homework, sport and friends
- see also ideas for younger children (opposite)



# Talking about the **diagnosis**

When you first learn of a cancer diagnosis, you may feel shocked and overwhelmed. Among the many decisions facing you will be when, where and how to talk to the children and young people in your life. However you decide to approach the conversation, remember to leave kids with feelings of hope that even though you or they may be upset now, there will be better times.



## When should I tell my children?

You might be 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 all the facts.

It may be hard for you to decide how much information to reveal, particularly if you are waiting on test results. However, keeping a secret can be stressful, and your children will probably sense that something is wrong.

Try to tell the kids as soon as you feel able. If you don't know how serious things are or what treatment is required, say so. Assure your children that as soon as you know more details you will tell them. For example, "Daddy is in hospital to have some tests. We're not sure yet what's wrong, but when we do know we will tell you."

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 observe changes in your child's behaviour.

It can be helpful to approach the conversation as a process and not a single chat. Imagine opening the door to conversation and questions, rather than having all the answers. This lets children and young people know that the topic is open for discussion.

## Where should I tell my children?

You will know the best place and time for your children to hear important family news. Try to find some time when you won't be interrupted or have to rush off without answering questions.

It can be intimidating to sit the family down for a formal discussion. Many people find that bringing up the subject casually while doing something else – like walking the dog or washing dishes – can help reduce the tension.

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 most likely to listen and take it in.

### 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.

- Don't attempt the conversation while you're in shock and feeling overwhelmed by your own feelings.
- Talk to a few trusted adults beforehand – this will allow you to articulate your own feelings and start getting used to the news yourself.
- Write 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. They may need to know different things because of their age or developmental stage. However, if you do 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?

Choosing the person who tells is another thing to consider. In general, it is easier if the information comes from someone who is close to your child. Ideally, that will be the parent who has cancer, or the other parent or both of you together. However, this is not always possible. An adult familiar to your child, such as a grandparent, aunt or uncle, or friend may be able to tell your kids or be there when you tell them. This may be particularly important if you are a single parent. You may also decide to break the news with the support of a doctor, nurse or social worker.

## How should 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 consider how to approach the subject. 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 plan what to say and you think you know how your kids will respond, be prepared to answer 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 bring the conversation to a close. You might want to plan an activity, such as playing a game or going to the park, to help your children settle again. Also plan to let them know that they can take some time to think about things and talk more about it later that day, or at any stage in the future as they develop 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 have many conversations ahead of you, and your children are unlikely to be affected by one discussion that doesn't go exactly to plan.

## What should I tell my children?

The following checklist is a guide to the kinds of information you might discuss in your initial conversations about cancer. The suggestions on pages 21–23 can help you tailor the information according to the ages and reactions of your children.

### 1. 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) or read books about cancer written for children (see page 61). Camp Quality has developed the *Kids' Guide to Cancer* app for children aged 8–13 to help answer their questions about cancer (see page 17).

Try not to overwhelm children with too much information. You can always give them more detailed information later if they are interested.

### 2. Find out what they already know

Ask your children what they know about cancer and then deal with any misinformation or myths (e.g. they might think that you can catch cancer, or that their naughty behaviour caused the 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.

Don't assume children will have the same fears as you. Ask them what they want to know, and only answer questions that they ask.

Give small bits of information at a time. You may need to keep repeating the information to ensure they understand what you have told them. Accept that they may ask the same question several times.

**“ 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

### 3. 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.

### 4. Tell them what to expect

Your children may 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 there will be a plan and that you will let them know about it.

### 5. Ask them if they want to tell anyone

Your children may also want to tell their friends, all the teachers, the whole class – or nobody else.

Explain that there will be a few people you will need to tell, such as their main teacher, the student wellbeing coordinator and the school principal. You might also want to mention other key figures in their life, such as a music tutor or sports coach. Discuss the best way to handle these conversations. See pages 26–27 for information about talking to the school.

## Coping with kids' reactions

**Crying** – If your children cry, let them know it's okay to do so and it's a natural reaction. Holding them will help them feel secure.

**Fear** – Some children will become fearful and worry endlessly. It can be hurtful if they start to fear the person who has cancer. Explain that the person with cancer is still the same person, despite having bad cells in their body and possibly

looking a bit different. Try to connect this to changes the child can relate to – a sick pet that got better or a tree that changes colour during the year.

Children may also fear 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.



## 6. Balance hope with reality

Tell kids that although cancer can be serious and going through treatment can be hard, most people get better. Explain that with the expert support of the doctors and treatment teams, you (or the person with cancer) are going to do everything possible to get well.

## 7. Offer a listening ear

Your children may say very little and not ask questions when you first tell them. Some kids need time to absorb the information, but it doesn't mean they don't understand. Let them know they can come back to you at any time with questions, worries and scary feelings.

## 8. Don't make promises you can't keep

If there's a chance you can't keep a promise, it's best not to make it. Rather than saying, "I'll definitely be at the swimming carnival", say something like, "I hope I can come to the carnival, but if I can't, it'll be great to see the photos. Maybe we can get someone to film your races."

## 9. Show your love and emotion

Tell your children that you love them, and assure them they will always be looked after. Express your love by hugging them, comforting them and making them feel valuable.

Try not to overwhelm or frighten children by your reactions, but it's alright to cry; this gives kids the message that it's okay to show feelings. Being honest with each other about fears and feelings can positively affect your relationship with your children and help your children's wellbeing and ability to cope.

**Anger** – It is natural for children to feel angry about the diagnosis as it means their lives could be disrupted. Older children may seem angry and uncooperative if asked to help out more. Younger children may be annoyed if asked to play quietly. Both may be upset if a planned outing 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 courage to talk. A lack of reaction isn't unusual – often the children are protecting themselves and need some time to digest the information. 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 told them.

## 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. Visit [campquality.org.au](http://campquality.org.au) or call **1300 662 267**.

## CanTeen

CanTeen helps young people aged 12–24 who have been affected by cancer. There are four membership categories: patient, offspring, sibling and bereaved. Counselling is offered in person or by phone, email or instant messaging. CanTeen's workshops, recreation days, camps and online forums also help young people cope with the impacts of cancer. To find out more about CanTeen, visit [canteen.org.au](http://canteen.org.au) or call **1800 226 833**.

## When another child has cancer

Your child may have a friend or cousin who has been diagnosed with cancer. While children often have some exposure to 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. Although cancer is a serious, life-threatening illness, the overall survival rate for children is now more than 80%.<sup>2</sup> This can vary depending on the diagnosis, but most children will survive cancer.

**Things will change** – Explain that things will change for the friend. They may not have as much energy to play or may be away from school a lot. They may have physical changes (e.g. hair loss, wheelchair). Ask your child to focus on what hasn't changed – their friend's personality and their friendship.

**Maintain the relationship** – Give your child the opportunity to maintain their friendship with the child with cancer. They may not see each other as often and might not interact in the same way, but both children will benefit.

**Visit the hospital** – Take your child to visit their friend in hospital if you can. It is confusing and daunting for your child if the person with cancer disappears from their life after diagnosis. They may imagine the worst.

**Keep in touch** – Help your child keep in contact with their friend. You could make a get well card, write a letter, make a decoration for their hospital room or design a board game. Older children may prefer to communicate by phone, email or social media.

**Encourage feelings** – Allow your child the opportunity to have fears and grieve. They need to feel that they can approach you when they want to discuss what they're going through.



## When a sibling has cancer

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

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.

You can help your child 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 child 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 their role is** – Explain that they have a role to play in supporting 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, their siblings are still kids and their needs 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 & 14

## If your child is diagnosed

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

Although this book concentrates on 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 provide will depend on the age, maturity and attitude of your child. Keep your initial explanations simple and take your cue from the child as to whether they want to know more. Remember that the first conversation will be followed by many others, so you will have the opportunity to give more detail as the need arises.

The clinical nurse consultant and social worker at your child's hospital will be able to provide further guidance and assist you with these discussions. Some hospitals also have child life therapists who teach children strategies to manage their illness and can help you explain the cancer and the treatment.

**“ We let Leo lead the way with what he wanted to know, and over time he wanted to know everything. Being sick is so disempowering. He really wanted to see the treatment flow chart so he could say, ‘This is where we are now.’ ”**

*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. If you have an older child with cancer, make contact 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 [youthcancer.com.au](http://youthcancer.com.au) for more information.

As much as possible, include your child in discussions about their treatment and recovery. Older children and teenagers may want to seek out information themselves. You can point them in the direction of reliable, age-appropriate resources such as CanTeen's information at [canteen.org.au](http://canteen.org.au). Redkite also offers support to young people with cancer and their families – visit [redkite.org.au](http://redkite.org.au) or call 1800 REDKITE (1800 733 548) to find out more.

# What words should I use?

It's often hard to find the right words to start or continue a conversation. The suggestions on the next two pages may help you work out what you want to say. Although these are colour-coded by age, 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.



## Newborns, infants and toddlers, 0–3 years

Obviously babies don't need explanations, but they do need physical reassurance. The older toddlers get, the more they understand basic ideas about themselves and their family.

## Young schoolchildren, 6–10 years

Young school-aged children can understand basic explanations about illness and family routines. They need regular reassurance so they continue to feel loved, safe and cared for.



## Preschoolers, 3–6 years

Preschool children are ready to understand very basic explanations about many things, including illness, family routines, and cause and effect. They will want to know how the cancer relates to them.

## Older children and teenagers, 10–18 years

In upper primary and high school, children have a more complex understanding of illness and issues affecting them and their families. Teenagers are starting to think more like adults. Explanations about the cancer can be more detailed. Children of this age need reassurance about their own wellbeing, and also about the person with cancer.



## 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. It means some lumps are growing inside my body that shouldn't be there, and they're making me sick. I am going to have an operation in hospital to have the lumps taken out. Then I'll have some more medicine to make sure they don't grow back.”

“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.”

“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.”

“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 beating it.”

## To address misunderstanding

“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.”

“Cancer is a disease of the body that can be in different places for different people.”

“Even though your friends at school 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.”

## Words for different ages

-  Newborns, infants and toddlers
-  Preschoolers
-  Young schoolchildren
-  Older children and teenagers

“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 is not hereditary (it doesn’t run in families).”

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

## To explain change and reassure

“Mummy has to stay in bed a lot and isn’t able to play, but she still loves you.”

“Daddy and Mummy need to go away for a couple of nights, so Grandma is going to come and stay at home with you.”

“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.”

“You don’t have to tell your friends about me having cancer if you don’t want to, but I would like to let your teachers know so they understand what’s happening at home.”

“Mummy needs to go to the hospital every day for a few weeks, so Daddy will be taking you to preschool/school instead. He’s looking forward to doing that.”

“Pop is sick so we won’t see him for a while, but he loves you very much.”

“I love your pictures, so maybe you can draw me some to take to hospital.”

“Things will be different at home when Dad’s having treatment, but we’ll be able to visit him at the hospital.”

“After my operation, there are a few things I won’t be able to do for a while, like lifting things and driving. So you’ll all have to pitch in at home, and Dad will leave work early to take you to your after-school activities.”

“Whatever happens, you will always be cared for. We will tell you what’s going on as soon as we are told.”

“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 on our holiday?"

Try to explore the question by asking, "Do you have something in particular you're worried about?" or "What were you thinking about?" Some children think that cancer is a death sentence, so it's good to explain that many people are cured through surgery and medicine, and that new treatments are being found all the time.

- A.** "Some people do die from the type of cancer I have, but I'm going to do everything that my doctor suggests to get better."

"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 are to blame for 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 is contagious. This belief may be reinforced because when patients have chemotherapy they need to avoid contact with other 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 be close to 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 a problem arises in the family, it's important for children to know what will happen to them and 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 there may be times when I 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 how the school can help and then chat about the best way to approach the school.

**A.** "You can tell your friends if you want to, but you don't have to. Many people find it helps to talk about the things that are on their mind."

"What comes into your mind when you think about talking to other people about cancer?"

"It's important that the school knows what's happening, but we can talk about who we should tell and how much we should say."

### Q. Is there anything I can do to help?

Answering this question can be a delicate balance. It's great to allow the kids to contribute, 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*

## Involving others

You don't have to tackle the task of talking to children about cancer on your own. There are many ways to lessen the burden and 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 58).

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

## Involving the school or preschool

Many parents or carers wonder if they should tell the school. If things are tough 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.

Here are some ways to involve the school that you may like to consider:

- Tell the principal, the school counsellor and your child's teachers. They may know of other people in the school community who have or have had cancer and this may affect your child's perception of the illness (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 they can respond consistently.
- Ask the school to keep an eye on your child and 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, talk to the principal about your child seeing 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 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 the Camp Quality Education Program to visit. Camp Quality has developed an educational puppet show to help children learn about cancer in a safe, age-appropriate way. For more details, visit [campquality.org.au](http://campquality.org.au).
- Explore what special provisions might be available for exams or admission into university.

### Key points

- Talk through your issues 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.
- Finish the conversation with feelings of hope.

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 another family member has cancer. If your child has cancer, you might also be interested in *What about school? A resource for parents of children, adolescents and young adults with cancer*, which is produced by Ronald McDonald Learning Program – visit [learningprogram.rmhc.org.au](http://learningprogram.rmhc.org.au) or call 1300 307 642.

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

*Mira, mother of two children aged 3 and 12*



3

# Talking about **treatment**

Cancer treatment can be challenging for the whole family, but children 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.



## Understanding treatment

It can help to understand the treatments and their 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). 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.

## What do children need to know?

### The treatment plan

Children often need age-appropriate information to prepare them for what is happening to the person with cancer. An understanding of the treatment, why and how it is done, and the side effects, if any, can help them cope.

- 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 radiotherapy is?” Then explain the basic facts using language they can understand (see the glossary on pages 62–64).
- Check if your kids have any questions, and make it clear that they can come back to you throughout the treatment period if they have other queries or concerns, or are feeling overloaded after your first discussion.
- Keep them up to date with how long treatment will take and how long you might be in hospital. Let them know that some treatments can take a few months, and the doctors will then decide whether the treatment can stop or if more treatment is needed.
- Explain who will be taking care of the person with cancer and the different ways they will help.

### How it will affect them

Routines can help children feel safe and secure. If you have to change a normal routine during treatment, tell them 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. Tell them where you'll be, such as at the hospital or resting at home, and that it's okay to ask who will be doing the cooking or giving them lifts.

## Explaining 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.

- 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.



### 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

- Tell your children what side effects to expect, based on what the doctor has said. 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.
- Let them know that the doctors will try to make sure treatment causes as few side effects as possible. After the treatment is over, a person's weight and hair will probably go back to what it was before.
- 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 cancer has progressed. Explain to them that the side effects are separate to the cancer symptoms. If there are no side effects, let them know that this doesn't mean the treatment is not working.
- 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.

## 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). 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, it can be worse if kids are separated from you and can't picture where you are.

“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



Ask your kids if they want to go to the hospital or treatment centre. If they would prefer not to, don't force the issue. If they are keen to visit, have a plan to help the visit go smoothly.

- Hospitals can seem strange and confronting for children and adults alike. Before children enter the hospital room, tell them what they may notice: the equipment, different smells and noises (e.g. buzzers, beeps), how the patients may look (e.g. tubes, bandages, drip, catheter bag full of urine hanging on the side of the bed), that 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 see some of the equipment in another room before going in the room for their visit.
- 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. It is common for small children to 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 go.
- 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 keeping connected with your kids.
- If you are staying in hospital for a while, 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.
- 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 and the children taking it in turns to draw the head, middle and legs of a character
- charades
- shared imaginary play with plastic animals, dolls or cars
- using your laptop or tablet to watch a favourite movie or program together
- simple craft.

# 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 to explain cancer treatment and to explore feelings. You can adapt these suggestions for different ages and interests.

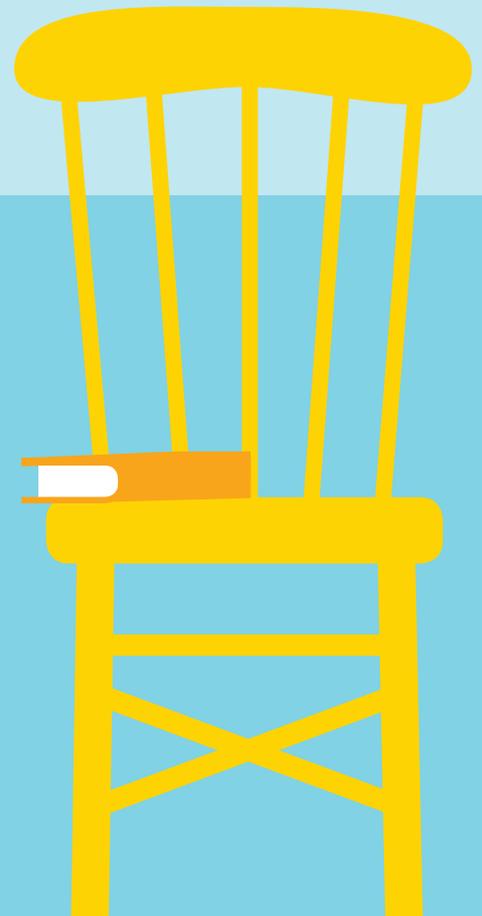
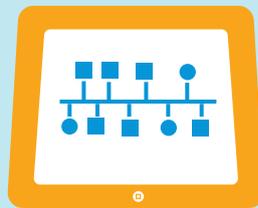


## Offer them a tour

Before treatment starts, you may be able to take your children for a tour of the treatment centre or hospital ward. Check with staff whether this can be arranged. This experience will mean your children get a clearer idea about what happens during treatment, they can picture where the person with cancer will be, and they can 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 the treatment, you can look at the chart together and see where you are up to and how far you have come.

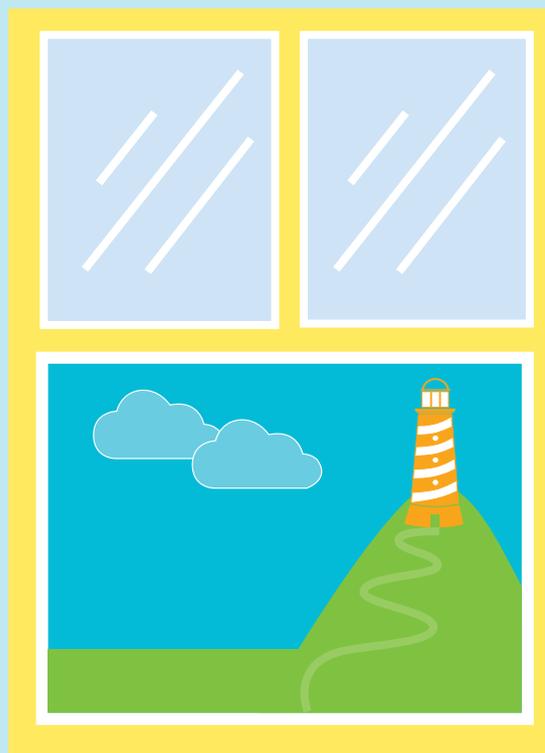


## Keep a journal

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.

### Tap into stories that kids love

Think of the good and bad forces in the Harry Potter series or *Dr Who*. 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).

### Make up stories and play games

Try explaining cancer treatment using stories or dolls, or by playing games. You could make up a story about the battle of the good cells and the bad cells, using surgery, radiotherapy, chemotherapy and other treatments as the weapons.



### Draw out feelings

Art is another 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?

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.

**A.** "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 radiotherapy make you radioactive?

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

**A.** "Radiotherapy 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 comprehend 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 talk to your family several times as things change. Update children regularly 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

Many parents are keen to keep life as normal as possible for their kids during treatment. But this can be difficult to do when you are coping with the changes cancer brings, such as changes to your appearance or to your energy levels. You may feel guilty about not being able to do all the usual things with your kids and you may try to push yourself to keep going, but some days you may not feel up to doing anything at all.

There are no easy answers to this problem, but you can make the best of your good days by forgetting the housework and doing fun things with the family. On the not-so-good days, if you can't take part in the kids' activities, you might be able to watch and cheer from the sidelines. On the days when you can't cope with much, 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. Even on days when you don't feel well, they may seem to be concerned only with how it affects them. You may find this reaction hurtful or frustrating, but it is normal and age-appropriate. It can be helpful to acknowledge your child's disappointment: "You're frustrated we can't go to the park today because I don't have the energy. I'm frustrated too because that's something I'd really like to do with you, and I'm sad that I'm just not well enough for us to do that together right now."

Children may be curious about body changes and ask some matter-of-fact questions. It will help to explain why you look or feel the way you do. If you are happy to talk about the changes, your kids are more likely to accept them.



### 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

It is important to let your children know that it is alright to joke and have fun. Laughter can often relieve tension and help everyone relax.

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.

### The emotional impact

Children's responses during treatment are as varied as children themselves. Anger, crying and emotional outbursts are some of the possible and normal reactions. These can be protective responses that allow a child time to deal with the information.

When kids don't know how to cope, their fears can be channelled into anger because it is a familiar response. An angry outburst can be a chance to find out what's going on – try not to shut down their response by getting angry yourself, but remind them that they can talk to you anytime about it. If the situation or their behaviour changes, you may need to talk again to check whether your child has any new questions or worries.

If your kids' reactions seem unusual or extreme, think about getting some expert advice (see pages 56–57). However, some children will choose not to let their feelings show because they do not want to add any more stress for their parents. Even if your child does not show outward signs or behaviours that indicate they are struggling, take the time to check in with them and acknowledge how hard this situation is for them.

**“ I made sure the kids knew it was okay to feel different feelings, to be angry or upset. But also that it was okay to laugh if something was funny – two years is a really long time not to laugh. ”**

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

## Managing emotions

Like adults, children are likely to feel a range of strong emotions when someone important to them has cancer. You can help them to understand and manage these emotions.

- Encourage kids to identify and name feelings. 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.
- Discuss ways to manage anxiety and stress.
- Make sure they have ample opportunities for physical activity.
- Provide plenty of physical comfort, such as hugs and cuddles.
- Offer creative outlets for children to express their emotions. They may like to write a story, play a game with dolls, draw or paint a picture, or make up some music using simple instruments.
- Create everyday opportunities for humour and fun.

### The emotions thermometer

The physical and emotional health of a person with cancer will fluctuate during and after cancer 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 the fridge or noticeboard.



## Finding a balance

It's important to try to maintain routines and family traditions as much as possible. Sometimes you have to strike a balance between doing regular activities and coping with the effects of the cancer. If you or your partner can't get your children to their after-school activities, maybe a friend or relative can 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.

Your children's activities and friends can help them to cope. Encouraging a child to excel at their favourite activity can help their sense of optimism about life in general. When a child's world is upside down, stability and routine often help them feel less anxious.

During treatment, when life may be disrupted and unsettled, try to protect the time your family has together. These tips may help:

- Limit visitors and don't answer the phone or mobiles 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.
- Put a message on the phone saying how you're doing and asking callers to ring a designated family member or friend for more information.
- Organise times for the kids to show you their achievements of the week.
- 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.

## One-on-one play sessions

When a family member is diagnosed with cancer, it can be difficult for parents to spend individual time with their children. One way to focus your attention, care and interest is to hold a 30-minute play session once a week for your child.

**“ There are good weeks and bad weeks, and when the good ones come, it is time for everyone to enjoy them with special occasions. ”**

*Martin, father of three children aged 2, 4 and 6*



If you have more than one child, you may need to alternate weeks depending on your energy levels. Teenagers may prefer a special time set aside to visit a favourite cafe or go for a walk, although some may still enjoy a session spent drawing or painting or playing games together.

These play sessions should be a special time for just you and your child in a room at home that is private. This is a chance for you to be fully present with your child. They may play on their own or invite you into their play.

A child may not yet have developed the thinking or language skills to fully describe their experience with words. Play can help the child to express feelings, make sense of events, and understand the world. Children use toys as their words, and play as their language. If you find it difficult to know how your child is feeling, they may show you through their play.

A child may express their feelings through various kinds of play, including:

- acting out a story with toys
- using fantasy and dress-up
- role-play
- drawing or painting
- using puppets
- using clay
- playing games
- talking about their experience.

During a play session, try to respond with statements of empathy or observation, which help to convey that you are fully there with your child and interested in what they are doing, saying and feeling. Avoid asking questions or correcting your child. This time is for them to lead the way. When children participate in play sessions, they feel important, valued and understood. They will often express an inner world through play that you may never have known about from their verbal communication.

A few simple guidelines can encourage an effective play session:

- Choose a private location in the house where there will be no disturbance.
- Put a sign on the door saying “Do Not Disturb – Sarah’s Special Time”.
- Arrange the toys in the same layout each time around the perimeter of a blanket or carpet.
- Tell your child when they have five minutes left.
- Set limits when necessary.
- Have fun! Children and parents report they both really value spending this special time together.

## 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 & 18



## Helping around the house

The internet is a good source of information about appropriate jobs around the house for children of all ages.

Try searching for 'age-appropriate chores'.

Some possibilities include:

### Ages 2–4

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

### Ages 4–8

- set table
- match socks
- help make 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

## 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.
- Agree on a set 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 a letter addressed to them in the mailbox.
- Send an email or recorded message.
- Leave notes and surprises for kids to find, such as a note in a lunchbox.
- Engage 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.

## Allowing children to help

Most children will want to help at home during treatment. If your children feel they are being helpful, it can increase their confidence and self-esteem because it shows that you trust, value and need them. Even quite young children can help.

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 allocate tasks fairly among all members of the family. Jobs that are obvious to you are not necessarily obvious to them, so make a point of discussing what needs to be done and how tasks can be divided up.

Keep in mind that it is important for teenagers to keep up at least some of their normal social activities. Losing the chance to socialise with their peers can make them feel resentful at a difficult time and can affect 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. Call on 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 Young Carers by calling 1800 242 636 or visiting [youngcarers.net.au](http://youngcarers.net.au). This organisation runs camps, 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 younger 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 17).

### Maintaining discipline

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

Keeping up children's chores, promoting good study habits, calling out inappropriate behaviours, sticking to regular bedtimes, and other areas of potential conflict 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 of caring for someone with cancer. Some parents say they feel bad for putting the family through the stress of cancer, so they don't want to keep pushing the 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 maintain your family's boundaries and keep to them 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.

### Key points

- Explain cancer 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 it 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.
- Let all children help out around the house.
- Maintain limits as much as possible.
- Realise that children and adults alike may become emotional or overreact occasionally.
- Reassure your family if you expect there to be better days ahead.
- Enjoy time just with the family.

“ I took on the role of Mum's carer. I had to learn how to iron, cook, wash clothes, vacuum. It was a lot of effort, but it has made me more determined and stronger. ”

*Emma, aged 15*



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'.

## A new normal

Many people say that cancer changes them. Normal life may have been put on hold during treatment, but now that treatment has finished, they find that they can't or don't want to go back to how life was before. With more time and energy to think, they feel they need to reflect on what's happened and re-evaluate their life. It may take months or years to establish a new normal. It is important to continue communicating with your family throughout this period as you all adjust. The person who has completed cancer treatment may:

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

**Continue to feel the physical impact** – The physical effects of cancer can 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, lymphoedema, 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 around you, 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 make adjustments 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.

**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. You may need to reassure your children that regular check-ups will help monitor the cancer.



### 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 & 14

## Family life after treatment

Celebrate the end of the cancer treatment, and thank your kids for their contribution to your recovery. Acknowledge the sacrifices your family has had to make; 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 about your emotional and physical state so they understand if you're not bouncing back as quickly as they expected. Keep using the emotions thermometer if you have one (see page 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 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. You may be able to incorporate lifestyle changes that help your recovery 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 keep looking after your own wellbeing. These strategies can help:

- Consider joining a support group. Many cancer survivors join a support group to meet people who understand what they have been through and how they're feeling. This can be an important outlet, which will 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, 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.



## 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 me. I will need to have check-ups every now and then. If the cancer does come back, we'll let you know."

### 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 mum or dad 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?

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

### 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 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.



5

# When cancer **won't go away**

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 use the bereavement services listed in the box on page 51.



## Coping with advanced cancer

If you are told that the cancer is advanced, you suddenly confront challenging emotional issues and the possibility of death. You might feel strong emotions, such as fear, anxiety, sadness, anger, guilt, loneliness or denial.

Many people with cancer that has come back say that the news was more devastating than the original diagnosis. Anxiety and depression are common and it can be harder to cope emotionally. You may be worried about the impact of the cancer on your family.

Some people avoid acknowledging the fact that they have advanced cancer because they don't know what to say or they want to avoid upsetting their family and friends. However, people who express their emotions and communicate openly may find it easier to cope. It can also help their family and friends to come to terms with the prognosis.

For some people, faith and spiritual beliefs can help them get through tough times. For others, cancer can test their beliefs. In either case, you may find it helpful to talk to a spiritual adviser.

## How children react

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.

How you react to a diagnosis of advanced cancer can affect how the whole family adjusts. 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 there is a lack of communication.

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 may be overlooked. They also need to be given the opportunity to see their ill parent, to ask questions, to prepare for the loss, and to say goodbye.

### The role of hope

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. 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.



### 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 should I tell my children?

Preparing children for the loss of a family member is an incredibly hard thing to do. The following guide may help you with the initial conversation.

### 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 as you can. 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 unresolved issues. The chance to talk through old arguments and make amends seems to be particularly important for older children.

### 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 the facing page for some examples of how to explain these concepts.

### Tell them what to expect

Prepare children by explaining how the illness might affect the person in the days ahead. For example, they might be sleepy or need a lot of medicine.

### Wait for your child to ask

Give brief answers to questions they ask. It usually doesn't help to offer lots of explanations if your child isn't ready to hear them.

### Balance hope with reality

Parents worry that if they talk about death they take away their children's hope. You can still be honest and offer hope. Tell your kids how the person with cancer is being cared for – the treatment they're having, what the doctors say, and the types of support that can be put in place to make things easier for the family.

# 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 pages 50–51 for tips on how to answer specific questions.

## When advanced cancer is diagnosed

“Some people with this sort of cancer get better, but some don’t. I am going to do everything I can to get better.”

“Some people with this sort of cancer recover, but most 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.”

## When end of life is near

“When Grandma died, her body stopped working – she stopped breathing and her heart stopped beating. A dead body can’t move or talk and it can’t feel anything. It also can’t come back to life. We won’t be able to see Grandma again, but we will always know she loved us.”

“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.”



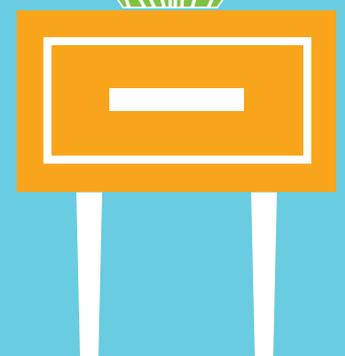
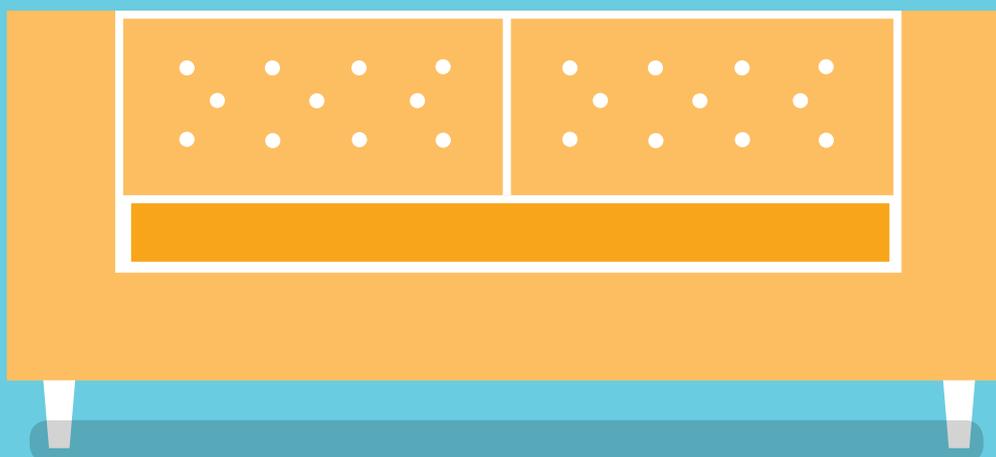
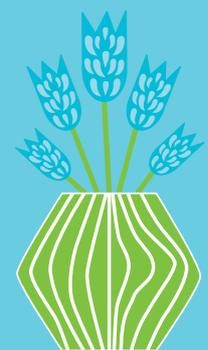
“The doctors say that the treatments haven’t worked for Dad. There isn’t anything else they can do. We think that means Dad will die soon. We want to make the most of the time he has left.”

### Words for different ages

-  Younger children
-  Older children

## To explain death

“I have some very sad news. Grandma died last night ... Is there anything you’d like to know about how Grandma died?”





## 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."

### 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. Most people die when they're old and their bodies get worn out. It's very unusual and sad for someone young like you to be so ill that the doctors can't make them better."

### Q. What happens to people when they die?

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 more 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**  
[www.grief.org.au](http://www.grief.org.au)

**GriefLine**  
**1300 845 745**  
[griefline.org.au](http://griefline.org.au)

**CanTeen**  
**1800 226 833**  
[canteen.org.au](http://canteen.org.au)

**Redkite**  
**1800 733 548**  
[redkite.org.au](http://redkite.org.au)

# Different views of death

In preparing children for the loss of a parent or another significant person, it can help if you understand how death is perceived at different ages. Do not underestimate the impact of a bereavement, even if the child is very young or does not seem sad. Their 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

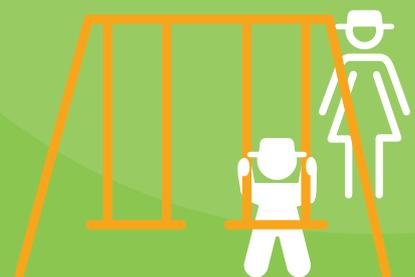
### Suggested approaches

- 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

## 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.

3-6 years



### 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



6-12 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

### 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. Teenagers are often more distressed when their parent is ill than 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

12-18 years





### 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.

## 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.

## Being together

When cancer is advanced and life is even more uncertain, many families find new ways to make the most of every minute. 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 child wants to say. Allow your child to express any regrets that they have.



6

# Further 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.



### Distress signals

A young person should be referred to professional help if they:

- say they want to die too
- are extremely preoccupied with dying
- suffer academically or at work for an extended period
- act sad and withdrawn, or demonstrate severe behaviour like self-harm
- have trouble socialising
- simply need someone to talk to.

## Getting professional help

Many professionals and organisations can help you to 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.

### Who can help?

A range of professionals may be able to help you if you are concerned about your child:

**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 constant contact you have with the treatment centre and are a source of valuable information and support

**Social workers** – talk to patients every day about communication issues and have a wealth of knowledge about services

**Psychologists and counsellors** – can help you with communication and behavioural issues (call Cancer Council 13 11 20 for more information)

**School counsellors** – are trained in child development and can be an enormous 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).

### When does your child need a professional?

A parent's instincts about their children are usually pretty accurate. If you feel concerned about how your child is coping, it is a good sign that it is worth seeing a professional. Some families tolerate and deal with behaviour that other families find unacceptable. You need to decide what is worrying behaviour in the context of your own family and the particular child.



If your child's behaviour has changed (e.g. aggressive or regressive behaviour) and the change persists, it may be worth seeking advice. It's not unusual for a child to revert to less mature ways of coping, such as wetting the bed. A few times is okay, but if it goes on every night for a month, the child is clearly struggling. Another example is when a child refuses to go to school. They may say they are too sick for school, but actually have separation anxiety and think they have to stay home to look after Mum. An occasional reluctance to go to school is not unusual, but if it becomes a pattern, it can be a warning sign.

Other warning signs include a persistent change in eating habits, noticeable concentration challenges (dropping grades), a significant increase in time spent online, altered sleeping patterns, increased risk-taking behaviours, and a lack of engagement with friends. If an adult notices such changes, especially if there are multiple changes, it would be worth seeking professional advice.

Teachers and other school staff can be among the first people to notice that something is troubling a young person. Because they see children five days a week for many weeks in a row, they are well placed to observe behaviour, concentration levels, grades, eating habits and engagement with peers. This is one of the reasons it is so important 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.

## Practical and financial help

A serious illness often causes practical and financial problems. Many services are available to help you deal with these difficulties:

**Financial or legal assistance** – Government benefits and pensions and community programs may help pay for prescription medicines, transport to medical appointments, utility bills or basic legal advice.

**Home nursing care** – Community nursing services or local palliative care services may be able to provide nursing at home.

**Help at home** – Meals on Wheels, home care services, aids and appliances can be arranged to help make life easier at home.

**Subsidised travel and accommodation** – If you need to travel long distances for treatment, you may be able to get help with transport and accommodation costs.

### If you feel overwhelmed

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

- Family and friends are usually keen to help. Let them know what you need – they will probably be relieved that you can ask for help and give them something to do.
- Practical assistance and information from Cancer Council and other organisations can help ease your worries (see details at left and on the next page).
- Manage stress by using complementary therapies, such as massage, hypnotherapy or relaxation techniques.
- CanTeen, Camp Quality and Redkite have 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 contact details.



## Related publications

You might also find the following free Cancer Council publications and resources\* useful:

- *Cancer in the School Community: A guide for staff members*
- *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*

Call Cancer Council **13 11 20** for copies, or download them from your local Cancer Council website (see back cover).

\* May not be available in all states and territories.

**Carers groups** – Carers Australia and the Carers Associations in each state and territory can provide information, referrals, counselling and support for people who are caring for someone with cancer. They also run Young Carers to support kids who are caring for a parent. Call 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au) or [youngcarers.net.au](http://youngcarers.net.au).

To find out which services are available in your area and whether you are eligible to receive them, call Cancer Council 13 11 20 or speak to your hospital social worker, occupational therapist or physiotherapist.

## Cancer Council services

Cancer Council offers a range of services to support people affected by cancer, as well as their families and friends.

**Cancer Council 13 11 20** – This is many people's first point of contact if they have a cancer-related question. Trained professionals will answer any questions you have about the situation in your family. For more information, see the inside back cover.

**Practical help** – Your local Cancer Council can help you access services or offer advice to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation or legal and financial support. Call 13 11 20 to find out what is available in your state or territory.

**Support services** – You might find it helpful to share experiences with other people affected by cancer. For some people, this means joining a support group. Others prefer to talk to a trained volunteer who has had a similar cancer experience. Cancer Council can link people with others by phone, in person or online at [cancerconnections.com.au](http://cancerconnections.com.au). Call us to find out what services are available in your area.

**Life after cancer** – It's natural to feel a bit lost after finishing treatment. You might notice every ache or pain and worry that the cancer is coming back. Cancer Council can provide support and information to people adjusting to life after cancer – call 13 11 20 for details.

**Printed, online and audiovisual resources** – Cancer Council produces easy-to-read booklets and fact sheets on more than 20 types of cancer, as well as treatment, emotional issues and recovery. All publications are developed in consultation with health professionals and consumers, and content is reviewed regularly.

## Support and information directory

### Support services

|   |   |
|---|---|
| <p><b>Camp Quality</b><br/>provides services to build optimism and resilience in children aged 0–13 who are living with cancer themselves or have a sibling or parent with cancer</p> | <p><b>1300 662 267</b><br/><a href="http://campquality.org.au">campquality.org.au</a></p>                   |
| <p><b>Cancer Council</b><br/>provides a wide range of support and information services for people affected by cancer (see opposite)</p>   | <p><b>13 11 20</b><br/>For your local Cancer Council website, see back cover</p>                            |
| <p><b>CanTeen</b><br/>supports young people aged 12–24 living with cancer, children and siblings of people with cancer, and young people bereaved due to a cancer-related death</p>   | <p><b>1800 226 833</b><br/><a href="http://canteen.org.au">canteen.org.au</a></p>                           |
| <p><b>headspace</b><br/>run by the National Youth Mental Health Foundation, provides mental health services to people aged 12–25</p>  | <p><a href="http://headspace.org.au">headspace.org.au</a></p>   |
| <p><b>Kids Helpline</b><br/>offers 24-hour telephone and online counselling for young people aged 5–25</p>  | <p><b>1800 55 1800</b><br/><a href="http://kidshelpline.com.au">kidshelpline.com.au</a></p>                 |
| <p><b>Lifeline</b><br/>offers 24-hour general crisis support</p>  | <p><b>13 11 14</b><br/><a href="http://lifeline.org.au">lifeline.org.au</a></p>                             |
| <p><b>Redkite</b><br/>offers financial, emotional and educational support for children and young people with cancer and their families and networks</p>                               | <p><b>1800 REDKITE</b><br/><b>(1800 733 548)</b><br/><a href="http://redkite.org.au">redkite.org.au</a></p> |
| <p><b>Ronald McDonald Learning Program</b><br/>provides tuition and liaison support for young people whose education has been disrupted by illness</p>                                | <p><b>1300 307 642</b><br/><a href="http://learningprogram.rmhc.org.au">learningprogram.rmhc.org.au</a></p> |
| <p><b>Young Carers</b><br/>runs camps, activities and support groups for kids who care for a parent with a serious illness</p>  | <p><b>1800 242 636</b><br/><a href="http://youngcarers.net.au">youngcarers.net.au</a></p>                   |
| <p><b>youthbeyondblue</b><br/>supports young people dealing with depression, anxiety and other mental health problems</p>   | <p><b>1300 22 4636</b><br/><a href="http://youthbeyondblue.com">youthbeyondblue.com</a></p>                 |
| <p><b>Australian Centre for Grief and Bereavement</b><br/>supports people caring for children and teenagers who have been impacted by trauma and loss</p>                             | <p><b>1800 642 066</b><br/><a href="http://www.grief.org.au">www.grief.org.au</a></p>                       |

## Support and information directory

### Online information

#### Online information for children aged 3–13 years

##### **Bearing Up Club**

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

[bereavementcare.com.au](http://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 – addresses the big questions kids have about cancer

[campquality.org.au](http://campquality.org.au)

#### Online information for teenagers aged 12–18 years

##### **CanTeen**

CanTeen's website for young people aged 12–24 who have been affected by cancer

[canteen.org.au](http://canteen.org.au)

##### **My Parents Cancer**

Cancer Australia's website for young people aged 13–19 whose mother has breast cancer

[myparentscancer.com.au](http://myparentscancer.com.au)

##### **ReachOut.com**

general information about mental health and wellbeing for young people going through difficult times

[reachout.com.au](http://reachout.com.au)

##### **riprap**

UK site for 12–16 year olds who have a parent with cancer

[riprap.org.uk](http://riprap.org.uk)

##### **Stupid Cancer**

US site for 15–39 year olds who are affected by cancer

[stupidcancer.org](http://stupidcancer.org)

#### General online information

##### **Cancer Council**

reliable information about cancer by topic and by type; PDFs and e-books 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](http://canceraustralia.gov.au)

##### **Children's Cancer**

information from Cancer Australia about many aspects of children's cancer

[childrenscancer.canceraustralia.gov.au](http://childrenscancer.canceraustralia.gov.au)

##### **Macmillan Cancer Support**

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

[macmillan.org.uk](http://macmillan.org.uk)

##### **American Cancer Society**

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

[cancer.org](http://cancer.org)

|                           |  |
|---------------------------|--|
| Picture books             | <i>Butterfly Kisses and Wishes on Wings</i><br>Ellen McVicker, S.N., 2006<br><b>butterflykissesbook.com</b>  |
|                           | <i>Nowhere Hair</i><br>Sue Glader, Thousand Words Press, 2010<br><b>nowherehair.com</b>  |
|                           | <i>Safina and the Hat Tree</i><br>Cynthia Hartman, Nomota, 2004<br><b>talesforkids.com.au</b>  |
| Books for younger readers | <i>Because... Someone I Love Has Cancer</i> (activity book)<br>American Cancer Society, 2002   |
|                           | <i>Beginnings and Endings with Lifetimes in Between</i><br>Bryan Mellonie & Robert Ingpen, Penguin, 2005   |
|                           | <i>I Know Someone with Cancer</i> series, 2014<br><b>bupa.co.uk/bupa-cancer-promise/i-know-someone-with-cancer</b>   |
|                           | <i>I'm a Kid Living with Cancer</i><br>Jenevieve Fisher, Isaiah 11:6 Publishing, 2010  |
|                           | <i>I Miss You: A first look at death</i><br>Pat Thomas, Barron's Educational Series, 2001  |
|                           | <i>Medikidz Explain Cancer</i> series (comics), 2015<br><b>medikidz.com</b>  |
| Books for teenagers       | <i>My Mum's Got Cancer</i><br>Dr Lucy Blunt, Jane Curry Publishing, 2009   |
|                           | <i>Allie McGregor's True Colours</i><br>Sue Lawson, Black Dog Books, 2006  |
|                           | <i>When Your Parent Has Cancer: A guide for teens</i><br>National Cancer Institute, 2005<br><b>cancer.gov/publications/patient-education/when-your-parent-has-cancer.pdf</b> |
| Books for adults          | <i>Cancer in Our Family: Helping children cope with a parent's illness</i> (2nd ed)<br>Sue P. Heiney & Joan F. Hermann<br>American Cancer Society, 2013                      |
|                           | <i>When a Parent Has Cancer: A guide to caring for your children</i><br>Wendy Schlessel Harpham, Perennial Currents, 2004  |
|                           | <i>Raising an Emotionally Healthy Child When a Parent Is Sick</i><br>Paula K. Rauch & Anna C. Muriel, McGraw-Hill, 2006  |

## Glossary

| Word                        | For younger children  | For older children and teenagers  |
|-----------------------------|---|---|
| <b>anaesthetic</b>          | 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.                           |
| <b>benign</b>               | A bump or lump on the body that isn't dangerous.  | Cells that are not cancerous (malignant).   |
| <b>biopsy</b>               | 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.   |
| <b>blood count</b>          | A test that checks how healthy the blood is.  | A test that counts the different types of blood cells in the body.  |
| <b>cancer</b>               | 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 more than 200 diseases in which abnormal cells grow and rapidly divide. These cells usually develop into a lump called a tumour. Cancer can spread to other parts of the body. |
| <b>cells</b>                | 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.                                 |
| <b>chemotherapy</b>         | Special medicine that kills the bad cancer cells.   | Special drugs that kill cancer cells or slow their growth.  |
| <b>child life therapist</b> | 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.   |
| <b>CT scan</b>              | A test that makes pictures so doctors can see what's happening inside the body.   | A procedure that takes x-rays to get 3D pictures of the inside of the body. The pictures show if cancer is present.   |
| <b>diagnosis</b>            | When the doctor works out what is making someone sick.  | Working out what kind of disease someone has.   |
| <b>dietitian</b>            | Someone who helps people work out the healthiest foods to eat.  | A health professional who supports and educates patients about nutrition and diet.  |
| <b>donor</b>                | A person who gives someone else blood or another part of their body.  | The person who gives blood, tissue or an organ to another person for a transplant.  |
| <b>haematologist</b>        | A doctor who treats people whose blood makes them sick.   | A specialist doctor who treats people with blood disorders.   |
| <b>hormone therapy</b>      | 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.   |
| <b>immune system</b>        | 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 helps protect the body from germs like bacteria and viruses, which can make people sick.   |

| Word                                | For younger children  | For older children and teenagers  |
|-------------------------------------|---|---|
| <b>immuno-compromised</b>           | When someone gets sick very easily.   | Weakening of the immune system, often caused by disease or treatment.   |
| <b>immunotherapy</b>                | A treatment that helps the body fight cancer.   | The prevention or treatment of disease using substances that change the immune system's response. Also called biological therapy.   |
| <b>intravenous (IV)</b>             | Putting a needle into a vein (where blood flows in the body).   | Putting something into a vein, like a drip for feeding, or a needle to give medication or take out some blood.  |
| <b>lymph nodes</b>                  | 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.  |
| <b>maintenance treatment</b>        | 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.  |
| <b>malignant</b>                    | Another way of saying cancer. Cells or lumps that are bad.  | Cancer. Cells that are malignant can spread to other parts of the body.   |
| <b>medical oncologist</b>           | A special doctor who uses strong medicine to treat people with cancer.  | A specialist doctor who treats cancer with chemotherapy.  |
| <b>metastasis (advanced cancer)</b> | 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.  |
| <b>MRI</b>                          | A special way of taking pictures of the inside of a person's body. MRI stands for 'magnetic resonance imaging'.   | A magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-section pictures of the body.  |
| <b>nausea</b>                       | Feeling sick in the tummy.  | Feeling as if you're going to vomit. Nausea is a common side effect of chemotherapy.  |
| <b>occupational therapist</b>       | 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.  |
| <b>palliative treatment</b>         | 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.  |
| <b>PET</b>                          | A special 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. PET stands for 'positron emission tomography'. | A positron emission tomography scan. 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. |
| <b>physiotherapist</b>              | 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.  |
| <b>prognosis</b>                    | What the doctors think might happen after treatment – i.e. how soon someone will get better.  | The likely outcome of a disease. This helps doctors decide on treatment options.  |

| Word                        | For younger children  | For older children and teenagers   |
|-----------------------------|---|--|
| <b>psychologist</b>         | Someone who helps people keep their minds healthy.  | A health professional who helps people with their thoughts, feelings and behaviours.   |
| <b>radiation oncologist</b> | 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 prescribes radiotherapy and organises the treatment.   |
| <b>radiotherapy</b>         | Invisible beams called x-rays that go into the body to kill cancer cells and make the cancer smaller.   | The use of radiation in the form of x-rays to kill or injure cancer cells so they can't grow or multiply. This is different to when you get x-rayed to see inside you (e.g. for a broken leg).   |
| <b>recurrence/ relapse</b>  | When cancer comes back and the person feels sick again.   | When cancer comes back after a period of improvement.  |
| <b>remission</b>            | When cancer goes away after treatment.  | When cancer cells and symptoms disappear because of treatment. Remission doesn't mean the cancer is cured, but it is now under control.  |
| <b>side effects</b>         | Treatment can stop good cells from working, as well as bad cells. This can sometimes cause problems for the person with cancer, such as feeling tired, feeling sick or losing their hair. Most side effects go away after a while.  | Unwanted effects of treatment, such as nausea, hair loss, rash or fatigue. They occur because treatment damages the cancer cells and some healthy cells as well, but the healthy cells usually recover after a while (e.g. hair grows back). |
| <b>stage</b>                | 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.   |
| <b>stem cell transplant</b> | 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 radiotherapy, then replaced with healthy stem cells. Stem cells are obtained from either the bone marrow or blood of the patient or a donor.            |
| <b>surgery</b>              | When someone has an operation and a special doctor cuts out the cancer.   | An operation by a surgeon to remove the cancer from the body.  |
| <b>symptoms</b>             | What people feel (e.g. sore, itchy) or see (e.g. redness, a lump) when something's not right in their body.   | Changes in the body caused by an illness, such as pain, tiredness, rash or stomach-ache. These help the doctor work out what is wrong.   |
| <b>targeted therapies</b>   | Special medicine that damages or kills cancer cells, but doesn't harm healthy cells.  | Treatments that attack specific weaknesses of cancer cells while minimising harm to healthy cells. Two types of targeted therapies are small molecule drugs and immunotherapies.   |
| <b>tumour</b>               | A lump in the body that shouldn't be there. The lump may or may not be cancer.  | A lump in the body caused by uncontrolled growth of cells. A tumour can be benign (not cancer) or malignant (cancer).  |
| <b>ultrasound</b>           | 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.  |

## References

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2. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia: An overview 2014*, Supplementary materials, AIHW, Canberra, 2014.



## 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](http://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 Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

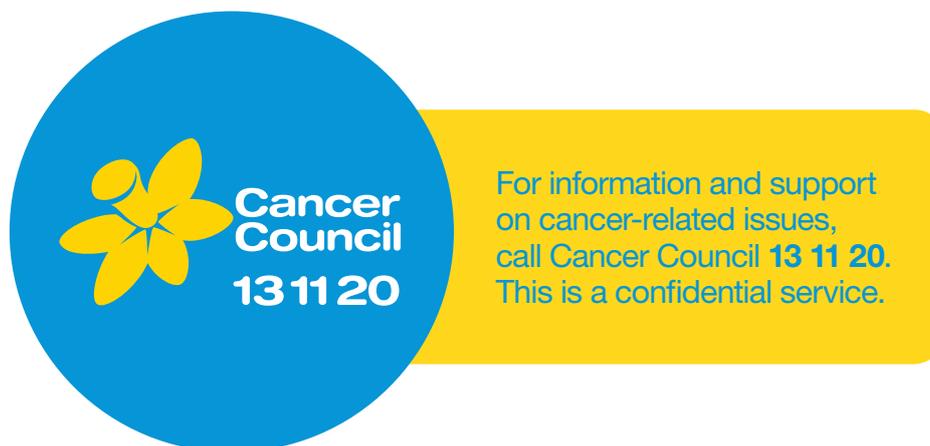
**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work supporting people with cancer and their families now and in the future.

**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.



## Visit your local Cancer Council website

**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[nt.cancer.org.au](http://nt.cancer.org.au)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
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[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

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[cancer.org.au](http://cancer.org.au)

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 To support Cancer Council, call your local Cancer Council or visit your local website.*