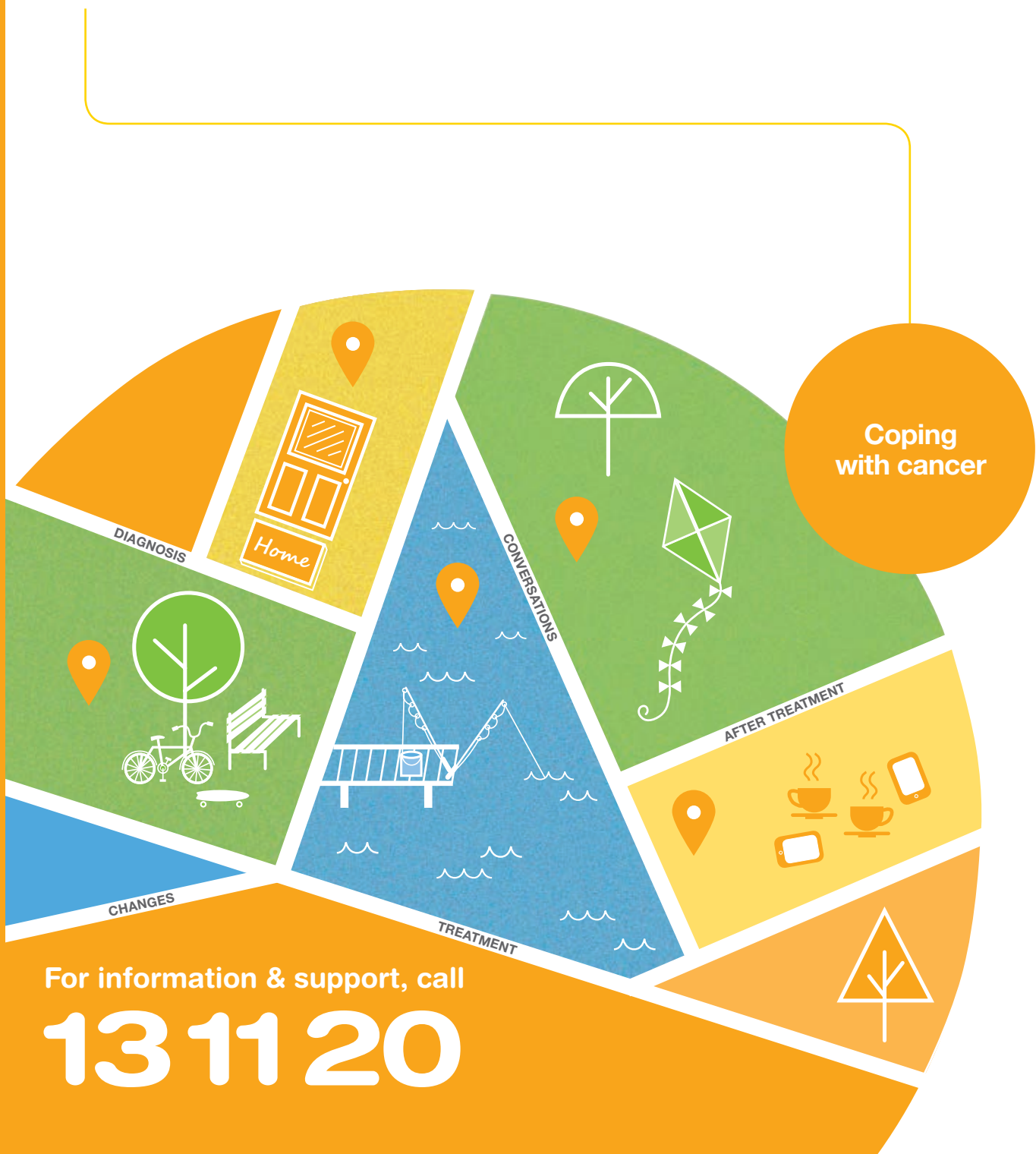


Talking to Kids About Cancer

A guide for people with cancer,
their families and friends



For information & support, call

13 11 20

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Note to reader

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

Cancer Council Australia

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



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About this book

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

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

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

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

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

A note about the language in this book

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



How to use this book

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

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

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



Tips



More information



Personal story



Key points

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



2

Talking about the **diagnosis**

When you first learn of a cancer diagnosis, you may feel shocked and overwhelmed. Among the many decisions you need to make will be when, where and how to talk to the children and young people in your life. However you decide to approach the conversation, try to be open and honest and leave kids with a feeling of hope.



When should I tell my children?

It's common to feel unsure of the best time to tell your children; often there may be no right time. You may wonder if you should tell them soon after you've been told yourself, or wait until you have more details about test results and treatment.

Although it is tempting to delay talking to your kids, try to tell them as soon as you feel able. Keeping the diagnosis a secret can be stressful, and your children will probably sense that something is wrong.

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

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

It may be hard to decide how much information to share, particularly if you are waiting on test results. Your children don't need to hear everything all at once. If you don't know what treatment is required, just say so – but also assure your children that as soon as you have more information you will tell them. For example, "Dad is in hospital to have some tests. We're not sure yet what's wrong, but when we do know we will tell you."

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

Where should I tell my children?

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

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

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

Looking after yourself

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

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

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



Hearing the news

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

James, aged 12

Should I tell them together?

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

Who should tell my children?

Deciding on the person to tell the children is another thing to consider. In most cases, it is easier if the information comes from someone who is close to your children. Ideally, that will be the parent who has cancer, the other parent or both of you together.

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

How can I prepare?

Parents often doubt their ability to find the right words and to answer the tricky questions their children ask. Take the time to plan what you'll say. Role-playing the conversation with your partner, friend, relative or the oncology social worker at the hospital can help you. It means you've spoken the words and perhaps dealt with some of the anxiety attached to those words before you talk with your kids. You can also practise in front of a mirror. This helps set the words in your mind.

Even if you practise what to say and you think you know how your kids will respond, be prepared for questions. You may not have all the answers, but it's okay to say you don't know or that you'll find out.

Work out beforehand how you might end the conversation. You could organise an activity, such as playing a game or going to the park, to help your children settle again. Older children may prefer some time alone. Also let your kids know that they can talk to you anytime they have questions or concerns.

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

What do children need to know?

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

Tell them the basics in words they can understand

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

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

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

Start with small amounts of information. Ask them what they want to know, and only answer questions that they ask – don't assume children will have the same concerns as you. You can give them more details later if they are interested. For younger children, accept that they may ask the same question several times. Each time you answer, they will absorb a little more information. Older children may be distant and quiet while they process the diagnosis.

Find out what they already know

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

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

Izzy, aged 15

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

Lily, aged 17

Be honest and open

Let them know if you don't know the answer to a question. Say you'll try to find out the answer from the doctor and let them know as soon as possible. Make sure you follow this through.

Tell them what to expect

Your children are likely to want to know what treatment will mean for them. If you are in hospital, who will drop them to school, make them dinner, take them to after-school activities? Reassure them that there will be a plan and you will let them know what it is.

Ask them if they want to tell anyone

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

Explain that it's helpful to share the diagnosis with a few key people, such as their main teacher and the school principal, as well as other important figures in their life, such as a music tutor or sports coach. Discuss ways to approach these conversations. See pages 26–27 for ideas about talking to the school.

Balance hope with reality

Tell kids that although cancer can be serious and going through treatment can be challenging, most people get better. Explain that with the help of the doctors and treatment teams, you (or the person with cancer) will be doing everything possible to get well.

Show your love and emotion

Tell your children that you love them, and show your love by hugging them, comforting them and making them feel valuable.

Some parents worry about crying in front of their children, but this is okay as long as you are not out of control. It can be helpful for kids to know that strong feelings such as anger and sadness are normal, and expressing them can make people feel better. Being honest with each other about feelings can help your children cope.

Coping with kids' reactions

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



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



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

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



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

Younger children may be annoyed if asked to play quietly. Older children may seem angry and uncooperative if asked to help out more. Both may be disappointed or upset if a planned holiday has to be postponed or cancelled.



No reaction – Sometimes children will appear not to have heard the news or do not react. You may be confused or hurt by this, especially if it took some planning and courage to share the diagnosis.

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

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



Support for children and young adults

Camp Quality

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

CanTeen

CanTeen helps young people aged 12–25 who are dealing with their own or a close family member's cancer. Young people can connect with others online; access counselling face-to-face, by phone, email or online; get specialist, in-hospital treatment; and take part in programs, camps and recreation days – all to help them cope with the impact of cancer. To find out more about CanTeen, call **1800 835 932** or visit **canteen.org.au**.

When another child has cancer

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

Causes of cancer – Let your child know that childhood cancers are not lifestyle-related (e.g. caused by sun exposure or smoking), nor does a child get cancer because of naughty behaviour or a minor accident like a bump on the head. There's nothing anyone did to cause the cancer.

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

Most children get better – Like adults, children may worry that cancer means their friend will die. Reassure children that although cancer is a serious, life-threatening disease, the overall survival rate for children is now more than 80%.² This can vary depending on the diagnosis, but most children will survive cancer.

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

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

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

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



When a sibling has cancer

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

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

For many children and teenagers, fitting in with their peers is very important. This means they may feel embarrassed or self-conscious about their family now being different to other families. Some may be reluctant to tell their friends and teachers about the situation at home. If cancer changes how their brother or sister looks, they may feel embarrassed and shy away from being seen with their sibling.

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

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

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

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

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

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

Family conversations

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

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

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

We wanted all the kids to feel involved with Leo's treatment – we said, "You are part of the team, you are part of this." The hospital became part of our family life.

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

If your child is diagnosed

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

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

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

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

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

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

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

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

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

Karen's story*

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

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

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

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

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

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

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

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

Continued on page 47



What words should I use?

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



Infants, toddlers & preschoolers

About cancer

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

“I have an illness called cancer. The doctor is giving me medicine to help me get better. The medicine might make me feel sick or tired some days, but I might feel fine on other days.”

To clear up misinformation about cancer

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

“How do you think people get cancer?”

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

To explain changes and offer reassurance

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

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

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

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



Younger children



Older children & teenagers

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

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

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

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

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

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

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

“Mum is going to be busy helping Grandma after she comes out of hospital. There are ways we can all help out, but mostly things won’t change for you.”

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

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

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

“The doctor doesn’t know why I got cancer. It doesn’t mean that you’ll get cancer too. It’s not contagious (you can’t catch it) and the cancer I have doesn’t run in families.”

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

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

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

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

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

Answering key questions

Q: Are you going to die?

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

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

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

Q: Was it my fault?

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

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

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

Q: Can I catch cancer?

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

A: *"You can't catch cancer like you can catch a cold by being around someone who has it, so it's okay to hug or kiss me even though I'm sick."*

"Cancer can spread through the body of a person with cancer, but it can't spread to another person."

Q: Who will look after me?

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

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

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

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

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

If you're planning to inform teachers, or the school counsellor or principal, talk to your kids first. Teenagers and even younger children may be reluctant for the school to know, so explain the benefits of telling the school and then chat about the best way to approach the discussion. Ask if your teenagers want to be involved in talking to key teachers or the principal with you – this way they are part of the agreement made with the school.

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

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

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

Q: Is there anything I can do to help?

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

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

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



Thinking the worst

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

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

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

Izzy, 15-year-old whose father had cancer

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

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

Involving others

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

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

Talk to other people who have cancer – Often the best support and ideas come from people who've already been there. You'll realise you're not alone and you can ask them how they handled things (see *Support services*, page 59).

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

Involving the school or preschool

Many parents or carers wonder if they should tell the school. If things are unsettled at home, school can be a place where kids can be themselves with their friends and carry on life as normal.

When the school is aware of the situation at home, staff will be more understanding of behaviour changes and can provide support. In fact, school staff are often the first to notice shifts in a child's behaviour that may indicate distress. A cancer diagnosis in the family can also affect academic performance, so the student may be entitled to special provisions, which can be particularly important in the final years of high school.

Ways to involve the school include:

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



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

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

Key points

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

Support and information directory

Support services

<p>Camp Quality provides programs and services to strengthen the wellbeing of children aged 0–13 growing up with cancer</p>	<p>1300 662 267 campquality.org.au</p>
<p>Cancer Council provides a wide range of support and information services for people affected by cancer (see opposite page for more details)</p>	<p>13 11 20 For your local Cancer Council website, see back cover</p>
<p>CanTeen supports young people aged 12–25 affected by their own or a close family member’s cancer diagnosis</p>	<p>1800 835 932 canteen.org.au</p>
<p>headspace run by the National Youth Mental Health Foundation, provides mental health services to people aged 12–25</p>	<p>1800 650 890 headspace.org.au</p>
<p>Kids Helpline offers 24-hour telephone and online counselling for young people aged 5–25</p>	<p>1800 55 1800 kidshelpline.com.au</p>
<p>Lifeline offers 24-hour general crisis support</p>	<p>13 11 14 lifeline.org.au</p>
<p>ReachOut general information about mental health and wellbeing for young people going through tough times</p>	<p>au.reachout.com</p>
<p>Redkite offers financial, emotional and educational support for people aged 0–24 with cancer, as well as their families and networks</p>	<p>1800 REDKITE (1800 733 548) redkite.org.au</p>
<p>Ronald McDonald Learning Program provides assessment, therapy and tuition for young people whose education has been disrupted by serious illness</p>	<p>1300 307 642 rmhc.org.au/our-programs/learning-program</p>
<p>Young Carers Network provides information and support for people under 25 who care for someone with an illness, disability or mental health issue</p>	<p>youngcarersnetwork.com.au</p>
<p>youthbeyondblue supports young people aged 12–25 dealing with depression, anxiety and other mental health problems</p>	<p>1300 22 4636 youthbeyondblue.com</p>
<p>Griefline offers phone and online counselling</p>	<p>1800 642 066 grief.org.au</p>

Online information for children aged 3–13 years

Bearing Up Club

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

bereavementcare.com.au

Kids' Guide to Cancer

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

campquality.org.au/kidsguidetocancer

Online information for teenagers aged 12–18 years

CanTeen

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

canteen.org.au/cancer-information

riprap

UK site for teenagers who have a parent with cancer

riprap.org.uk

Stupid Cancer

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

stupidcancer.org

General online information

Cancer Council

reliable information about cancer by topic and by type; PDFs and ebooks of *Understanding Cancer* booklets and fact sheets; links to local programs and services

For your local Cancer Council website, see back cover

Cancer Australia

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

canceraustralia.gov.au

Children's Cancer

information about many aspects of children's cancer

childrenscancer.canceraustralia.gov.au

Victorian Paediatric Integrated Cancer Service (PICS)

information for families when a child is diagnosed with cancer

pics.org.au

American Cancer Society

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

cancer.org

Cancer Research UK

detailed information about the diagnosis and treatment of different cancer types

cancerresearchuk.org

Macmillan Cancer Support

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

macmillan.org.uk

Picture books

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

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

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

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

For younger readers

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

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

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

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

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

The Memory Tree
Britta Teckentrup, Hachette, 2014

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

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

For teenagers

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

The Honest Truth
Dan Gemeinhart, Scholastic Press, 2015

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

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

For adults

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

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

Glossary

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

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

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

References

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



Cancer Council 13 11 20

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

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

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

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

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



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

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



How you can help

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

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

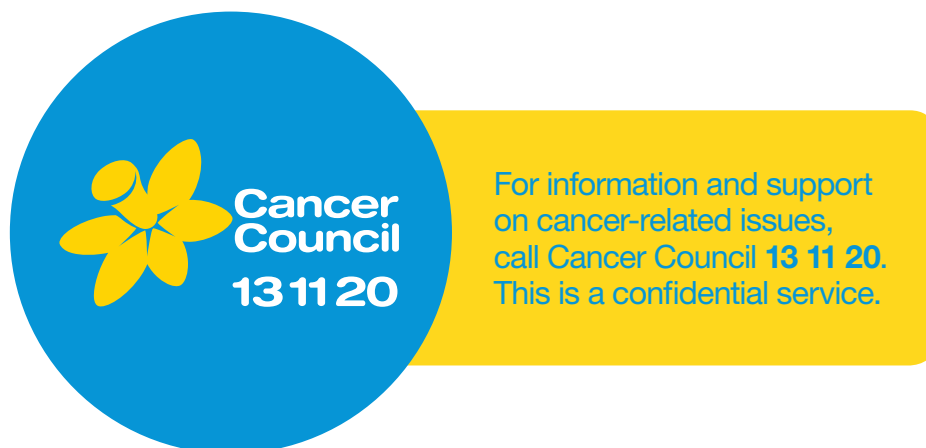
Make a donation: Any gift, large or small, makes a meaningful contribution to our work supporting people with cancer and their families now and in the future.

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

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

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

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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