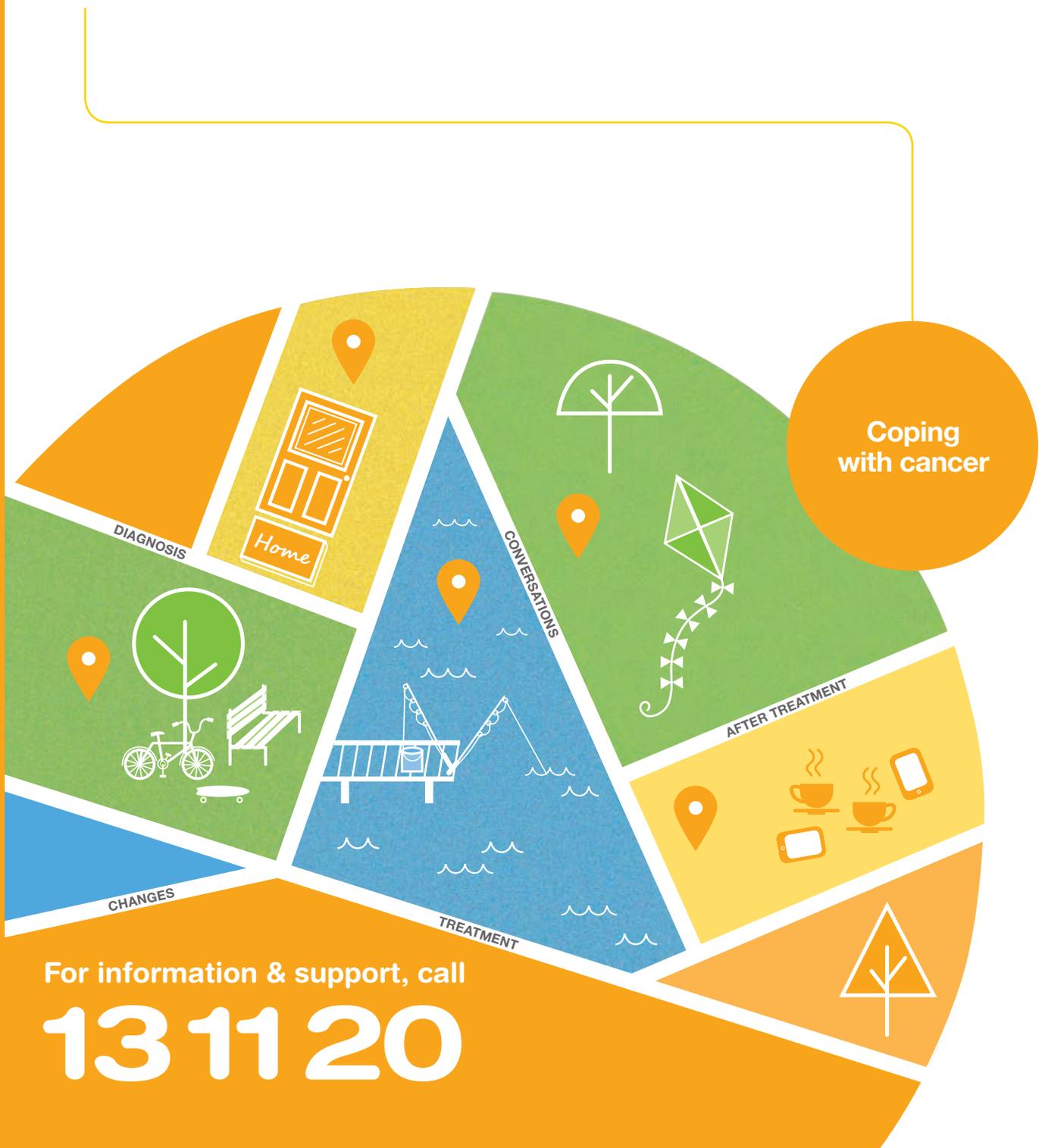


# Talking to Kids About Cancer

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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This book is funded through the generosity of the people of Australia.

## 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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ABN 91 130 793 725

# 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.



5

# Living with **advanced cancer**

This chapter is a starting point for talking to your children if someone they love has cancer that has come back or spread. The issues are complex, emotional and personal, so you may find reading this chapter difficult. If you want more information or support, talk to hospital staff or contact the services listed on page 51.



### A big hole

*I was in my teens when my mother died of cancer. These were the days when patients were not told the truth. In case she didn't know, when I visited my mother I kept up the charade and didn't mention death. She didn't bring it up. This was a great loss to me and I'm sure to her too. A big hole in my life, to this day, is that I don't know how she felt about her death's effect on me, my sister and our father.*

Eva, now a mother herself with teenage daughters

## What do children need to know?

Some people's cancer may be advanced when they are first diagnosed. For others, the cancer may spread or come back (recur) after initial treatment. If the cancer has advanced, it is important to keep talking with your children. Again, just as with the initial diagnosis, children may sense that something is happening, and not telling them can add to their anxiety and distress.

Children may have similar feelings to adults after hearing the cancer has advanced. These include shock, denial, fear, anxiety, sadness, anger, guilt, or loneliness.

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

### Be honest and open

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

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

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

### Tell them what to expect

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

# Karen's story\*

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

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

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

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

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

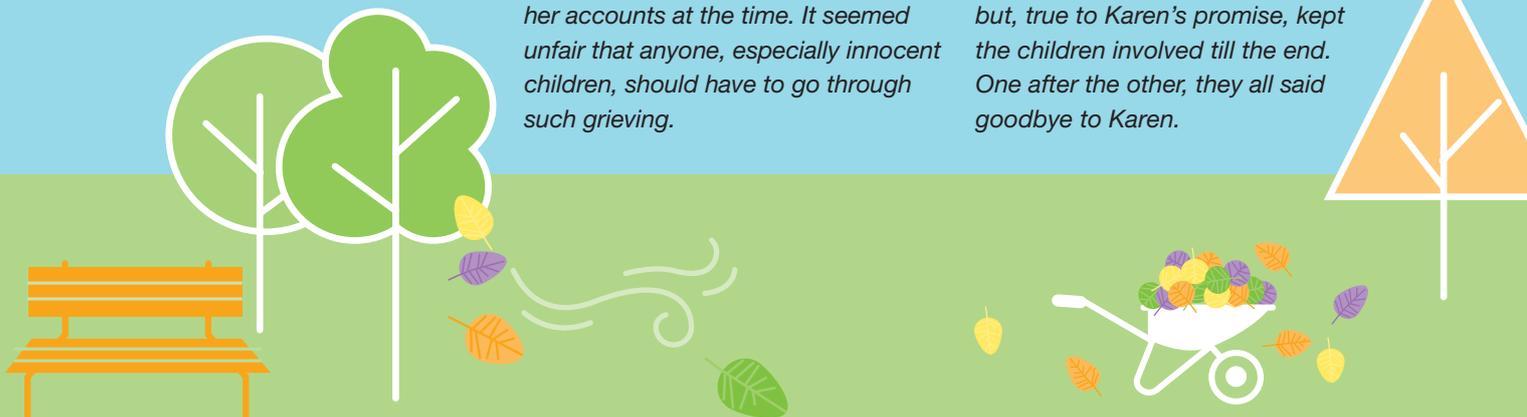
*As Karen began her new treatment, the children again settled into their routine and accepted a slightly different normality. Although it's easy to relate Karen's experiences here, I found it heart-wrenching to hear her accounts at the time. It seemed unfair that anyone, especially innocent children,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

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

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

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

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



### **Balance hope with reality**

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

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

### **Wait for your children to ask**

When you talk with your children about death, offer simple and short explanations. Give brief answers to questions they ask. Wait for the next question to emerge and respond to that. It usually doesn't help to offer lots of explanations if your children aren't ready to hear them. If they ask a question you don't know the answer to, say you'll find out and let them know.

### **Use words they can understand**

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

## **How children react**

How you react to a diagnosis of advanced cancer can affect how the whole family responds. If you are anxious and depressed, the family may be too. Some studies of people with advanced cancer show that family members often feel more distressed than the person with cancer. This seems to be more common if family members don't communicate well.

When children find out that the cancer is advanced, they may have similar but more intense reactions than when they found out about the original diagnosis. They are likely to feel insecure, although teenagers may not want you to see this. Depending on their age, kids usually have different immediate concerns when they hear the news. See pages 52–53 for typical reactions from children and young people.

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

# What words should I use?

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



**Infants, toddlers & preschoolers**



**Younger children**



**Older children & teenagers**

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



## 48 hours

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

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

*I wasn't there when he died. I went to a netball dinner. I didn't want to be around it – that's not how I wanted to remember him, it's not what he was like. Dad told me, "Do what makes you feel comfortable. Do the things you need to do to cope."*

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

Izzy, 15-year-old whose father had cancer

## Answering key questions

How you answer these questions depends on the nature of the cancer and the effects of treatment. Work out in advance what your children might ask and think about how you want to respond.

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

### Q: Why?

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

**A:** *"I don't know. Life feels unfair sometimes and we don't always know why sad things happen. Why do you think sad things happen?"*

### Q: Is it my fault?

**A:** *"It's no-one's fault. Nothing you, or anyone else, did or said made me ill. And being kind and well-behaved can't stop someone from dying either."*

### Q: When will you/they die?

Time is a difficult concept for young children, so it may not help to give even vague time frames. Older children may want some idea. It is still important to balance hope with reality.

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

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

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

*"No-one can answer that, but we are hoping that there will still be some good days."*

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



### Q: Who will look after me?

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

**A:** *"It's very important to me that you will always be safe and looked after. Dad will be there for you, and your aunty will help all of you."*

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

### Q: What happens if Mum/Dad dies too?

**A:** *"When someone you love is very sick, it can make you feel very scared. But Mum/Dad is well and healthy now and they will be around to look after you. Whatever happens, we'll make sure you are safe and loved."*

### Q: Am I going to die as well?

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

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

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

**A:** *"The body goes to a funeral home until it's time for the funeral. Then they will put the body in a big box called a coffin, which will be carried into the funeral service. After the funeral is over, the coffin is buried in the ground in the cemetery."*

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

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

### Supporting grieving children

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

Children often work through feelings slowly, facing them in bearable doses. Allow children space to grieve – you do not need to "fix" their sorrow. Let them know that it is natural for people to express sadness in various ways, just as they express other emotions.

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

**Australian Centre for Grief and Bereavement**  
**1800 642 066**  
[grief.org.au](http://grief.org.au)

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

**CanTeen**  
**1800 835 932**  
[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's helpful to understand how death is perceived at different ages. Children's grief may be expressed through play or behaviour.

0-3 years



## Newborns, infants and toddlers

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

3-5 years



## Preschoolers

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

### Possible reactions

- 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

### Possible reactions

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

### Suggested approaches

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



5-12 years



### Primary schoolchildren

By the primary school years, children may understand death but often don't have the emotional maturity to deal with it. Younger children may think death is reversible and that they are responsible.

#### Possible reactions

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

#### Suggested approaches

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

12-18 years



### Teenagers

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

#### Possible reactions

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

#### Suggested approaches

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



### Key points

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

## Family life

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

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

## Issues with going to school

It can be difficult to know whether to send your children to school each day if you think someone in the family may die soon. You may feel like you need to let them spend as much time as possible with their loved one. Maintaining routine in a child's life can help them to feel more stable and safe. It might help them to go to school and see that normal life can continue, even though things are changing at home. However, there may also be days when keeping your children home feels like the right thing to do.

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

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

## Support and information directory

## Support services

<p><b>Camp Quality</b> provides programs and services to strengthen the wellbeing of children aged 0–13 growing up with cancer</p>	<p>1300 662 267 <a href="http://campquality.org.au">campquality.org.au</a></p>
<p><b>Cancer Council</b> 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><b>CanTeen</b> supports young people aged 12–25 affected by their own or a close family member’s cancer diagnosis</p>	<p>1800 835 932 <a href="http://canteen.org.au">canteen.org.au</a></p>
<p><b>headspace</b> run by the National Youth Mental Health Foundation, provides mental health services to people aged 12–25</p>	<p>1800 650 890 <a href="http://headspace.org.au">headspace.org.au</a></p>
<p><b>Kids Helpline</b> offers 24-hour telephone and online counselling for young people aged 5–25</p>	<p>1800 55 1800 <a href="http://kidshelpline.com.au">kidshelpline.com.au</a></p>
<p><b>Lifeline</b> offers 24-hour general crisis support</p>	<p>13 11 14 <a href="http://lifeline.org.au">lifeline.org.au</a></p>
<p><b>ReachOut</b> general information about mental health and wellbeing for young people going through tough times</p>	<p><a href="http://au.reachout.com">au.reachout.com</a></p>
<p><b>Redkite</b> 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) <a href="http://redkite.org.au">redkite.org.au</a></p>
<p><b>Ronald McDonald Learning Program</b> provides assessment, therapy and tuition for young people whose education has been disrupted by serious illness</p>	<p>1300 307 642 <a href="http://rmhc.org.au/our-programs/learning-program">rmhc.org.au/our-programs/learning-program</a></p>
<p><b>Young Carers Network</b> provides information and support for people under 25 who care for someone with an illness, disability or mental health issue</p>	<p><a href="http://youngcarersnetwork.com.au">youngcarersnetwork.com.au</a></p>
<p><b>youthbeyondblue</b> supports young people aged 12–25 dealing with depression, anxiety and other mental health problems</p>	<p>1300 22 4636 <a href="http://youthbeyondblue.com">youthbeyondblue.com</a></p>
<p><b>Griefline</b> offers phone and online counselling</p>	<p>1800 642 066 <a href="http://grief.org.au">grief.org.au</a></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](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 – answers the common questions kids have about cancer

[campquality.org.au/kidsguidetocancer](http://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](http://canteen.org.au/cancer-information)

**riprap**

UK site for teenagers who have a parent with cancer

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

**Stupid Cancer**

US site for people aged 15–39 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 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](http://canceraustralia.gov.au)

**Children's Cancer**

information about many aspects of children's cancer

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

**Victorian Paediatric Integrated Cancer Service (PICS)**

information for families when a child is diagnosed with cancer

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

**American Cancer Society**

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

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

**Cancer Research UK**

detailed information about the diagnosis and treatment of different cancer types

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

**Macmillan Cancer Support**

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

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

## Picture books

*Butterfly Kisses and Wishes on Wings*  
Ellen McVicker & Nanci Hersh, S.N., 2006  
[butterflykissesbook.com](http://butterflykissesbook.com)

*Nowhere Hair*  
Sue Glader & Edith Buenen,  
Thousand Words Press, 2010  
[nowherehair.com](http://nowherehair.com)

*In the Rainbow*  
Tracey Newnham, 2017  
[intherainbow.com.au](http://intherainbow.com.au)

*Safina and the Hat Tree*  
Cynthia Hartman & Hayley O'Brien, Nomota, 2004  
[talesforkids.com.au](http://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](http://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
<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.	Not cancerous or malignant. Benign tumours are not able to spread to other parts of the body.
<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 how many red blood cells, white blood cells and platelets there are in the blood.
<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 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.
<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.	A cancer treatment that uses drugs to 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 uses x-rays to create detailed, cross-sectional pictures of the body that 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 people about nutrition and diet.
<b>donor</b>	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.
<b>haematologist</b>	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.
<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 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
<b>immunocompromised</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.	Treatment that uses the body's own immune system to fight cancer.
<b>intravenous (IV)</b>	Putting a needle into a vein (where blood flows in the body).	Injected into a vein.
<b>leukaemia</b>	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.
<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 word for cancer.	Cancerous. 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 scan</b>	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".
<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 scan</b>	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".
<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, 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
<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 treats cancer by prescribing and coordinating a course of radiation therapy.
<b>radiation therapy (also called radiotherapy)</b>	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).
<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 reduce or disappear because of treatment. Remission may not mean that cancer is cured, but that it is now under control.
<b>side effects</b>	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).
<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 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.
<b>surgery</b>	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.
<b>targeted therapy</b>	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.
<b>tumour</b>	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).
<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.
<b>x-ray</b>	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](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 other Pink events, or hold your own fundraiser or become a volunteer.

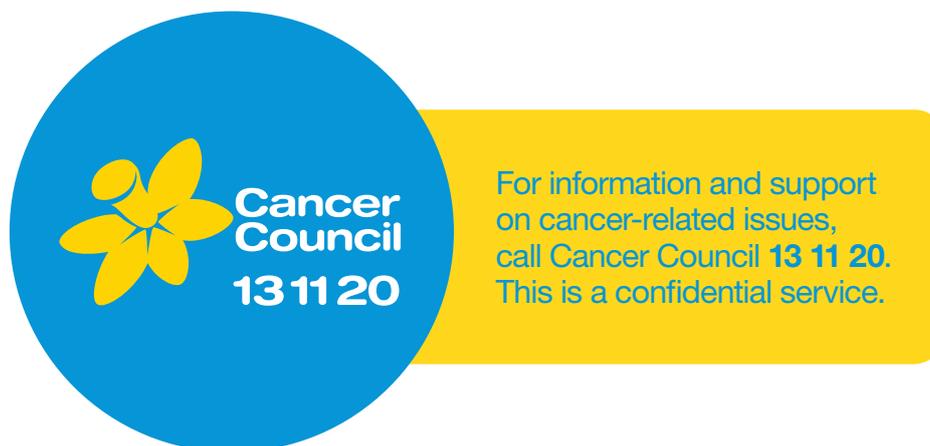
**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work supporting people with cancer and their families now and in the future.

**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](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**  
[cancertas.org.au](http://cancertas.org.au)

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

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

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

*This booklet is funded through the generosity of the people of Australia.  
 To support Cancer Council, call your local Cancer Council or visit your local website.*