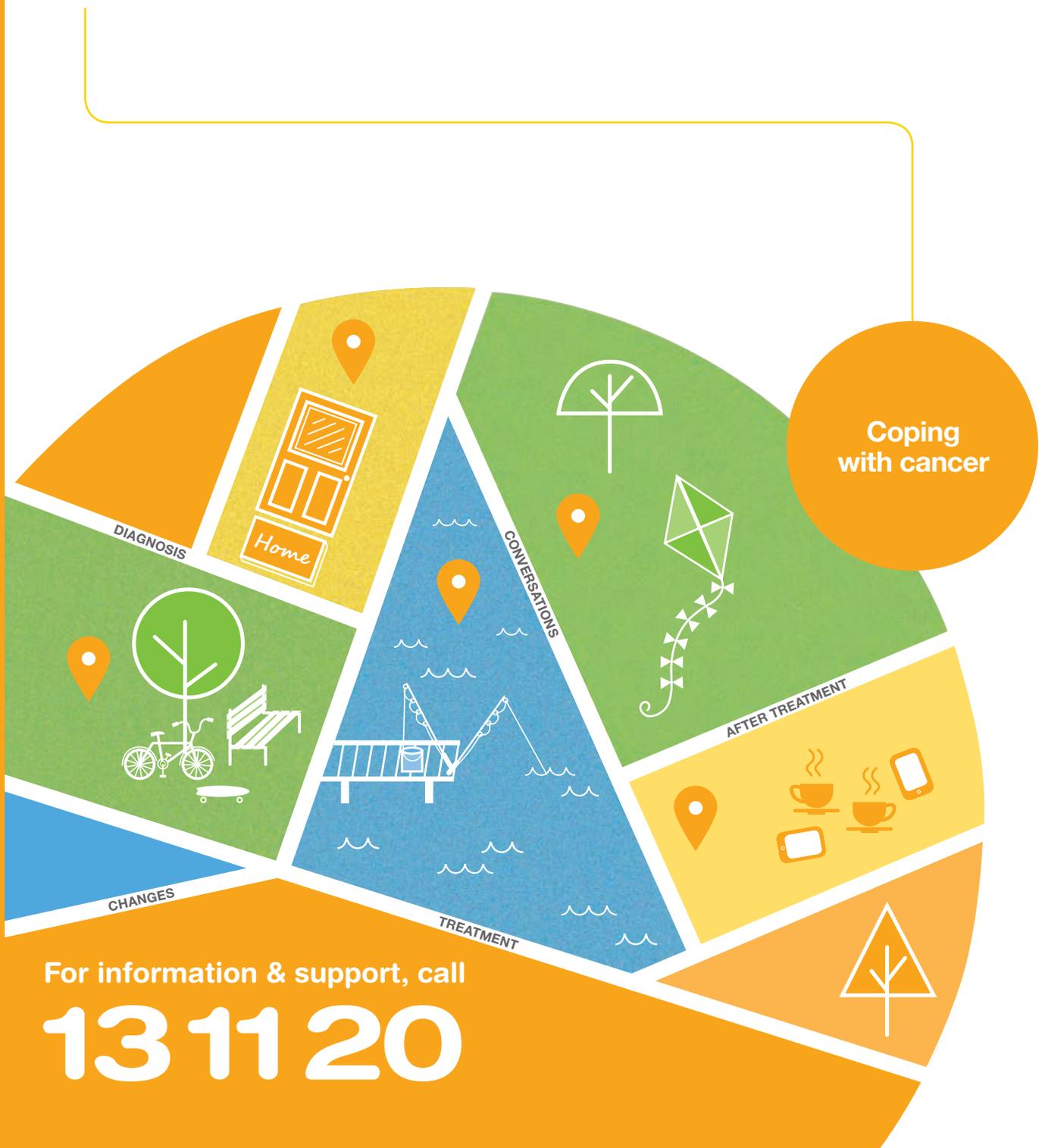


Talking to Kids About Cancer

A guide for people with cancer,
their families and friends



For information & support, call

13 11 20

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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 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.



Talking about **treatment**

Cancer treatment can be challenging for the whole family, but children and young people often manage better when they know what to expect. How much detail you provide will depend on the child; in general, kids like to know what the treatment involves, how it works, and why there are side effects. While you may not be able to say exactly what will happen, you can promise to keep your children updated.

What do children need to know?

Providing children and young people with information about the treatment, why and how it is done, and possible side effects can prepare them for what to expect and help them adjust.

Outline the treatment plan

- Let the children be your guide as to how much they already know and how much they want to know about treatment.
- Start with questions such as “Have you heard the word chemotherapy?” or “Do you know what radiation therapy is?” Then explain the basic facts using language they can understand (see the glossary on pages 62–64).
- Check if your kids want to know more, and let them know that they can ask questions throughout the treatment period if they have other queries or concerns.
- Talk to kids about how to search for accurate information online (see page 60 for a list of recommended websites), to avoid incorrect or unhelpful information.
- Keep them up to date with how long treatment will take and the length of the hospital stay.
- Explain who will be taking care of the person with cancer and the different ways they will help.

Explain side effects

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

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



Understanding treatment

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

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



Making a day of it

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

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

Anna, mother of two children aged 9 and 13

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

Prepare for hospital and treatment centre visits

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

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

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

- Before children enter the hospital room, tell them what to expect and what they may notice: the equipment; different smells and noises (e.g. buzzers, beeps); how the patients may look (e.g. tubes, bandages, a drip or catheter bag full of urine hanging on the side of the bed); doctors and nurses might keep coming in and out to check on the patients.



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

How to play with a child in hospital

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

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

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

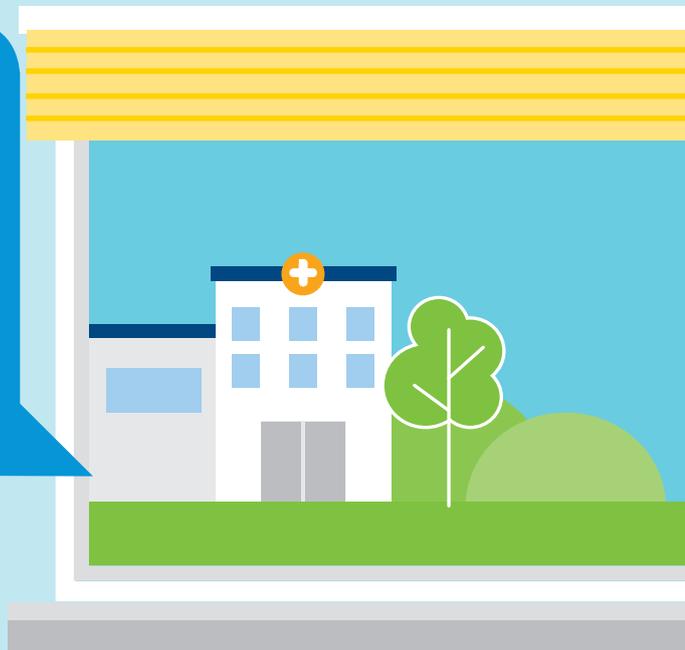
Simon, father of a four-year-old

Creative ways to explain cancer

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

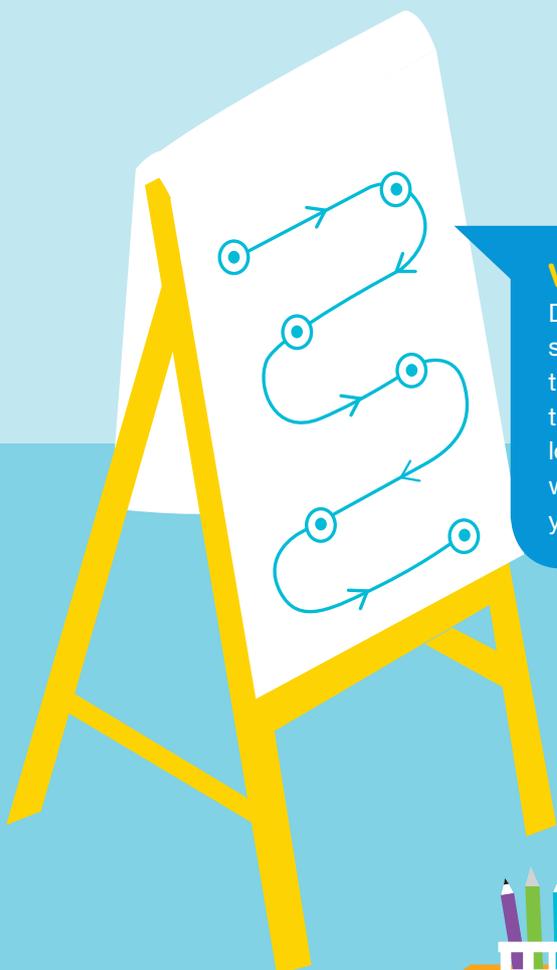
Offer them a tour

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



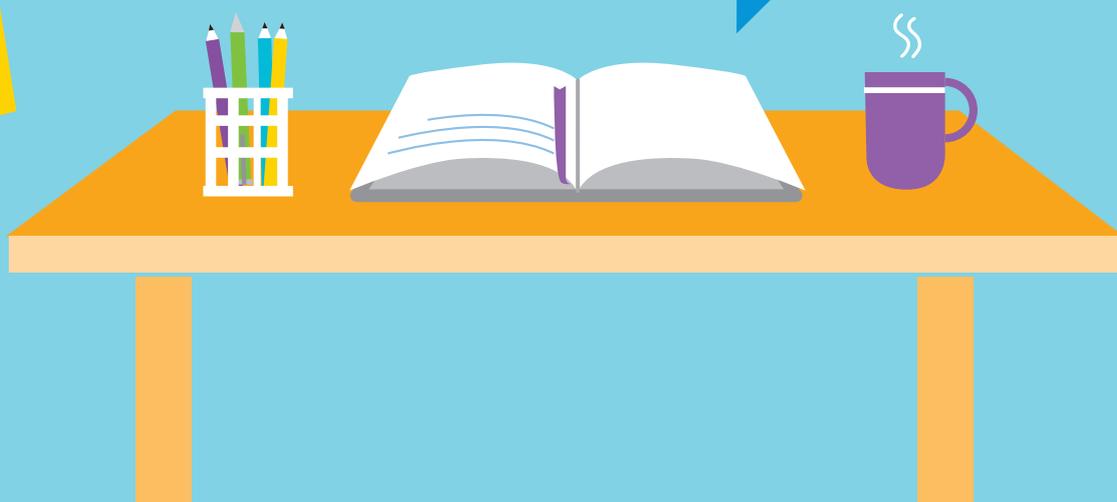
Visualise it

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



Keep a journal

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



Make up stories and play games

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



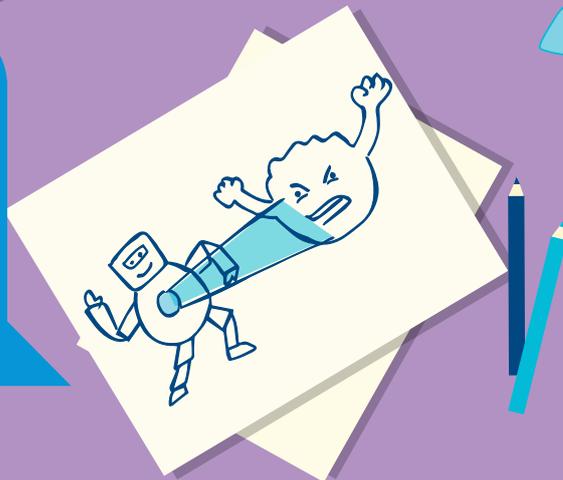
Say it with music

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



Draw out feelings

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





Chemo days

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

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

Anna, mother of two children aged 9 and 13

Answering key questions

Q: Is it going to hurt?

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

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

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

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

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

Q: Will your hair come back?

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

A: *“The doctor says I may lose my hair because of the chemotherapy. It will come back but probably will look a bit different, especially at first. I can wear wigs, scarves or hats until it grows back.”*

Q: Does radiation therapy make you radioactive?

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

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

Q: Why do you need to rest so much?

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

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

Living with uncertainty

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

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

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

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

Family life during treatment

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

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

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

If you are a parent caring for someone with cancer, such as your partner or your own parent, you may feel like you have little time and energy left for your children. Although asking for and accepting help can be difficult, it may relieve some pressure and allow you to spend more time together as a family. Cancer Council's book *Caring for Someone with Cancer* discusses ways to look after yourself and how to take a break, and includes a list of support services for carers. Call 13 11 20 for a free copy, or download it from your local Cancer Council website.



Changed behaviour

My husband, Bruce, had a brain tumour and his personality changed because of it. At the dinner table one night, our four-year-old, Emma, announced, "I wish Daddy was dead."

I calmly asked Emma what she meant. She replied, "I don't like the man who's in my Daddy's body. I want my real Daddy back." I could then explain why Bruce's behaviour had changed.

Debra, mother of a four-year-old

Managing emotions

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

If your kids' reactions seem unusual or extreme, consider getting some professional support (see page 56). However, some children may hide their feelings because they do not want to add to their parents' stress. Even if your child's behaviour doesn't suggest they are struggling, let them know you appreciate how hard this situation is for them.

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

- Encourage, but don't push, kids to identify and name feelings. For younger children, you may need to recognise and identify the emotion for them (e.g. "you look angry" or "you seem really worried").
- Reassure them that there are no right or wrong feelings. Everyone reacts in their own way.
- Let them know that anger, guilt and sadness are normal feelings. You feel them too and it is okay to talk about them.
- Remind them that they can talk to you anytime about how they're feeling.
- Discuss ways to manage anxiety and stress.
- Make sure they have plenty of opportunities for physical activity and spending time with friends.
- Provide plenty of physical comfort, such as hugs and cuddles.
- Offer creative ways for children to express their emotions.
- Create everyday opportunities for humour and fun. Let your children know that it is alright to joke and have fun. Laughter can often relieve tension and help everyone relax.

The emotions thermometer

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

An emotions thermometer may help. This simple tool allows you to show

how you're feeling every day. You can make one yourself and ask the kids to help. Choose which feelings to include and add a pointer that moves to the different feelings.

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

Encouraging family time

Maintaining routines and family traditions as much as possible will help children and young people feel safe and secure. Sometimes you have to strike a balance between doing regular activities and coping with the effects of the cancer.

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

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

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





Family time

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

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

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

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

Spending one-on-one time

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

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

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

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

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

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

Maintaining discipline

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

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

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



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

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

Encouraging children to help

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

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

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

Single-parent families

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

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

You may want to get in touch with Carers Australia Young Carers Network at youngcarersnetwork.com.au. This organisation runs activities and support groups for children and young people up to 25 years of age who care for a parent with a serious illness. Even young children may be considered young carers – for example, if they are helping with cooking or cleaning. Camp Quality and CanTeen can also offer support to children when a parent has cancer (see page 59).

Helping around the house

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

Ages 2–4

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

Ages 4–8

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

Ages 8–12

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

Over 12

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



Key points

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

Staying in touch

If you live in the country and need to travel for treatment, or if you have extended hospital stays, you may be away from your family for long periods. In some cases, both parents may need to travel to a major hospital and leave their children with family members or friends. The following tips may help you stay in touch. They might also be useful if you don't need to leave home but want extra ways to communicate with your kids.

- Ask your kids to do drawings and take photos to send to you.
- Set a time to call home each night when you're away, then read a favourite story together over the phone or via video calling (e.g. Skype, FaceTime).
- Write an old-fashioned letter. Kids love finding mail addressed to them in the letterbox.
- Send an email or recorded message.
- Leave notes and surprises for kids to find, such as a note in a lunchbox.
- Connect through social media or personal blogs.
- Use private messenger phone apps for one-on-one chats with teenagers.
- If they're able to visit, children can bring cards or pictures from home, flowers picked from the garden, or a toy to "mind" you in hospital.

The Thing About Cancer podcast

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

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



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

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.

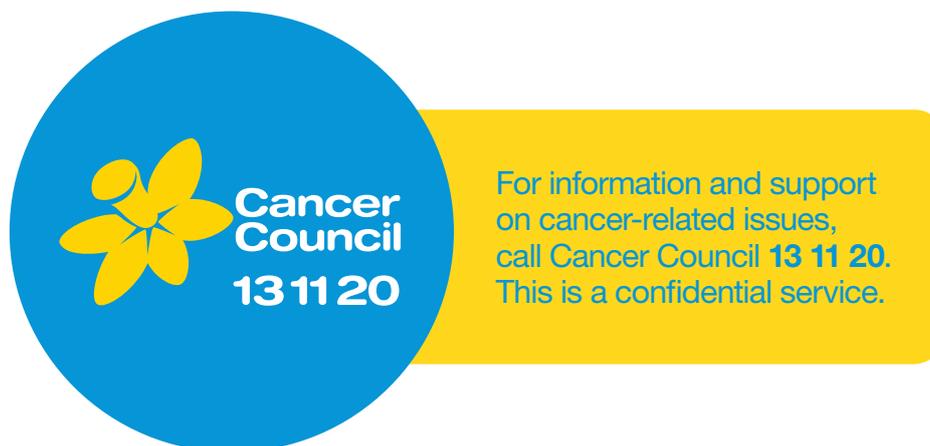
Make a donation: Any gift, large or small, makes a meaningful contribution to our work supporting people with cancer and their families now and in the future.

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.*