When a parent has cancer: how to talk to your kids

A guide for parents with cancer, their families and friends.
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The editorial committee
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The Cancer Council New South Wales
The Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.

To make a donation to help defeat cancer, visit The Cancer Council’s website at www.cancercouncil.com.au or phone 1300 780 113.

Before commencing any health treatment, always consult your doctor. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor’s or health professional’s advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

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About this book

Cancer can have a profound impact on your life and your family.

It's hard enough dealing with the impact of cancer on your own life – especially in the whirlwind of the days and weeks after diagnosis. You not only have to come to grips with your cancer, you have to work out how to help your family cope and how to talk about issues you hoped you would never have to face.

The prospect of telling your children you have cancer can be frightening and upsetting. Parents often say they initially avoid telling their children because they are trying to protect them from anxiety and distress, or that they don’t want to spoil family occasions, such as holidays. Some parents also want to avoid confronting questions about the possibility of death.

These issues can be overwhelming, but they don’t change the fact that you know what works best for your family. You know your children better than anyone else. You know how to soothe them when they are upset or angry, and the best times and situations to talk to them.

You are the expert

Don’t be afraid that you won’t be able to talk with your children about cancer. As a parent who knows and cares about your children, you are the best person to do this.

With careful thought and preparation, you can use your expert knowledge of your children to find the best ways to communicate about cancer.

This book aims to help you use that knowledge to firstly tell your kids about the cancer, and then to keep talking throughout your cancer journey.

Many parents want simple answers. However, just like with cancer, there is no easy solution and sometimes it may take a few attempts before you find the best way for your family.

This book has general principles about how to communicate with your kids and how to help them cope. It also has many families’ stories (with names changed for confidentiality) and ideas from other parents that you can try or adapt to suit your children. It also includes some wording that may help you answer your kids’ questions. These are just ideas and you will need to vary the words according to your children’s ages and understanding of cancer.

We can’t tell you exactly what to do or say, but we hope this book at least gives you a starting point and some ideas to ease the way.
Who is this book for?

This book is for people with cancer who have children. It has been written with the newly diagnosed person in mind, but will still be useful for people who have had cancer for some time. It may also help people with cancer who are grandparents.

We hope it will also be useful for partners, close friends and relatives, and anyone else who may talk to your children about your illness.

How this book was developed

There are few Australian books on how parents can talk with their children about cancer. Aiming to fill this gap, The Cancer Council NSW, Cansupport and the Pam McLean Cancer Communications Centre worked together to produce this book.

It is based on medical evidence, and input from experts – such as psychiatrists, oncologists, psychologists, social workers and counsellors – who help families deal with the challenges of cancer.

Most importantly, parents who have cancer have helped us to ensure this book deals with the main issues they have faced – and continue to face – in communicating with their children about cancer.

How to use this book

This book follows the cancer journey – from breaking the news about your diagnosis and treatment issues, to life after treatment. You may choose to read all the book at once or to read each chapter as it becomes relevant to you.

Please keep in mind that Chapter 7, When cancer won’t go away, may be confronting for some readers, particularly those who have just been diagnosed. Remember, not everyone will need to think about those issues. Cancer treatments are becoming more effective all the time and more people are surviving cancer.

A good summary of the key principles of this book is on pages 10 and 11. Feel free to photocopy these pages and hand them out to family and friends to help them understand what you’re dealing with. These pages can also be a good starting place for you, if you don’t feel ready to read more of the book at this point.

We have used the terms ‘kids’ and ‘children’ interchangeably in this book, because that is how parents speak.
Why children need to know

When you were told you had cancer, your first worries may have been for your children: How will they cope if you get really sick? What will you tell them? How will it affect their lives?

You’re not alone – each year in NSW, 30,000 people are diagnosed with cancer. About one-quarter of these people have a child under 18.

It can seem overwhelming, but there is strong evidence that being open and honest with your children is the best way to help them cope with your cancer.

This chapter looks at the reasons for telling your children about your cancer and includes general tips to help your family.

There are several reasons why it is best to be honest with your children about your cancer.

Secrecy can make it worse

Some parents avoid talking about their cancer because they want to protect their children. However, there is strong evidence that children who are told about their parent’s cancer have lower levels of anxiety than children who are kept in the dark. The problem with secrets is that they are very hard to keep.

A family’s story

Bronwyn did not tell her children she had breast cancer, despite having had a mastectomy and needing a wig to cover hair loss from chemotherapy. Because her own mother had died from breast cancer, Bronwyn refused to tell her children because she feared they would worry that she would also die.
You can’t fool kids

Children are observant. No matter how hard you try to hide the cancer diagnosis, most will suspect something is wrong. They will notice changes at home, such as your sadness, whispered conversations, closed doors and the many phone calls. These signs may be obvious to older children and teenagers, but even young children can sense a change.

If your kids suspect you are facing a serious problem, and you haven’t told them about it, they may make up their own explanation. Their fantasy is often worse than the reality.

They have a right to know

Children can feel deeply hurt if they suspect or discover they have been excluded from something important to them and their family.

If you involve them, you show you trust their ability to participate, which can enhance their self-esteem and can be a chance for growth. This may be a powerful opportunity for your kids to learn about living with uncertainty – and how to cope when life doesn’t go to plan.

They might find out from someone else

If you tell close family and friends, there is a chance your children will hear about the cancer from someone else or overhear a conversation. The worst way to hear difficult news is to overhear it. It can give your children the wrong idea. They may think the topic is so terrible you can’t talk about it, or that they are not worthy of being included in the discussions.

Kids can cope

When you have cancer, it can be tough on your children and you may wonder how they will get through it. But there is evidence that, with good support, kids can cope.

Research has shown that a key factor that helps kids get through difficult times is a close relationship with an adult. That adult can be you, the other parent, grandparents, a favourite aunt or uncle or family friend. Whatever the connection, an adult who is a source of support and good communication can help a child withstand the toughest of times.

What parents say

“I didn’t tell her straight away because I didn’t want her to worry over Christmas. I didn’t want this Christmas to be any different to all the other lovely Christmases we’ve had.”

Father of a 16-year-old.

“Sooner or later they were going to find out. Why not tell straight away? I tell them frankly what is happening. I think they find it much easier to cope because they are ready for things.”

Mother of three children, aged 16, 13 and 12.
Children need a chance to talk

Talking to your children about cancer gives them the chance to tell you how they feel and lets them know it is okay to ask questions.

Parents who can’t tell

While more parents are choosing to be open about their cancer, some find it hard to tell their children and try hard to hide their illness.

Some parents have their own reasons for not telling their children, including cultural differences, family circumstances and the death of a close relative from cancer.

If you need support about issues that prevent you from talking to your children about cancer, please call the Cancer Council Helpline on 13 11 20, where trained oncology nurses can talk to you about your children and the difficulties you face.

How The Cancer Council can help

Talking to kids about your cancer can be very difficult. To help you in this situation, The Cancer Council NSW offers telephone support groups.

This service provides the opportunity to talk to other parents in a similar situation guided by two specially trained facilitators.

In the groups you can practise what you would say to your kids and can hear from others what has worked and what hasn’t gone so well.

If you live in NSW and would like more information, or want to enrol in a group, call the Cancer Council Helpline on 13 11 20.

What parents say

“We mustn’t brush them away. Children are aware and children can cope, so I’ve never pretended with them, but I’ve certainly accentuated the positive.”

Mother of a five-year-old.

“Try to be positive and look at the cup half full. My own experience was that it was a very positive year for our family and a time for closeness. We had lots of fun and learnt to treasure each other more.”

Mother of three boys, aged 18, 16 and 10.

A family’s story

Ron, whose wife had cancer, had two daughters, Kelly and Marie. Kelly was sporty and Ron found the best time to talk to her was when they played basketball in the backyard. Between shots, Ron would occasionally ask a question about how she was feeling. For Marie, the best time to chat was storytime before bed. Ron would use that quiet time to talk with her about how she was feeling about mum. Sometimes she would say she was okay and would want to go on with story, other times she wanted to talk.
Cancer in the family: ten ways to help your kids cope

1. Open the door

For many people, cancer is a long and uncertain journey. At diagnosis you may know little about your cancer, so it’s difficult to know what to tell your children.

This means that telling your children about cancer is not a one-off event. It is an unfolding story, and your children will need regular updates as you find out more information.

When you first break the news (see page 19), let your children know they can come to you at any time with questions or concerns. Children often won’t say they are worried, so they need lots of chances to talk and for you to draw out those concerns.

So it’s a case of opening the door to talk about cancer and trying to leave that door open throughout your cancer experience.

2. Don’t expect to be perfect

Talking to your kids about cancer can be confronting and upsetting. Sometimes it can be tricky to talk to them, and you may make a bit of a mess of it. Don’t panic. If things don’t work out the way you planned, take time to work out what you will do differently next time.

Kids will cope if a conversation doesn’t go exactly as planned. And a setback can be a great chance for growth for both you and your kids.

Give yourself a break – you weren’t a perfect parent before cancer and you won’t be a perfect parent after the diagnosis.

3. Let your kids ask questions

Try not to overload children with too much information at once. One way to avoid this is to give them small amounts of information, wait and then ask them if they have any questions. If they don’t, leave it at that. They may come back a day or two later to ask you a question.

Answer their questions as accurately as possible, considering their age and experience of cancer in the family.

If your kids know they can ask you anything at any time and you’ll do your best to answer, this opens the door for continued communication. It can help to show you appreciate their questions by saying something like: “You have such great questions.”

Often children’s questions have a hidden meaning, so try to tease out the real meaning with responses like: “That’s interesting. What got you thinking about that?”

You don’t have to immediately answer questions. If you don’t know the answer or want to think about it first, say you’ll come back with an answer. You could say something like: “That’s a really good question and I want to talk to dad/mum/the doctor. I’ll let you know what they say.”

This shows that you welcome all questions.
4. **Take every opportunity to communicate**

Most parents know the times and situations when their kids are more likely to open up. For one child it may be bath or bedtime, for another it may be the walk or drive to school.

Try to tap into those times and be creative in finding ways to talk to your children and find out how they are feeling. You don’t have to sit down and have a heart to heart, which children may find threatening. Sometimes the best conversations are in the car or while you’re doing the washing up.

Tune into how your kids like to play, because games can often reveal a lot about what they are thinking and feeling. From sandpit play and journal writing to playing with toys or kicking a soccer ball, there are many ways to gently find out how your children are feeling.

Art is also a great way to get kids talking. For younger children, you can ask them to draw a house, and draw each of the family members, so you start to get the picture of how they see the family.

(See Chapter 2 for tips on talking to kids of different ages.)

5. **Be honest and maintain trust**

You can’t protect your children by avoiding the truth. Once you’ve established good communication about cancer, keep it going by being as open as you can, even if the news isn’t good.

6. **Ask them what they know**

Encourage your children to tell you what other people have said about your cancer. This gives you the chance to clear up any misunderstandings and, if they hear anything that upsets them, they know they don’t have to worry alone.

7. **Set them straight**

Children often worry that they caused a parent’s cancer. Make it clear that nothing they have done caused your cancer and nothing they do can affect the course of the cancer.

8. **Show your love and emotion**

As always, take every opportunity to tell your children that you love them. Assure them they will be looked after throughout your cancer treatment, even if you can’t always do it yourself. And don’t be afraid to show your emotions in front of your children. This shows them that it’s okay for everyone to show their feelings, and that you don’t always know what to do or say.

It’s also important to show your children that you love them, with lots of hugs and spending special time together.

9. **Preserve family time and change their routine as little as possible**

Continue with your normal routines as much as possible. If you can, during treatment try to set aside time for the whole family as well as for each of your kids.

Depending on your family, there may be many people coming to your house to help. This is great, but it is important to make sure that helpers don’t take over and visit too much. Sometimes it can be useful to let helpers know that a particular day or afternoon is family or quiet time.

Tell your kids it’s okay to go about their life as usual – to see friends, play sport, do after-school activities and have fun. Welcome their efforts to help out at home but don’t take it for granted.

10. **Be prepared to listen**

When you’re talking about the cancer and treatment, remember to stop and listen to your children. Sometimes parents are so intent on talking about the medical information they don’t hear how their kids really feel.
From toddlers to teenagers – what to say

Regardless of age, all children need to know that they are loved and will be cared for when a parent has cancer.

This chapter includes general information about how different age groups understand and react to a parent’s cancer, and some tips for helping them cope. Every child is different, so use your knowledge of your child’s personality to help work out how they may react.

For detailed information about how kids of all ages understand a cancer diagnosis and react to it – and how to help them cope – see the table on pages 16-17. On the next few pages, we have tips and parents’ stories to get you started.

Newborns, infants and toddlers

Children in this age group usually have little awareness of illness but will react to being separated from you and changes in routine. They may not be able to talk about it, but they often pick up on physical and emotional changes. Their level of awareness can be surprising.

For this age group, the key issues are meeting their basic physical and emotional needs and reducing the impact of separations.

What you can do

- Routine is important for children in this age group. If you bring in extra helpers, ask them to try to follow the same routine.
- Create a familiar environment that can travel with the child. This could be a travel cot that has the child’s favourite blankets and toys. Your child could sleep in the travel cot at home and away.

A family’s story

Melissa, mother of Maddy, 2, and Anna, 4, was having chemotherapy. Every afternoon when she came home after treatment, Maddy would check her mother’s arm for the Band-Aid. If she found one, Maddy would bring her mother a bowl in case she had to vomit. For months after the chemo finished, Maddy continued to check her mother’s arm.

Preschool children, 3-5 years

Children in this age group are beginning to understand the difference between being well and being sick.

They often think the world revolves around them and believe in magical thinking, which means that wishing or hoping can make something happen – like wishing for a special Christmas present. But it also means they believe that being naughty or thinking angry thoughts can make things happen too. So it makes sense that a preschooler may worry that they caused a parent’s cancer, perhaps by being naughty.
A family’s story

Pauline, who had breast cancer, looked after her grandson, Kyle, two nights a week. Kyle, 4, slept in the same bed as his grandma. He liked to snuggle close to her and would often rest his head on her chest. After her mastectomy, Kyle wasn’t able to stay for a while until Pauline recovered. When he returned, Pauline wisely realised that she needed to explain why her breast wasn’t there. Kyle simply accepted the change, and occasionally would whisper secretively to her: “We know you’ve only got one boobie.”

What you can do

- Find out what your preschoolers know by saying: “What do you think cancer is?” Ask them to draw a picture of cancer and then explain it.
- Ask them what they think caused the cancer by saying: “How do you think daddy got his cancer?”
- Set them straight by saying: “Sometimes kids worry that they thought or did something to cause cancer. Kids never cause cancer.”
- Reassure them that you are not about to die and there are ways to treat your disease.
- Help them to feel important by saying things like: “I love the pictures you bring into the hospital.”
- Maintain routines and limits, which help children feel secure. Bedtime rituals can help ease fears of separation.

School-age children, 6-12 years

By this age, some children know about cancer, but may not know what causes it. They are likely to fill in their gaps in understanding with their own theories.

They have simple cause-and-effect logic. For example, it is common for children of this age to think that cancer is contagious, that all people with cancer die, and that smoking causes all cancer.

They usually understand the permanence of death, so they may ask questions about death.

This age group can feel guilty about things they have said or done to the parent and may try to be ‘very good’ to avoid troubling their parents.

School and best friends are often important to them. School can provide time out if things are stressful at home. Many children of this age will want their lives to be as normal as possible and may not want their friends to know that mum or dad has cancer. This means that, even if you are talking openly about your cancer at home, your children may not want to be open with their friends.

Also, their main concerns are for themselves. They may be thinking: Did I cause it? Can I catch it? Who will look after me?

Sometimes their feelings and words are separated – they will feel upset but their words don’t express it. An example would be the four-year-old who announces, all smiles, at preschool: “Guess what? My dad’s got cancer!”

A family’s story

Nicole and her nine-year-old daughter agreed to share their feelings by writing and drawing in the same journal. Nicole was surprised by how much came through in the journal. Her daughter found it easier to write about some feelings than talk about them.
What you can do

• Be open and truthful so they don’t fill in the gaps with their own interpretation.
• Give them little tasks to help around the house and to help you feel better (eg, bringing you a glass of water). If they want to do more, let them.
• Reassure them that cancer is not contagious, that its causes are complex and often unknown, and that smoking does not cause all cancer.
• Let them know it’s not selfish to enjoy themselves.
• Tell the school about your cancer (see page 21).
• Help your children to understand that what their schoolmates say may not always be right. You could say something like: “I know Tom says that cancer is really bad and I will get very sick, but Tom doesn’t know everything about my cancer. I will let you know exactly what is happening.”

Teenagers, 13-18 years

Teenagers have an adult understanding of cancer, and often want detailed information about their parent’s illness.

Teenagers are at a stage when they are starting to separate from the family and to think about who they are as young, independent adults. This time can be turbulent enough, but if a parent is diagnosed with cancer, it can become even harder.

Teenagers can feel an overwhelming sense of responsibility to become more involved and help out at a time when many of them are looking for independence. This conflict can make them feel frustrated and guilty.

A family’s story

Graham’s wife had advanced cancer. Their 13-year-old daughter, Ellie, wouldn’t talk to him, and he struggled to find ways to communicate with her. He found that simply spending time together helped them to stay in touch. Sometimes they would sit on the lounge and watch TV together, and she would put her feet on his lap and let him massage them. Graham felt it was Ellie’s unspoken way of connecting with him.

What kids say

“When my mum was diagnosed I was only nine years old, so I didn’t know how serious it was. All I knew was that my mum was sick and may never get better. For me cancer didn’t really change my life heaps because I didn’t understand what cancer was all about.”

Julia, aged 14.
Teenagers’ relationships with people outside of the family are important. It’s normal for teenagers to confide in an adult who is not a parent, such as their best friend’s mum. Their friends are also very important. However, relationships may become strained with their friends who are having trouble coping.

Some teens may worry that they will also get cancer, particularly daughters of women with breast cancer.

Teenagers will worry about you, but they will also want to get on with life – and this may cause problems.

What you can do

• Check in with teenagers if they’re okay and if they’re getting enough information. They may not tell you what they’re thinking or feeling. You can ask permission to see how they’re going by saying something like: “It’s important for me that I check in with you at least once a week to see how you’re going. Is that okay with you?” This can help you feel better, and your teenager, even though they may resist, may feel better too.

• Realise that even though cancer is tough, kids will be kids. When you’re feeling low, a teenager’s normal behaviour can be upsetting, but it’s no reflection on you or how much they care for you.

• Be careful about assuming that the teenager should take a parenting role with younger brothers and sisters. Some teenagers may be happy to do this because they feel they are helping, but if they feel it has been dumped on them, it can lead to anger and stress.

• Understand that some teenagers may not want, or need, to talk about the cancer. Keep providing the information without forcing them to talk about it.

• Encourage their relationships with other adults. If you say things like, “It’s good that you and (their best friend’s mum, for example) worked that out together,” it gives the message that you appreciate it, rather than think it is disloyal.

• Talk to them about how to find a balance between going out and staying home. Let them know that you understand how difficult it is for them.

• Welcome their help with household chores but don’t expect it. It’s reasonable to expect teenagers to help out. If they are given jobs they can do, they will feel they are contributing. The key thing is to negotiate what is fair, rather than taking the teenager for granted. Teenage girls are more likely to become stressed if they feel you expect them to do too much.

• Keep an eye on the information they’re getting from the Internet. Explain that not all websites are reliable and that everyone’s case is different. See Chapter 8 for some reliable websites, including the excellent National Breast Cancer Centre site, www.myparentscancer.com.au/.
## Children’s reactions and needs at different ages

### Newborns/infants/toddlers

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<td>fussy and cranky</td>
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<td>Infants are aware of feelings that parents show, including anxiety.</td>
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<td>They are aware of periods of separation from parents.</td>
<td>change in sleeping or eating habits</td>
<td>Give plenty of physical contact (patting, hugging, holding).</td>
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<tr>
<td>They can get upset when the presence of a physical and loving parent is missing.</td>
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<td>Observe play for clues to their adjustment.</td>
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<tr>
<td>Toddlers may react to physical changes in their parent or presence of side effects (eg, vomiting).</td>
<td>slight skin rash</td>
<td>Provide daily contact to help them feel secure.</td>
</tr>
<tr>
<td></td>
<td>toddlers: tantrums, more negativity</td>
<td>Express your feelings and fears with others.</td>
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<td>returns to thumb sucking, bedwetting, baby talk etc.</td>
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### Preschoolers (3-5 years)

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<td>Talk about the illness with pictures, dolls, or stuffed animals. Read a picture book about the illness.</td>
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<td>Infants are aware of feelings that parents show, including anxiety.</td>
<td>fear of the dark, monsters, animals, strangers and the unknown</td>
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<tr>
<td>They are aware of periods of separation from parents.</td>
<td>nightmares</td>
<td>Explain what they can expect; describe how schedules may change.</td>
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<td>They can get upset when the presence of a physical and loving parent is missing.</td>
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<td>Reassure them that they will be taken care of and will not be forgotten.</td>
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<td>sleepwalking</td>
<td>Provide brief and simple explanations. Repeat explanations when necessary.</td>
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<td></td>
<td>bedwetting</td>
<td>Encourage them to have fun.</td>
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<tr>
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<td>Assure them that they have not caused the illness by their behaviour or thoughts.</td>
</tr>
<tr>
<td></td>
<td>baby talk</td>
<td>Paraphrase for children what their behaviour might mean.</td>
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<tr>
<td></td>
<td>hyperactivity</td>
<td>Continue usual discipline and limit setting – provide outlets for aggression that are positive.</td>
</tr>
<tr>
<td></td>
<td>apathy</td>
<td>Be sure children get physical activity to use up excess energy and anxiety.</td>
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<tr>
<td></td>
<td>fear of separation from significant others (especially at bedtime and going to preschool)</td>
<td>Assure them they cannot catch the illness.</td>
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**Children’s reactions and needs at different ages**

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School-age children (6-12 years)

Children’s understanding of illness
• They are able to understand more complex explanations of cancer diagnosis.
  Can understand what cancer cells are.
• They still may feel responsible for causing illness because of bad behaviour.
• Children aged nine and over understand that parents can die.

Children’s possible reactions
• irritable
• sad, crying
• anxiety, guilt, jealousy
• physical complaints: headaches, stomach aches
• separation anxiety at time of going to school or away to camp
• hostile reactions toward sick parent, like yelling or fighting
• poor concentration, daydreaming, lack of attention
• poor grades
• withdrawal
• difficulty adapting to change
• fear of performance, punishment, or new situations
• sensitivity to shame and embarrassment

Parents’ possible response
• Use books to explain illness, treatment and potential outcomes.
• Assure them that they did not cause the illness by their behaviours or thoughts.
• Reassure them about their care and schedule.
• Tell them the other parent is healthy.
• Let them know how they can help.
• Take time to listen and let them know you care about their feelings.
• Address issue of parent dying even if children do not bring up the topic.
• See also ideas for preschool age children.

Teenagers (13-18 years)

Children’s understanding of illness
• They are capable of abstract thinking: they can think about things they have not experienced themselves.
• They are able to begin thinking more like adults.
• They are able to understand that people are fragile.
• They are able to understand complex relationships between events.
• They are able to understand reasons for symptoms.
• They are more likely to deny fear and worry in order to avoid discussion.

Children’s possible reactions
• want to be more independent and treated like adults
• anger and rebellion
• may criticise how parents handle the illness situation
• depression
• anxiety
• worry about being different
• poor judgment
• withdrawal
• apathy
• physical symptoms: stomach aches, headaches, rashes
• more likely to turn feelings inward (so parents are less likely to see reactions)

Parents’ possible response
• Encourage them to talk about their feelings, but realise they may find it easier to confide in friends, teachers or other trusted people.
• Provide plenty of physical and verbal expressions of love.
• Talk about role changes in the family.
• Provide privacy as needed.
• Encourage them to maintain activities and friendships.
• If there are problems, provide opportunities for counselling.
• Set appropriate limits.
• Don’t rely on them to take on too many added responsibilities.
• Provide resources for learning more about the disease and getting support.
• See also ideas for school-age children.
What parents say

“It’s hard to think about talking to your kids when you are diagnosed. You are so overwhelmed with your own information that to stop and be calm and in control is hard.”

Mother of two teenagers.

Dealing with the diagnosis

Look after yourself

Telling your kids you have cancer is confronting and difficult. It’s important not to attempt it while you’re in shock and still grappling with your own feelings.

You may have trouble helping your kids cope with cancer if you’re struggling yourself. You are facing a big emotional and physical challenge and will have to make many decisions, but you don’t have to do it on your own.

• Call in the cavalry. Family and friends will be keen to help out but may not know how. Write a list of things they can do to help, or ask a friend to co-ordinate offers of help.

• Use support services. There are many services to help people newly diagnosed with cancer. Some are listed in Chapter 8. A good starting point is the Cancer Council Helpline (13 11 20). For the cost of a local call, you can talk to an oncology nurse, who can help explain treatment options, provide emotional support and refer you to local services.

When to tell

Deciding when to tell – and how much to tell initially – can be difficult, depending on the type of cancer you have and how much is known about your case. Parents sometimes decide to hold off telling their children until they know more about their prognosis, such as if they’re waiting on test results to see if the cancer has spread.

Keeping a secret while you’re waiting for results will increase your stress and your children will probably sense that something is wrong. So try to tell the kids the truth as soon as you feel able. If you don’t know how serious it is, say so.

Getting started

In the blur of the first few days after a cancer diagnosis, these things can help you prepare for the first conversation with your children.

• Make sure you understand the facts. If there are things you don’t understand, make an appointment to see your doctor so you can check on any grey areas. It can help to take a relative or partner with you who can take notes. Another option is to call the Cancer Council Helpline (13 11 20) and talk to the oncology nurses who may be able to answer some of your questions.
• **Talk through your feelings with another adult.** This can help you to deal with your emotions before talking to your kids. You may choose to talk to a close friend, family member or a spiritual adviser.

• **Practise what you want to say.** Parents often doubt their ability to find the right words and to answer tricky questions from their children. Role-playing the conversation with your partner, friend, relative or the oncology social worker at the hospital can show that you can do it. It means you’ve spoken the words and perhaps dealt with some of the anxiety attached to those words before you talk with your kids.

### The first conversation

#### How to tell

The choice of who tells the children may depend on how your family already communicates. In most two-parent families, one parent usually does most of the talking, so it may be best if that parent breaks the news, ideally with the other parent present.

If possible, the key thing is that you tell your children before they start to worry.

Depending on the ages and temperaments of your children, you may decide to tell them separately or together. Ideally, you should tell them at a time and in a place where they are most likely to listen and take it in.

Have a plan of what to say but be prepared for anything. If your plan falls over and you end up blurting out the bad news, don’t panic. You have many conversations ahead of you and your children won’t be damaged by one discussion that doesn’t go according to plan.

#### What to say

• **Tell them the basics in words they can understand.** Breaking the news in the beginning can be just a few short sentences explaining what you know so far and what will happen next. You can use children’s cancer books to help explain cancer terms (see Chapter 8).

• **Find out what they already know.** Ask your children what they know about cancer and then deal with any myths (eg, you can catch cancer).

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### What kids say

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

*James, aged 12.*

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

*Lily, aged 17.*

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### In a nutshell

• Tell your kids what has happened.

• Explain what will happen next.

• Leave them with feelings of hope that even though you are upset now, there will be better times.

• Assure them they will continue to be loved and cared for.
• Ask them what they want to know. Only answer questions that the kids ask, and don’t assume they have the same fears as you. Avoid giving too much information.

• Be honest and open. Don’t be afraid to say you don’t know the answer to a question. Say you’ll try to find out the answer from the doctor and let them know as soon as possible. Make sure you follow through.

• Tell them what to expect. Let them know about changes to their routine that may happen (eg, mum won’t be able to pick them up from school).

• Ask them who they want to tell. They may want to tell their best friend, the teacher, the whole class – or no one.

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

• Balance hope with reality. Tell your children that although cancer can be serious, many people get better and you are doing everything you can to be well.

• Listen. Let them know that they can talk to you about anything – even scary and awful feelings. You can’t always take away those feelings, but you will understand and help them to cope.

Words you can use

Here are some ways to tell younger and older children you have cancer.

For younger children

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

“I have an illness called cancer. It means something is growing inside my body that shouldn’t be there. I am going to have an operation to have the cancer taken out and some more treatment to make sure it doesn’t grow back.”

For older children and teenagers

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

“You know I’ve been sick a lot lately. The doctors told me today that the tests show I have cancer. The good news is that I have an excellent chance of beating it.”
Ask for help

You don’t have to tackle the task of talking with your children about cancer on your own. There are many ways to lessen the burden and to ensure they hear a consistent message from people who are involved in their lives.

- **Tell key adults.** Think about other people who talk with your kids (grandparents, friends and housekeepers). Tell them about your diagnosis and your plan for talking to the children, so that you all say the same things.

- **Talk to other parents who have cancer.** Often the best support and ideas come from people who have already been there. Talking with other parents makes you realise you’re not alone and gives you access to a wealth of creative ideas. Contact the Cancer Council Helpline (see Chapter 8) for ways to get in touch with other parents.

- **Ask a professional.** Get some tips from the oncology social worker, psychologist or other health professionals at the hospital.

Involving the school

If things are wobbly at home, school can be a haven for your kids – a place where they can be themselves with their friends and carry on life as normal. School can also be a source of support.

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

- **Tell the principal and your child’s teachers.** They will know of other parents at the school who have cancer and this may affect your child’s perception of cancer (eg, if a parent of a child at the school has died of cancer).

- **Ask the school to keep an eye on your children and to let you know of any worrying changes, such as bullying.** But ask the teacher not to probe – some well-meaning teachers could push too hard (eg, they may ask your child if they are okay when they are happily sitting on their own).

- **Ask a parent of one of your child’s best friends to help you keep track of notes, excursions, homework and events.** When life is disrupted at home, kids may feel doubly hurt if they miss out on something at school because a note goes missing.

What parents say

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

Mother of two children, aged 12 and three.

A family’s story

Gemma, aged 8, asked her mother, Gayle, to not pick her up from school because Gayle was wearing a wig. Children at school had teased Gemma about the way her mother looked. Gayle confronted the issue head on. After asking permission from Gemma, the school and her classmates’ parents, Gayle visited the class and spoke about her cancer and treatment side effects, and why she wore the wig. Once the children understood, the teasing immediately stopped, and the children started to support Gemma.
Answering key questions

Here are some ways to deal with the most common questions that kids raise at diagnosis.

Are you going to die?

This is the question that most parents fear, but often it doesn’t mean what you think. Firstly, try to explore what the child means, by saying: “Do you have a special worry?” or “What were you thinking about?”

Younger children may really mean, “Can we still go on that holiday?” while older children may mean, “Who is going to look after me?”

Some children think that cancer is a death sentence, so explain that many people are cured of their cancer and that new treatments are being found all the time.

Words to use

“Some people die from the type of cancer I have, but I plan to do everything that my doctor recommends to get better.”

“We’re not planning on that, but I’ll probably be sick for a while.”

Am I to blame?

Some children may ask you directly if they are to blame for your cancer, while others worry in silence, so it’s best to confront the issue.

Words to use

“It’s no one’s fault that I have cancer. Nothing you did or said made me get sick.”

“You can’t make my cancer better or worse, but you can make me laugh with a funny story.”

“Don’t ever think that you caused this cancer or that your behaviour can make the cancer better or worse.”

Can I catch cancer?

A common misconception for many children (and some adults) is that cancer is contagious. This belief can be reinforced after chemotherapy when a patient has to avoid contact with people who are sick, because of the risk of infection.

Words to use

“You can’t catch cancer like you can catch a cold, so it’s okay to be close to me when I’m sick.”

“No, even though cancer can spread through a person’s body, it can’t spread to another person.”

What parents say

“Spend time together as a family. Special times together will often open up questions from kids.”

Mother of three children, aged 18, 16 and 10.

“It helps to focus on what is happening now, what is actually known – not all the possibilities. One step at a time. It is important to reassure children that you are not going to die immediately, that cancer is not a death sentence and that everything will be done to ensure that you live. Children often have unusual ideas about this.”

Mother of three children, aged 18, 16 and 10.
Who will look after me?

When a parent has cancer, the most important thing for children is what will happen to them and how will it affect their lives. Children need to know the basics: who will look after them, who will pick them up from school, and how roles will change. Try to give them as much detail about changes as possible, so they know what to expect.

For older children, it’s important to ask them what arrangements they prefer.

Words to use

“We will try to keep things as normal as possible, but there may be times when I have to ask dad/mum/grandpa to help out.”

Do I have to tell other people about it?

Your children may not know who to tell about your cancer and how much to say. They may not want to say anything at all. So it helps to explore their feelings about talking to other people – this can trigger a discussion.

If you’re planning on telling your children’s teachers, counsellor or principal, it’s important to let your children know.

Words to use

“You don’t have to tell anyone, but would you like to speak to anyone?”

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

“You don’t have to tell anybody, but if you feel comfortable, it might help.”

What can I do to help?

Answering this question can be a delicate balance. It’s great to allow the kids to help out and contribute, but it’s important that they don’t feel overwhelmed with responsibility.

Words to use

“Yes, there are lots of things you can do to help out. We can work out together what those things could be, and that will make things easier for everyone.”

What parents say

“Let the kids know how much you appreciate the little things they do. Give them ways of helping and looking after you so they can share in your treatment and help make you better (eg, “I love the way you make my tea. It is important for me to drink lots of fluids.”).

Mother of three children, aged 18, 16 and 10.
Talking about treatment

For many people, cancer is their first experience of major illness, so it can be difficult enough to prepare for chemotherapy, radiotherapy, surgery and other treatment, let alone prepare the kids.

But there are things you can do to help your kids understand and cope with what is about to happen.

Understanding treatment

Firstly, it can help to understand the treatments and how they will affect you. Don’t be afraid to ask the doctor to explain anything you don’t understand. The nurses, hospital social worker and Cancer Council Helpline (13 11 20) are also good sources of information about treatment options and side effects.

Once you have a good understanding of the treatment, you should find it easier to explain it to your kids and answer their questions.

What do children need to know?

The treatment plan

Children often need information to prepare them for what is about to happen to you and how it will affect their lives. Just like you, they need to understand the treatment, why and how it is done, and the side effects.

Again, let your children be your guide to how much they want to know about your treatment. Firstly, explain the basic facts of your treatment – using language they can understand (see table next page).

Ask them what they understand so far and if they have any questions. Make it clear they can come back to you throughout your treatment with questions and concerns.

What parents say

“I turned my yuck chemo days into ‘treat’ time for the kids and me. We’d go to the video shop the day before the chemo to make a family selection. The TV and video were moved into my bedroom ready for the next day. When they came home from school/crèche, they’d come to my room and we’d watch the videos together. I didn’t take much in and often dozed, but at least we were all in the same cosy room. It made the times very special and something that was positive to enjoy in the midst of all the awful treatment!”

Mother of two children, aged 12 and three.
### How to explain cancer words

| Word                  | To young children                                                                                                                                                                                                 | To older children and teenagers                                                                                                                                   |
|-----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Cancer**            | Cancer is when bad cells – or trouble-maker cells – stop the good cells from doing their job. These bad cells can grow into a lump and can spread to other parts of the body.                                               | Cancer is the name for more than 100 diseases in which abnormal cells grow and rapidly divide. These cells usually develop into a lump called a tumour. Cancer can spread to other parts of the body.                        |
| **Cells**             | The body is made up of millions of tiny things called cells, and each has a job to make your body work and stay healthy.                                                                                              | Cells are the basic building blocks of the body. Our bodies constantly make new cells: to enable us to grow, to replace worn-out cells or to heal damaged cells after an injury.                                   |
| **Chemotherapy**      | Medicine that kills the bad cancer cells.                                                                                                                                                                           | Special drugs that kill cancer cells or slow their growth.                                                                                                          |
| **Malignant**         | Another word for cancer.                                                                                                                                                                                                 | Cancer. Malignant cells can spread to other parts of the body.                                                                                                    |
| **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.                                                                                                        |
| **Palliative care**   | Sometimes the doctors and nurses can’t stop the cancer from growing, and they will give mum/dad medicine to make them feel better and stop the pain, even though the cancer can’t be stopped.          | Treatment that controls symptoms without trying to cure the cancer.                                                                                                 |
| **Prognosis**         | What the doctors think might happen to mum/dad after treatment and their chances of getting better.                                                                                                               | The likely outcome of a disease, especially the chance to get better.                                                                                              |
| **Radiotherapy**      | X-rays or a laser beam that goes into the body to kill cancer cells and make the cancer smaller.                                                                                                                                 | The use of x-rays to kill or injure cancer cells so they can’t grow or multiply.                                                                                     |
| **Recurrence/relapse**| If cancer cells are left in the body, they can start to grow again, and the cancer comes back.                                                                                                                      | When cancer comes back because of cancer cells that evaded treatment.                                                                                               |
| **Remission**         | When the cancer goes away after treatment.                                                                                                                                                                           | When cancer cells and symptoms disappear because of treatment. Remission doesn’t mean the cancer is cured, but that it is under control for a period.                    |
| **Side effects**      | Problems that can make mum or dad feel sick or tired or lose their hair after treatment. This is because the treatment stops good parts of the body growing as well as the bad parts.                              | The unwanted effects of treatment such as nausea, hair loss and fatigue from chemotherapy and/or radiotherapy.                                                   |
| **Surgery**           | This is when mum/dad will have an operation and a surgeon will cut out the cancer.                                                                                                                               | An operation to remove the part of the body where there is cancer.                                                                                                |
Explaining side effects

It’s important to prepare your children for treatment side effects, such as changes in your body after surgery, weight changes, fatigue and hair loss.

When you talk about side effects, two important things to say are:

• **Not everyone gets all side effects.** People who have the same cancer and treatment will not necessarily have the same side effects. Your doctor knows what happens to most people who have your treatment, but can’t be exactly sure what will happen to you. Tell your children what the doctor has told you, and say you will tell them if you start to experience side effects.

• **The side effects don’t mean you are getting sicker.** It’s common for kids to get really upset on chemotherapy days, when they see you looking sick, and worry that the cancer has progressed. Explain to them that the side effects are separate from the cancer symptoms. Also, let them know that if you don’t get side effects it doesn’t mean the treatment isn’t working.

What will happen to them?

Routines can help children to feel safe and secure. If you have to change a normal routine during treatment, tell them what the change will be and how it will affect them. Let them know the basics, such as who will pick them up from school or take them to swimming lessons.

Creative ways to explain treatment

**Use resources.** For younger and school-aged children, children’s books and comics can be a great tool to explain the basics of treatment. *Chapter 8* lists these books.

**Make up stories and play games.** Try explaining cancer treatment to your kids through stories and games. You could make up a story about the battle of the good cells and the bad cells, with surgery, radiotherapy, chemotherapy and other treatments as the weapons.

Tap into stories that kids love; think of the good and bad forces in *Harry Potter* and *Lord of the Rings*. You could build a Lego game to show how, in the battle to defeat the bad cells, some good cells get hurt too (side effects). Kids who love Game Boy or PlayStation will quickly get the idea about chemotherapy zapping the bad cells.

There are many ways to tell such a story or play a game. Once you get your kids started, their imagination will do the rest.

Also, think about ways to use art, drawing and music to talk about cancer treatment. Simply asking your kids to draw cancer can show a lot about what they understand. You could ask them to draw how they think radiotherapy x-rays kill cancer cells. Sometimes, drawing is not as threatening as talking about cancer.
Offer them a tour. Before treatment starts, you may like to take your children for a tour of the treatment centre or hospital ward.

Primary schoolchildren are often interested in the science of treatment. With notice, the cancer treatment centre staff may be able to arrange a tour of the radiotherapy unit and explain how the technology works. This experience will mean your children can understand how it works and can picture where you are and what you’re doing during treatment. It may also be a conversation starter.

Hospital and treatment centre visits

Cancer treatment can involve short but frequent visits to the hospital as an outpatient or inpatient stays. You might worry your children will be stressed and anxious if they see you in hospital or having treatment, but it can be worse if they are separated from you and can’t picture where you are.

Ask your kids if they want to go to the hospital or treatment centre. If they refuse, don’t force the issue.

If they are keen to visit you, and you can make it happen, have a plan to help the visit go smoothly.

- Tell them what they will see before they enter the room.
- Let them decide how long they should stay.
- Bring along a friend or relative, who can take the kids out of the room if they feel overwhelmed and take them home when they’re ready to go.
- If your kids are reluctant, their first visit could be in the ward lounge room.
- Bring art materials, a book or toys to keep them occupied.
- After the visit, talk to them about how they felt.

Living with uncertainty

One of the many challenges of living with cancer is dealing with uncertainty. When first diagnosed, many people want a clear map of what’s going to happen and when it will be over. But with cancer the path is not always clear.

You can communicate this uncertainty to your children by saying something like: “The doctor is pretty confident that treatment will do ‘xyz’, but if that changes, we’ll let you know, and we may have to look at another treatment.”

What parents say

“One of my children was dragged kicking and screaming to the hospital visit, which lasted all of one minute. It was of little benefit to anyone. You need to assess children individually.”

Mother of two children, aged four and one.

What kids say

“I always brought a pack of cards so we could play as soon as I got to the hospital after school. Dad made sure that there were biscuits ready for me that he had taken from the tea lady that does the rounds.”

Belle, aged 12.
Family life during treatment

Finding a balance

It’s hard to predict how you will feel during cancer treatment, but you can do things to try to maintain routines and family traditions.

Sometimes you have to strike a balance between doing regular activities and coping with the effects of the cancer. If you or your partner can’t get your children to their after-school activities, maybe a friend or relative can help out. If that’s not possible, you may have to cut back activities for a while, but involve your children in the decision.

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

Doing your best

Many parents are keen to keep life as normal and stable as possible for their kids while they deal with the disruptions of cancer. But it can be difficult to carry on as normal when you are coping with cancer and treatment side effects. You may feel guilty about not being able to do the usual things with your kids, but some days you may not feel up to doing anything.

There are no easy answers to this problem, but you can make the best of your good days by forgetting the household chores and doing fun things with the family. On the not-so-good days, if you can’t take part in their activities, watch and cheer from the sidelines. On the days when you can’t cope with much at all, let your kids know, rather than protect them from the reality of how you’re feeling.

Protecting family time

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

• Limit visitors and turn off the phone at meal times.
• Ask your friends to send an e-mail rather than call. For phone calls, ask them to ring when the children are at school or well after bedtime.
• Organise times for the kids to show you their achievements of the week.
• Organise special activities (when you’re feeling up to it).
• Ask a close friend or relative to co-ordinate all offers from friends and family to help out with household chores. This will give you more time with the family.

What parents say

“I took the kids on weekend outings while my wife rested. My kids and I set up an organic vegetable patch to provide vegies for juices.”

Father of two children, aged 10 and eight, whose wife had breast cancer.

A family’s story

Andrew, a single father, had brain cancer. His four children were aged between one and fifteen. Andrew used to surf with his older son but had to stop swimming because of seizures caused by the cancer. Instead, he worked on engines with his son. He liked to play cricket with the two middle boys – aged nine and seven – but had to stop doing that as well, so cheered them on from a chair in the backyard.
The emotions thermometer

Your physical health and emotions will fluctuate during and after cancer treatment. It can sometimes be hard to let your family know how you’re feeling and they may find it hard to ask.

An emotions thermometer may help. This is a simple device that allows you to show how you’re feeling each day. You can make one yourself and ask the kids to help.

Decide on the feelings you want on the thermometer and make a pointer that moves between the feelings. Put it up where everyone can see it, such as the fridge.

You can decide on the feelings you want to include on the thermometer, but here are some ideas:

- Feeling some pain – gentle hugs only.
- Feeling tired – offers of help greatly appreciated.
- I need a hug today.
- I need some space today.
- Feeling great – let’s do something fun.

Allowing children to help

Most children will want to help at home during treatment. If you let them help, it can increase their confidence and self-esteem because it shows that you trust and need them. Even quite young children can help. It can take longer to let a three-year-old carry in groceries from the car, but they feel they’re helping and contributing. It’s important to match the task to the child’s age and confidence.

With older children and teenagers, it’s reasonable to want them to help more around the house, but talk to them about it first.

Teenage girls are often expected to pitch in more than their siblings, which can take them away from their normal social activities, such as time with friends and chatting on the Internet. This can make them feel worse at an already difficult time and can affect self-esteem.

So it’s critical to negotiate tasks with teenagers – and share them equally if possible.

What parents say

“It was also important for me 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.”

Mother of three children, aged 18, 16 and 10.
Maintaining limits

The issue of discipline is a common concern of parents with cancer. Maintaining the family’s usual limits and discipline can enhance your children’s security and ability to cope.

Sometimes parents say they have trouble maintaining discipline during cancer treatment. 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 treatment.

It’s okay to bend the rules up to a point but try to maintain limits as best you can.

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.

The tips below can help you stay in touch. They may also be useful if you don’t have to leave home but want extra ways to communicate with your kids.

- Ask your kids to do drawings and send you their artwork.
- Read a favourite story together over the phone.
- Write an old-fashioned letter. Kids love finding a letter addressed to them in the mailbox.
- If you’re away from home, have a set time to call home each night.
- Send a tape-recorded message.
- Leave notes and surprises for kids to find, such as a note in a lunchbox.

How kids might react

Children’s responses during treatment are as varied as they are. Anger, crying and emotional outbursts are some possible and normal reactions of children who have a parent with cancer. But if their reactions seem unusual or extreme, think about getting some expert advice (see Chapter 5).

When kids don’t know how to cope, their fears can be channelled into anger because it is a familiar response. An angry outburst can be a chance to find out what’s going on – try not to shut it down and get angry yourself.
Answering key questions

Is it going to hurt?
Many children – and adults – are frightened of cancer because they think it will be painful. But cancer doesn’t always cause pain and, when pain does happen, it can be relieved or reduced.

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

Why do you look so sick when the doctors are meant to be fixing you?
Often people who have cancer look perfectly well when diagnosed. It’s only when they have treatment and the side effects kick in that they start to look sick. This can be hard for children (and adults) to understand.

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

Will your hair come back?
Hair loss can be upsetting for you and your children, so it can help to be prepared so the children know what to expect and what you plan to do about it.

Words to use
“The doctor says I might lose my hair because of the treatments. It will come back but may look a little different, especially at first. I can wear wigs, scarves or hats until it comes back.”

Does radiotherapy make you radioactive?
A common fear among children is that they can become radioactive by touching you after radiotherapy. This is not possible and you may need to make this clear to your children.

Words to use
“Radiotherapy doesn’t hurt me. It’s just like having an x-ray. It is safe to touch me.”

What kids say
“Mum developed lymphoedema, which filled her arm with very heavy fluid. Her specialist had her arm bandaged up – as mum says, like the Michelin tyres logo-man.”
Mark, aged 10.

A family’s story
Linda’s two daughters, aged six and four, made up a play in which Barbie dolls were the stars. The girls shaved the dolls’ heads and put bandannas on them. Linda joined in the game and talked about what it was like for Barbie to go through that ‘treatment’. The girls’ game not only allowed Linda to talk about cancer and treatment in a relaxed way with her daughters, it showed her how much the girls had picked up about her illness.
Getting professional help

Many professionals and organisations can help you communicate with your children throughout your cancer experience. You don’t need to have a worrying problem to contact any of the services listed in this chapter.

You can ask for help even before breaking the news to your children. They can practise the conversations with you, so that you feel better prepared.

You can also ask health professionals and organisations for help if you are worried about your children’s behaviour. You may choose to see or call the professional yourself, and to use their advice to sort out the problem. Most parents, with the right advice, can support their children through the most difficult situations.

Occasionally, a child may need to attend for a consultation, and parents may be asked to come too.

Who can help?

There are several places to look for professional help. Here are some ideas:

• Your specialist and GP. Not all doctors feel comfortable about how to talk to children about cancer. It will depend on the doctor and the relationship you have with them. Ask them if they can help.

• Nurses. Nurses may be the most constant contact you have with your treatment centre and are a source of valuable information and support.

• The oncology social work department at your hospital. The social workers talk to patients every day about communication issues and have a wealth of knowledge. They can also help you work out the best type of professional help for your family’s needs.

What parents say

“I think all members of the family should get some form of counselling. My wife found it very hard looking after a sick husband and two young kids. We didn’t have any help either outside or from the family, as they live overseas.”

Father of two children, aged four and two.
• Psychologists and counsellors. These professionals can help you work through communication and behavioural issues. Call the Cancer Council Helpline on 13 11 20 for ideas on how to find a psychologist or counsellor experienced in the area.

• Psychiatrists. Depending on the seriousness of the situation, you may need to see a psychiatrist. You will need a referral from a GP if you are being treated privately.

• Cancer organisations. The Cancer Council NSW, Cansupport and Canteen all have programs that may help. See Chapter 8 for contact details.

• School counsellors. They are trained in child development and can be an enormous source of support and ideas.

When to seek additional help

These two rules of thumb may help:

• If you are worried. A parent’s instincts are usually pretty accurate. Some families can tolerate and deal with behaviour that other families find unacceptable. You need to decide what is worrying in the context of your family.

• If your child has changed behaviour and the change persists over time. It’s not unusual for a child to revert to less mature ways of coping, such as wetting the bed. Once or twice is okay, but if it goes on every night for a month, the child is clearly struggling. Another example is when a child refuses to go to school. A child may say they have a tummy-ache and are too sick for school, but they may have separation anxiety and think they have to stay home to look after mum. The occasional reluctance to go to school is okay, but if it becomes part of a pattern, it is a warning sign.

A family’s story

This is a story of how a couple called in a team of experts to help their 14-year-old daughter cope with her father’s terminal cancer.

At diagnosis, Brian’s cancer was very advanced. Although it was hard to be sure, it seemed likely that he would survive only another few months.

Brian and his wife Jenny arranged to see the oncology social worker to talk through their options. Their daughter, Alex, didn’t have any behavioural problems, but they knew it would be a rough time for her and wanted a strategy in place.

The social worker had two sessions with Jenny and Alex, and talked about how Brian’s health would deteriorate, so Alex knew what to expect. They also discussed how Alex could make the most of time she had left with her father.

The social worker also contacted the counsellor at Alex’s school, and met with Alex and her three best friends. Alex wanted to draw on their support while her father was dying and to know it was okay to talk to her friends about him.

If you feel overwhelmed

Research shows that a child’s ability to cope is closely linked to how their parents are faring. Kids often copy their behaviour from their parents, so if mum or dad is depressed and anxious, their kids are more likely to be too.

There are many sources of support to help you. For many people, family and friends will be keen to help. You need to let them know what you need, because they may not know the best way to help. They probably have a limited understanding of what you are going through and will be relieved that you can ask for help.

For more information about coping with cancer, call the Cancer Council Helpline (13 11 20) for a copy of the free booklet, Emotions and Cancer, or download it from www.cancercouncil.com.au.
After treatment

How parents may feel

Emotional effects

The end of treatment is a time of relief and celebration, but it is also a time when many people have mixed emotions.

After treatment, some people feel at a loss. With more time and energy to think, some people start to attach meaning to the cancer.

This period can be unsettling and lead to changes, such as relationship breakups, and changes in work, diet and lifestyle. It is important to continue communicating throughout this period as you and your family adjust to a ‘new normal’.

One of the biggest fears for survivors may be that the cancer will come back. This is an understandable fear, which can be triggered by regular checkups and even minor aches and pains.

Physical effects

The physical effects can last long after the treatment is over – and some may be permanent. Fatigue is a big problem for most cancer survivors and can interfere with daily activities. Many have to deal with temporary or permanent side effects, such as physical scars, lymphoedema, premature menopause, and fertility and sexual problems.

How your children may feel

Like many adults around you, children may find it hard to understand why things simply can’t go back to the way they were before the cancer. They’ve had to make adjustments while you were sick and now may want to get back to normal.

Your children may also:

- **Expect you to bounce back.** Often children don’t understand the fatigue that lasts after cancer treatment.
- **Become clingy.** Separation anxiety that started during treatment may continue after you are well.
- **Worry that the cancer will come back.** Recurrence is also a big fear for children, just like it is for you.
Tips for helping your children cope when treatment is over

• Celebrate your achievement of surviving cancer, and thank your kids for their contribution to your recovery. Acknowledge the sacrifices your family has had to make; this is particularly important for teenagers.

• Be open about your emotional and physical state, so your children understand if you’re not bouncing back. Keep using the emotions thermometer if you have one (see page 29).

• Be open about your fears, such as if you’re feeling anxious before a follow-up visit. This may encourage your kids to talk about their fears when you go for a checkup.

• Explain changes that are being made to the family’s lifestyle and negotiate where possible.

• Encourage them to have fun. They have lived with fear for months and may need your permission to relax again.

• Consider joining a support group. Many cancer survivors join a support group to meet people who understand what they have been through and understand how they’re feeling. This can be an important outlet, which will help you cope and will therefore benefit your kids.

What parents say

“Let your children know how you will be monitored. It is important to share new information, such as results of tests, and celebrate milestones.”

Mother of three children, aged 18, 16 and 10.

“My children are too young to understand that the cancer might come back and so we didn’t burden them with this possibility. Instead we said that I was sick, had medicine and now I’m fine.”

Father of two children, aged four and two.

A family’s story

Barbara, who had early breast cancer, had surgery and chemotherapy. She had spoken openly and honestly with her son, Tom, 14, throughout the experience. When treatment was over, Tom said: “I wasn’t worried, mum. You always told me the truth and I believed you.”
Answering key questions

Will the cancer come back?
You probably wish you could tell your children that everything will be fine now, but the uncertainty of cancer lasts long after treatment is over.

Words to use
“The treatment is over and we all hope that will be the end of it. We hope that the cancer won’t come back and the doctors will keep a careful eye on me. If it does come back, I’ll let you know.”

As well as giving a positive message, this may be a chance to listen to your child’s concerns about “What if?” Allowing a child to talk about their fears and concerns is important in helping them cope.

Why are you still tired?
Cancer survivors often feel tired for many months after treatment finishes. This can be hard for kids, who want their old energetic mum or dad back.

Words to use
“I’m feeling a lot better, but it might take many months, even a year, to get all my energy back.”

Can’t we get back to normal now?

Words to use
“Things will start to get more like normal as I feel better, but there may be some changes, like I might take some time off work and have a rest. Maybe during that time we can find some new things we like to do together.”

“We’ve all been through a lot and I know it’s been hard for you too. Things might not get back to exactly how they were before I got sick, but together we can find a new way that works for all of us.”

What parents say

“It is a major psychological hurdle to be positive after treatment. It is a relief for it to be over, but during tests afterwards you always wonder if the treatment has worked. It takes time to heal mentally and it can take years, as was my case. Every year was an even better year. The family need to understand that life does not always return to normal mentally due to a near death experience and they need to support this. Sometimes you get sick afterwards, but it doesn’t always mean it is cancer or related to the treatment. It may just be the flu and children need to know this.”

Father of three children, aged six, four and two, who was diagnosed with bowel cancer when his wife was pregnant with their first child.

“This can be a strange time. The patient, partner and/or children may have expectations that life can now return to normal. The patient and family may have mixed feelings and fears, and may feel less supported than during the diagnosis and treatment period.”

Mother of two children, aged eight and four.

36 The Cancer Council New South Wales
When cancer won’t go away

How to talk with your children about advanced cancer can be very hard to explain in detail in a booklet. The issues are complex, emotional and personal. This chapter is a starting point for some of those difficult issues. If you want more information, talk to the professional staff at the hospital or the services listed in Chapter 5.

How parents react

When cancer becomes advanced, you confront difficult emotional issues and the possibility of death perhaps more than at any other time of your illness.

Many people say the news that the cancer is advanced is more devastating than the original diagnosis. Significant anxiety and depression are common and it can be harder to cope emotionally. However, people with advanced cancer who express their emotions and communicate may find it easier to cope.

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

How children react

How you react to advanced cancer can affect the adjustment of the whole family. 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 where there is a lack of communication. Some people avoid talking about the advanced cancer because they don’t know what to say.

When cancer is advanced, your children may have similar but more intense reactions than when you were first diagnosed.

Children (12 and under)

• They may worry about the well parent.
• They may think that they, or their behaviour, caused the cancer to become advanced.

Teenagers

• One of the biggest issues is that teenagers are striving for independence while feeling drawn back into the family.
• They may hide their feelings to protect you.
• They struggle with not being able to do their normal social activities – this is a significant loss for teens.

A family’s story

Jonathan’s father was dying of lung cancer. He had told Jonathan, 16, about the cancer, but not that he was dying. However, his mother had told him. Jonathan became stressed and upset because he knew his father was dying but couldn’t talk to him about it.
Keeping the door open

If cancer becomes advanced, it is more important than ever to keep talking with your children. Again, just as with diagnosis, children may sense that something is happening, and not telling them can add to their anxiety and distress.

Show them that they can talk about it and ask questions. You can say to them: “It’s okay to talk about this; you don’t have to protect me from scary feelings because you’re worried about me.”

What information do children need?

If the cancer is advanced and unable to be cured, your children may need to know how much time you have left. What you say depends on the cancer, the information you have, and the age of your children.

With some cancers, the prognosis is fairly clear and people will know that they may only have months to live. However, more people with advanced disease are surviving for a longer time, sometimes for many years.

Facing a parent’s death: how different ages react

In preparing children for the possible loss of a parent, it can be helpful to understand what death means to kids of different ages.

**Toddlers**

Very young children have some sense that something is happening. They often confuse death with sleep. While they don’t understand the permanence of death, children as young as three can grieve.

But realising he needed to tell the truth, Keith said, “I really hope so, but sometimes I’m scared that she won’t be.” This open response allowed them both to talk about their feelings.

**A family’s story**

Tom’s mother had advanced cancer, and her prognosis was not good. When Tom, 12, asked his father, Keith, if his mum would be okay, Keith’s first instinct was to say: “Yes, of course she will be mate.”

But realising he needed to tell the truth, Keith said, “I really hope so, but sometimes I’m scared that she won’t be.” This open response allowed them both to talk about their feelings.

**Ages 3-5**

Preschoolers understand the concept of death, but they struggle with the permanence of it (eg, they may ask when the dead parent is coming home).

Also, death can be hard to explain to young children because they have no adult concept of time. They can only understand what’s happening now. For example, a six-year-old can understand what it means to have five sleeps until her birthday but will not be able to understand the meaning of your reduced life expectancy.

Try to avoid explaining death to young children as sleeping, because it can cause distress about sleep.
When cancer won't go away

Ages 6-12
Primary schoolchildren know about death but often don’t have the emotional maturity to deal with it, so their behaviour may change.

Ages 13-18
Teenagers understand death as much as an adult, but may not have an adult’s emotional capacity to deal with its impact.

Facing questions about death

Honest communication
If death is likely in the short term, it is best to be as honest as possible. This is an incredibly hard thing to do and 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 tell your children.

Being open about the possibility of death gives you and your family the chance to show and say how much you care for each other – and the opportunity to resolve conflicts. The chance to talk through old arguments and make amends seems to be particularly important for older children.

Another advantage of being open about death is that it allows you to develop strategies to help your kids. For example, when a child’s parent dies, an important factor that helps them cope is having a link with the dead parent. This could be a material reminder of the parent such as a piece of jewellery, handkerchief, a rug or a cardigan that smells of dad. We don’t know how much those links can be established before death, but parents can help the child talk about those things if there is open communication.

Explore the question
When children ask a parent if they are going to die, sometimes they are really asking: “Am I going to be okay?”
A key concern for kids is who will look after them if the parent dies. This is particularly important for single-parent families.

It is very normal for a young child to worry about themselves in this situation. If you can, stop and explore the question before answering by saying something like: “Do you feel scared sometimes?” or “Have you been thinking about that a lot?”

When your child asks questions, sometimes there won’t be a hidden meaning, but other times there will. Exploring the question is a great chance to identify the feelings behind the question.

What parents say
“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 dying or how she felt about her death’s effect on me, my sister and our father.”

Mother of teenage children.
A family’s story

Marie, who had lived with advanced breast cancer for about eight years, started to deteriorate when the cancer spread to her liver. She had three daughters, including 18-year-old Kate, who had been taking drugs and having unsafe sex.

Marie knew death was close but didn’t want to talk to her daughters about it because she thought it would upset them. She was also getting increasingly angry with Kate because of her wild behaviour. Both parents despairs about the girl and had stopped trying to talk to her.

Kate’s behaviour showed she wasn’t handling her mother’s illness. After some counselling, Marie agreed to try to patch up things with Kate, and they managed to reconcile before she died. It meant Kate was able to cope with her mother’s death without terrible guilt, and allowed mother and daughter to put some of the past behind them.

Balancing hope and reality

Parents worry that if they talk about the possibility of death they take away their children’s hope. You can still be honest and offer hope.

Words to use

“The treatments can’t take all the cancer away. Now I am working to live with the cancer as long as possible.”

“It’s possible I will die from the cancer, but I’m doing my best to survive.”

“Some people with cancer get better and some don’t. I’m trying my best to get better.”

Being together

When cancer becomes advanced and life even more uncertain, many families find new ways to make the most of every minute. Here is what some people have done to maximise their time with their family:

- Accept any offers of help from family and friends. It not only allows them to feel that they are contributing, it frees up your time and energy for your kids.
- Save your energy for what matters most to you. If you want, let the housework slide and spend more time with your kids.
- Sift through old photos and make a scrapbook of your lives together, as a way to establish memories.
- Make an audio tape for each child. You could make tapes for special occasions like 21st birthdays or weddings.
Answering key questions

Who will look after me?

What happens if mum/dad/nana dies too?

The way you answer these questions depends on the nature of your cancer and the effect of treatment. Some people with advanced cancer can expect to live for many years, while for others death may be close and plans for the future more urgent. Either way, children will still be worried about who will look after them, so it’s best to tackle the question early on.

Words to use

“In case you’re worried about what will happen if the treatment doesn’t work and I’m not around, I’ve already talked to grandma/Uncle John and he/she will be here for you and look after you.”

“It’s very important to me to make sure you will be safe and looked after, so I’ve talked to mum/dad/grandpa about what is going to happen. We will talk to you about it as well.”

“When someone you love is very sick, it can make you feel very unsafe. But mum/dad/nana are well and healthy now and they will be around to look after you. Whatever happens, we will make sure you are cared for and looked after.”

What parents say

“Some of the things we have thought about are taping some video footage, reminiscing and laughing (something they can look back to) and writing each child a letter telling them some of your special thoughts, hopes and dreams.”

Mother of two children, aged four and one.
Where to find more information

The books listed here are available at the Cancer Council’s library and can be borrowed for free. Call 13 11 20 for information on how to borrow.

A detailed list of resources about cancer is available online at www.cancercouncil.com.au/.

Books for young children

*Safina and the hat tree*
(Picture book) By Cynthia Hartman
Publisher: Nomota Pty Ltd, 2004

*Sammy’s mommy has cancer*
(Picture book) By Sherry Kohlenberg
Publisher: Magination Press, 1993

Books for older readers

*She’s got what? A story about cancer*
By Carrie Lethborg and Angela Kirsner
Publisher: St Vincent’s Hospital Melbourne, 1999

*What about me? For children when a parent has cancer*
(Comic book)
Publisher: Anti-Cancer Foundation of South Australia, 1999

*Because…someone I love has cancer*
(Kids’ activity book)
Publisher: American Cancer Society, 2003

Books for parents

*Cancer in the family: helping children cope with a parent’s illness*
By Sue P Heiney, Joan Hermann, Katherine V Bruss (Editor)
Publisher: American Cancer Society, 2001

*When a parent has cancer: a guide to caring for your children*
By Wendy Schlessel Harpham
Publisher: Perennial Currents, 2004

*Raising an emotionally healthy child when a parent is sick*
By Paula K Rauch, Anna C Muriel
Publisher: McGraw-Hill, 2006
Organisations

The Cancer Council NSW
Contact: 13 11 20
www.cancercouncil.com.au
The Cancer Council is the largest cancer charity in NSW. It runs several programs to support parents with cancer, including:

- **Telephone support groups for parents with cancer**: Groups of parents with cancer and/or partners meet by telephone to get professional advice and support, and to share information with other parents. Trained facilitators guide the sessions.

- **The Cancer Council Helpline**: A free and confidential service for people with cancer, their family and friends. It is staffed by oncology nurses, who provide information and emotional support. You can call the helpline if you just want to talk to someone about how to communicate with your kids about cancer. The nurses can also refer you to local services.

- **Cancer Council Connect**: The Cancer Council can match you with a volunteer who has been through a similar cancer experience and who understands how you’re feeling. This service links people who have had breast, prostate, bowel or gynaecological cancers. Call 13 11 20 for more information.

Cansupport
Contact: (02) 9926 7246
Cansupport provides information, support and encouragement to people with cancer, their families and carers in the northern Sydney and Central Coast regions. Cansupport has volunteers who are trained to offer peer support, using their own cancer experience. It also runs information and support groups, with professional speakers, where people can share ideas and experiences, including how to communicate with children.

Canteen
Contact: 1800 639 614
www.canteen.org.au
Mainly an organisation for young people who have cancer, but also runs groups for siblings and children who have a parent with cancer. Canteen runs camps, recreation days, seminars and workshops.

Carers NSW
Contact: (02) 9280 4744
www.carernsw.asn.au
Runs camps and support groups for kids who have a parent with an illness – not cancer specific. Also offers free counselling for carers.
**What kids say**

“I look at my family’s cancer experience as a positive thing. It’s brought our family even closer than we were, especially us siblings, and my relationship with dad has definitely grown stronger. We have made it through 21 weeks of treatment and two years of remission. We are cheering! I am confident our family can make it through anything now!”  
*Lily, aged 17.*

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**Lifeline**  
Contact: 13 11 14  
www.lifeline.org.au  
A general telephone counselling service.

**Kids Helpline**  
Contact: 1800 55 1800  
www.kidshelp.com  
A telephone counselling service that also provides a website where questions can be answered. The aim of this service is to help young people aged 5-18 to develop strategies and skills that enable them to more effectively manage their own lives. It is not cancer specific.

**Websites**

**Australian**

**My Parents Cancer**  
www.myparentscancer.com.au  
This website, produced by the National Breast Cancer Centre, is aimed at young people aged 13-19 whose mother has breast cancer. It will also help young people whose parents have a different cancer. Designed with young people in mind, it features personal stories and reliable, practical and sensitive help.

**International**

**The American Cancer Society**  
www.cancer.org  
Publishes information to help parents and children cope with cancer.

**Cancerbackup**  
www.cancerbackup.org.uk  
A UK service that offers practical advice and support for cancer patients, their families and carers.
Regional offices

**Central Coast Region**
127 Erina Street Gosford NSW 2250
Ph: (02) 4325 5444  Fax: (02) 4325 5688

**Far North Coast Region**
120 Tamar Street Ballina NSW 2478
Ph: (02) 6681 1933  Fax: (02) 6681 1936

**Hunter Region**
22 Lambton Road Broadmeadow NSW 2292
Ph: (02) 4961 0988  Fax: (02) 4961 0955

**Mid North Coast Region**
121 High Street Coffs Harbour NSW 2450
Ph: (02) 6651 5732  Fax: (02) 6652 1530

**North West Region**
Shop 2
218 Peel Street Tamworth NSW 2340
Ph: (02) 6766 1164  Fax: (02) 6766 7053

**South West Region**
1/37 Tompson Street Wagga Wagga NSW 2650
Ph: (02) 6937 2600  Fax: (02) 6921 3680

**Southern Region**
1 Lowden Square Wollongong NSW 2500
Ph: (02) 4225 3660  Fax: (02) 4225 1700

**Sydney Metropolitan Region and Head Office**
153 Dowling Street Woolloomooloo NSW 2011
(PO Box 572 Kings Cross NSW 1340)
Ph: (02) 9334 1900  Fax: (02) 9334 1739

**Western Sydney Region**
43 Hunter Street Parramatta NSW 2150
Ph: (02) 9687 1399  Fax: (02) 9687 1118

**Western Region**
84 Byng Street Orange NSW 2800
Ph: (02) 6361 1333  Fax: (02) 6361 1863

How you can help

At The Cancer Council NSW we’re dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

**Join a Cancer Council event:** join one of our community fundraising events like Daffodil Day, Australia’s Biggest Morning Tea, Relay For Life, Girls Night In, Pink Ribbon Day, hold your own fundraiser or become a volunteer.

**Make a donation:** any donation whether large or small will make a meaningful contribution to our fight to defeat cancer.

**Buy your sun protection products from our website or our retail stores:** every purchase contributes to our work.

**Help us speak out and create a cancer-smart community:** The Cancer Council is a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us defeat cancer by living and promoting a cancer smart lifestyle.

To find out more about how you or your family and friends can help, please call 1300 780 113.
Cancer Council Helpline 13 11 20

For support and information on cancer and cancer-related issues, call the Cancer Council Helpline. This is a free and confidential service.

Cancer Council Helpline .............................. 13 11 20 (cost of a local call)
TTY ................................................................. (02) 9334 1865 for deaf and hearing-impaired
Cantonese and Mandarin .............................. 1300 300 935
Greek ............................................................. 1300 301 449
Italian ............................................................ 1300 301 431
Arabic ........................................................... 1300 301 625

For further information and details please visit our website:
www.cancercouncil.com.au