



Parenting through cancer

A guide for parents of adolescents and young adults dealing with cancer in the family.

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This booklet was funded by the Greater Charitable Foundation.



It was developed in consultation with parents who have been diagnosed with cancer. It is based on findings from our research with young people who have had a parent diagnosed with cancer, and other resources developed by leading cancer organisations.

The advice in this booklet works for most people, but may not be right for everyone.

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Introduction

Being told 'You have cancer' is stressful for anyone. When you're a parent, it's not just your world that's turned upside down, it's your whole family's.

Parenting is a tough enough job without adding cancer to the mix. While there is no single formula that can make parenting through cancer easy, there are some practical tools, strategies, resources and services that can help.

This booklet is designed for parents with adolescent or young adult children and provides insights into common questions and issues that many parents with cancer face.



The impacts of cancer

Cancer affects every aspect of your life – your health, relationships, work and social life, finances and more. It can feel like your world has been turned upside down. As a parent, you have the extra worry of how your cancer might affect your children. It's completely normal to feel overwhelmed, confused and anxious.

The impact on your family

When a parent has cancer, it affects everyone. For some families, a challenge like this strengthens their relationships and brings them closer together. But living with cancer places an enormous amount of pressure on everyone and tension can arise between even the most loving family members. Financial stress is common too, as people face unexpected costs and often reduced household income (see page 14).

Dealing with cancer can often cause significant changes to your family routines and roles. You may feel like you've lost your independence. Your partner might be struggling to juggle work and caring duties while your children might be taking on more responsibilities at home like cooking, cleaning or looking after other siblings.

Changing roles can be difficult for everyone. Most young people want to help, but feel unsure about what to do and it's normal for them to sometimes feel angry or stressed.

Find out more about ways to support your children on page 10 or head to canteenconnect.org.au for strategies to cope with changes in family relationships and how to communicate effectively.

The impact on your parenting

Dealing with cancer is unfortunately only going to make parenting tougher. It's common for parents to feel guilty about the impact cancer has, for example when having treatment means you get to spend less time as a family or have to miss an important event at school.

You need to take care of yourself, and not sweat the small stuff. If you tell your children what's going on, involve them and ensure they know they're loved, everything else becomes easier.



Tip: Prioritise open and honest communication. Talking about cancer can be incredibly difficult, but we have tips to help you do it on page 6.

It's okay

(whatever you're thinking or feeling)

There is no right or wrong way to feel about cancer – everyone's different. It's okay to feel scared and wish this wasn't happening to you. It's also okay for your children to see you cry or get angry – you're human!

Your children are probably experiencing a wide range of emotions as well and will be looking to you for help with how to cope. Showing them your emotions lets them know they can let their feelings out too.

It's absolutely fine (and normal!) to show your feelings when you're talking about cancer. If you think you might be totally overwhelmed with emotion, it might be helpful to have a support person with you. Call CanTeen on **1800 835 932** to explore ideas – you're not alone.



Head to canteenconnect.org.au to read about coping strategies that other parents have found helpful.

It's completely normal to feel overwhelmed by cancer, but if you're worried that you're not coping, get help. You can talk to a doctor or the oncology social worker at your hospital or work with a counsellor or psychologist to develop strategies to manage stress and anxiety.

Talking to your children about cancer

Even though it's hard, being honest and open with your children about cancer is the best way to help them cope. Young people want to be told the truth, even if it's difficult news for you to share and them to hear.

Secrecy often makes things worse and only adds to your stress. In contrast, being honest about what's happening helps young people to adapt and shows them that you trust and value them.

Telling your children you have cancer

Telling your children you have cancer is probably one of the most difficult things you will ever have to do. Your instinct might be to keep the news from them altogether or delay telling them, but young people quickly work out that something is wrong.

Tackling that first cancer conversation might seem overwhelming, but here are some tips that other parents have found helpful:

- Make sure you're ready (or as ready as you can be)
- Think about what and how you're going to tell them
- Use simple language and avoid medical jargon
- Try not to overload them with too much detail
- Build on what's worked for you in the past when you've handled bad news or talked about difficult issues like drugs or sex
- Start with questions. For example, "I've been diagnosed with cancer. What do you know about cancer?". This will help you adjust your explanations to their level and correct any misunderstandings.

How you explain what cancer is and the type of information you give your children will depend on their age, how much they can understand and what they want to know.

The key things your children need to know are:

- the type of cancer you have
- the treatment(s) you will have, and how long it will take
- the sort of side effects you might experience such as weight changes, tiredness, hair loss
- the other ways cancer might affect you, such as not being able to work
- how your cancer is going to affect them and your family life, for example changes to routines or extra responsibilities they may have to take on at home
- that you will keep them informed and let them know about any changes
- that your cancer has nothing to do with anything they did, said or thought



Keeping cancer communication going

CanTeen's research and work with other families has shown that young people who are kept up to date about their parent's cancer have lower levels of anxiety than those who are 'kept in the dark'.

Once you've overcome the initial hurdle of telling your children you have cancer, keep communication going by being as open as you can, even if the news isn't good. Young people can be deeply hurt if they sense that information is being withheld from them. They can feel left out or may assume the worst.



Tip: Some families find it helpful to agree on a certain day and time to talk about cancer stuff. This can make it easier to start conversations, but also creates permission to focus on 'normal life' at other times.

At the same time, be careful not to overload your children with information. Give a brief explanation, then open the door to questions – so they can dictate how much and what type of information they want.





Tip: Your children may ask questions you don't know the answer to, or don't want to answer straight away. Tell them you need to check or think about it and that you'll come back to them. You could say something like, "That's a really good question and I don't know the answer so I would like to talk to Dad/Mum/the doctor about it. I'll let you know what they say".

For more detailed information and advice about talking to your children about cancer, check out:

- **CanTeen Connect for Parents website:** canteenconnect.org.au
 - **Cancer Council's Talking to Kids about Cancer booklet:** cancerCouncil.com.au/cancer-information/for-family-and-friends/talking-to-kids-about-cancer/
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Your children's reactions

Every young person will react differently to the news that their parent has cancer. How they react depends on many things including their age, maturity, their relationships with other family members and whether they still live at home. Siblings, even of similar ages, can respond very differently.

Adolescents and young adults may be more worried and afraid than younger children because they're old enough to understand the potential seriousness of cancer. It's also a time when they're trying to establish independence, so the fact that cancer might draw them back to the family (for example having to look after younger siblings) can be very challenging.

Some common reactions from children include:

- **Feeling sad, afraid or angry**
Reassure them that whatever they're feeling is okay. Let them know you understand that dealing with all this is difficult for them as well.
- **Not reacting**
Your children might need time to process everything - let them know that it's okay and that they can talk to you and ask questions any time.
- **Not appearing upset**
This doesn't mean they don't care - it might just be their own way of coping right now.
- **Worrying that your cancer is contagious**
Explain to them that you can't 'catch cancer' in the same way you catch a cold.
- **Being afraid they'll inherit a 'cancer gene'**
Ask your treatment team for more information about the likelihood of your children facing an inherited risk of cancer.

How to support your children

Finding out your parent has cancer is really tough for young people. You can't make all their fears and worries disappear, but here are some strategies you can try to make it a bit easier for them.

+ Prepare them for changes

Telling your children about possible physical changes or side effects in advance helps them feel less worried down the track. If they're not prepared, they can mistake normal side effects as signs that your cancer is getting worse.

+ Maintain normal family routines and rules (as much as possible)

Keeping family life as normal as possible reduces the amount of change your children have to cope with and can help younger children in particular to feel more secure. You may feel guilty about having less time with your children, but they still need consistent boundaries. Ensure that they continue their education or work, do their usual chores and correct inappropriate behaviour.

Where changes to family routines are unavoidable, ensure that you talk openly and honestly about what will happen and why.

+ Nurture your relationship

Young people cope better with a parent's cancer if they feel confident that your relationship with them will not change. As much as you can, make time for each of your children so they know you're still interested in what's happening in their life. Do something together like watch a movie, go shopping or go out for a meal.

If you're going to have to spend a long time in hospital, get creative about how you maintain your relationships with your children. Keep in contact using Skype, FaceTime or even old-fashioned postcards. Plan fun things to do together when they visit, like playing a board game or ask them to make your favourite snack.

If you want more tips and advice on supporting your children, visit canteenconnect.org.au to connect with other parents in a similar situation or chat to a CanTeen counsellor.



Tip: Offering your children the chance to see the hospital and meet your doctors and nurses before you start treatment can help their understanding of what's going to happen. It's also a good idea to prepare them for what they might see when they visit you in hospital, for example that you'll be hooked up to an IV drip.

+ Build connections with other adults

Having a close relationship with an adult is a key factor that helps children get through difficult times. Your children might avoid sharing their true feelings with you, because they feel you already have enough to deal with.

Telling family, friends, teachers and others who are involved in your children's lives about your cancer means there are other adults they can talk to as well as other adults keeping an eye out for them.

Sometimes you might decide to tell certain people confidentially, but generally it's a good idea to let your children know who you've told, and ask them who they'd like you to tell (or not tell).



+ Get support for your children at school, uni or work

If your children are at school, tell their teacher what's happening and if you're meeting with the school, ask your children if they'd like to come along.

If your children attend university or TAFE or are working, talk to them about how they can explain what's going on to the relevant staff or their manager. Informing others can create a more supportive environment for your children and ensure they get extensions or special consideration as needed.

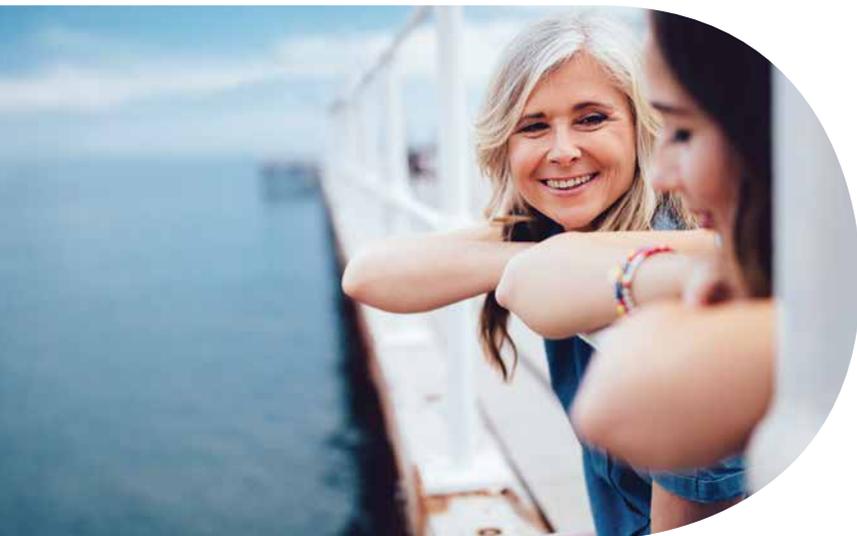
Get more information including templates of letters to inform people about your cancer on www.canteenconnect.org.au

+ Connect them with others who get it

Young people can find it difficult to talk to friends about a parent's cancer or may be disappointed when their friends don't provide the support they need. Through CanTeen, young people can connect with others their age who are also dealing with a parent's cancer. Find out more at canteen.org.au or call **1800 835 932**.

+ Make sure your child gets 'time out' from cancer

Some young people feel guilty about having fun when their parent is sick, but it's really important that they have some 'time out' away from cancer, especially if they've taken on more responsibilities at home. Tell your children it's okay to do 'normal' things like see their friends, play sport or go to concerts.



Tip: Accept or ask for help from others so that your children can continue some of their after-school or weekend activities like sport or music.

CanTeen runs programs specifically designed to give young people a break from cancer – everything from pizza nights to free concert tickets. Find out more at canteen.org.au or call **1800 835 932**.

+ Point them to reliable sources of information

Young people often cope with uncertainty by seeking information – so it's important to make sure it's reliable. There is A LOT of information online, but it's not always accurate, so encourage them to check anything they hear or read about your cancer with you.

CanTeen has easy to understand information specifically for young people dealing with a parent's cancer. Download it for free at canteen.org.au/resource

Signs your children might not be coping

Young people don't always tell their parent how they're feeling, that they want to talk, or that they're not coping.

It's normal to be sad and worried when a parent has cancer and it's common - for teenagers especially - to feel down, tense, angry, anxious or moody. If these feelings seem overwhelming, persist for a long time or start to get in the way of daily life, they can have a negative impact on your child's mental health.

You know your child well, so be on the lookout for:

- changes in eating habits, appetite or sleeping patterns
- trouble concentrating or paying attention
- withdrawing from friends and spending a lot of time alone
- not enjoying or wanting to do things that they used to enjoy

If you're worried about your children, you can talk to a specially trained CanTeen counsellor. Visit canteenconnect.org.au or call **1800 835 932** for more information.



Money matters

Unfortunately for many people, cancer brings financial stress. Having cancer can mean there will be extra, unexpected costs, and reduced income, particularly if you or your partner have to stop work for a while or reduce your work hours.

Cancer tests, scans and treatment (particularly hospital stays) can be more costly than expected. Other out-of-pocket costs include travel and accommodation if you (and a carer) have to travel for treatment, car parking and medicines or medical equipment.

Worrying about money is another stress when you are trying to deal with cancer. Applying for financial support and other support programs can be challenging, but can also be really helpful. There are federal, state and local programs and services that may be available.

How to get financial help

A good starting point can be to talk to someone in your treatment team, the oncology social worker or the Cancer Council on **13 11 20** for information about local services (e.g. local council practical services, lawn mowing, cleaning...) and funding available in your area.

If you have to stop work because of your treatment you may be eligible for assistance from the government or other organisations. Your partner or child may also be able to get assistance if they have to stop work to care for you.

Depending on your circumstances and location, you may also be able to get help with things like:

- rent assistance
- pharmaceutical allowance
- concession cards
- parking vouchers at the hospital
- accommodation during treatment for you or your partner
- transport costs (under the NDIS – if you're eligible)
- no interest loans for medical appliances or other essential items
- accessing superannuation early or making a claim on insurance.

You may be facing financial difficulties for the first time and need advice about what to do if you can't pay your bills or meet repayments. There's no shame in applying for assistance – it is there for all people in your situation no matter what your finances were like before cancer.

Looking after yourself

One of the best ways to help your children is to get help and support for yourself.

Don't try to do it all alone – call on your friends, family and others for help. Accepting support can reduce the burden on you and your children and help to limit the changes to family roles and routines.



Tip: Family and friends are usually keen to help, but don't know how. So be specific and let them know what you need. It can even be helpful to ask someone to coordinate offers of help from others, for example cleaning, driving you to appointments, taking children to school or picking up groceries.



Other ways to get help:

- The CanDo app (candoapp.com.au) lets cancer patients easily ask their network for help on day-to-day tasks, while removing the awkwardness of face-to-face conversations
 - Many organisations provide practical help, like transport to treatment, home nursing care, or legal and financial advice. Ask the oncology social worker at the hospital, or contact Cancer Council on 13 11 20.
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Tip: Make a list of all the things that need to be done – anything you need to organise for your treatment, childcare, household chores, etc. Decide which ones are most important for you to do, which ones someone else can do, and which ones can wait.

Take some pressure off

Life as a parent was already busy and now you're dealing with the demands of cancer as well. On top of that, parents with cancer often feel like they have to pack more in to every day because the future is uncertain, or make every moment with their children fun because of the stress that cancer is putting on the family.

This just adds to the pressure on you.

Accept that you don't have the time and energy for everything right now. Instead, work out what's most important to you and focus on those things. Find smaller chunks of quality time you can spend with your children.





Take care of your body and mind

- + **Eat well:** Eating healthily helps you cope with the physical and emotional impact of cancer, but it can also be difficult to prepare meals and easier to order takeaway. Do your best and try to find balance where you can.
- + **Try to be active:** Regular exercise helps to reduce stress, anxiety, anger and depression, improves sleep and helps you feel less tired. Even a short daily walk can help. Discuss what you can do with your doctor or ask to be referred to an exercise physiologist.
- + **Make time for yourself:** Try to make time, every day if you can, to do something that brings you joy, like reading a book, listening to music or walking in a park.
- + **Clear your mind:** Meditation and mindfulness can help you feel calmer and more connected with the things that are important to you, as well as boost your mental health. Many people find yoga or tai chi helpful.
- + **Talk to people who understand:** Connect with other parents who are dealing with cancer at canteenconnect.org.au. You can also talk to a CanTeen counsellor about the parenting challenges that cancer brings or call the Cancer Council on **13 11 20** for more general support.

Where to get more info and help

There is a lot of information and support available to help you manage the impact cancer has on your family and strengthen your relationships and communication throughout this challenging time.

Here are some places to get more information and help:

+ CanTeen’s counsellors offer support to young people by phone, email or live chat.

Parents can talk to trained CanTeen counsellors about family communication and parenting challenges that cancer brings.

1800 835 932 | support@canteen.org.au

+ The CanTeen Connect for Parents website (canteenconnect.org.au) has much more detailed information about all aspects of dealing with cancer while parenting including:

- how to talk to your children about your diagnosis, and how to explain cancer and cancer treatments
- how to talk with children about death and dying
- managing your children’s reactions and supporting them
- how to manage your stress and worries, and take care of yourself
- maintaining family roles and rules, and nurturing your parent-child relationship
- tips and sources of support if your child is your carer
- single parenting during cancer
- how to tell people including your children’s school
- challenges couples face and tips for communicating as a couple during cancer
- when cancer won’t go away.

There is also an online parent community, where you can read advice from other parents who have been diagnosed with cancer, post questions or share your own experiences.

+ Your oncology social worker or psychologist. Did you know you can talk to an oncology social worker or psychologist who is part of your treatment team? They specialise in helping people diagnosed with cancer and their families get whatever support they need – emotional, practical, financial or other. If you have not met yours yet, ask your doctor or contact the hospital or treatment centre.

+ Cancer Council provides a wide range of information as well as practical and emotional support for people affected by cancer.

13 11 20 | www.cancer.org.au

References

This booklet was developed in consultation with parents who have been diagnosed with cancer. It is based on findings from our research with young people who have had a parent diagnosed with cancer, and other resources developed by leading cancer organisations. Key sources of information were:

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canteen.org.au

**For further details
please contact**

**CanTeen
1800 835 932**

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