



Dealing with  
your parent's  
cancer

Now what?



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## headstuff

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introduction  
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introduction



You've just been told that one of the most important people in your life has cancer.

### **Now What...?**

There are probably so many things running through your head – questions, feelings, new thoughts – that it's hard to know where you are, let alone where you might be going or what you might do. You are probably asking now what?

Well, this book is designed to help you understand some of what is going to happen, make sense of it and give you some directions for the challenge that your parent's cancer diagnosis has thrown at you.

Cancer is the last thing that anyone would invite into their lives but like lots of other things, you don't have much control over it.

Having the right kind of help and information can make a big difference.

This is not a “book” to be read from beginning to end but rather something for you to dip into when you need it. It contains information, practical tips plus some support and encouragement to assist you.

You can also log onto the website [www.nowwhat.org.au](http://www.nowwhat.org.au) to access the information as well as read some more detailed information about some topics. The website also has other useful resources, stories, blogs and forums to support you through this tough time.

We have used the words parent, mum or dad when referring to the person who has cancer in your family. This is for simplicity even though we know that for some of you reading this, the person who looks after you could be a grandparent or another adult. It doesn't matter who that person is, the journey is still the same.



## Top Tips

Don't let others keep on giving you bad advice



You may use all of what's inside this book or you may only choose to use a bit. That's OK.

We've had a lot of input from other young people who have shared the same stuff, so we hope that you find something in here that helps to unscramble the world you have suddenly landed in.



OK, you now know that your parent has cancer and the path of your life has taken a great big turn.

As hard as it may be at this point to focus on anything, there are a few things that can help you to get a better handle on the situation.

(And while you are reading these you can stop holding your breath!)

### **Many people survive cancer**

There are over 250,000 people living with cancer in Australia today. Discoveries of new and more effective ways of diagnosing and treating cancer are being made all the time, leading to improved survival rates. Even though you may

be completely freaked and your parent may be quite sick, remembering this may give you some hope during tough times.

### **There are others out there (no, not just aliens!)**

While no-one will feel exactly the same way as you, there are lots of other young people out there who are living with a parent who has cancer. It can help to know that others are experiencing similar things. See "Where to get help" for websites to connect with other young people.

### **It is not your fault**

Cancer is caused by lots of things, many of which doctors don't even understand. But none of these have anything to do with anything you said, did or thought.

### **Knowledge is power**

Having the right information can be a big help in dealing with your parent's cancer. Learning about the particular cancer and its treatments can take some of the fear out of it. Things imagined can often be worse than the reality.

### **Hope**

Hang on to hope. It doesn't matter how dark things may get, try and find something to be hopeful for.

No-one can take that from you; never give it up.



# cancer facts straight up



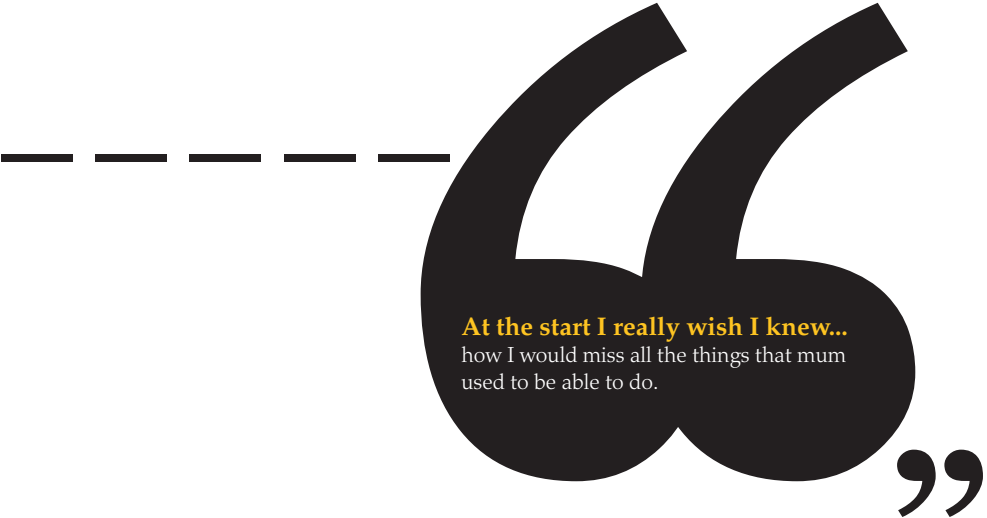
You would have been familiar with the word cancer even before your parent was diagnosed. But knowing what it actually is, is a different thing. There are so many stories about it and so much written about it, but not all of what you read in the mags, newspapers and the net or see on TV is correct. (What a surprise that must be.)

Part of the difficulty of understanding what cancer is comes from the fact that cancer refers to more than a hundred different diseases. All of these diseases have one thing in common: cells that divide and grow abnormally.

Our bodies are made up of billions of cells – they are basically like building blocks.

Normally, cells grow and divide to make more cells only when the body needs them.

This orderly process helps to keep the body healthy, replace worn out cells and to heal after an injury.



**At the start I really wish I knew...**  
how I would miss all the things that mum  
used to be able to do.

However, sometimes this process doesn't go according to plan and the cells can get out of control, producing new ones even when they aren't needed. This behaviour by the cells can form a mass of tissue called a growth or a tumour. Tumours can be benign (not cancerous) or malignant (cancerous).

Benign tumours can often be removed and don't spread to other parts of the body.

Malignant tumours can invade and damage nearby tissues and spread to other organs in the body. The spread of cancer from one part of the body to another is called metastasis.

Cancers are usually named for the organ or type of cell in which they begin. So lung cancer would have started in the lungs.

Some, like leukaemia, do not form tumours but are diseases of the bone marrow and blood.

The most common adult cancers are explained in the "What cancer is that" chart on page 55.

## **Why do people get cancer?**

The causes of most cancers are unknown. However some things like smoking, spending too much time in the sun, not getting enough exercise and not having a healthy diet, may put people at a higher risk of getting certain types of cancer. Coming in contact with certain chemicals and toxins can also increase the risk.

If you have a particular risk factor for cancer, this does not mean that you will definitely get cancer, just as not having it does not mean that you won't get it. It is all about probability.

Smoking is a good example of this: if you smoke, it is not certain that you will get cancer.

## Head Stuff/Cancer facts

If you don't smoke, it is not certain that you won't. But if you smoke, your risk of getting lung cancer is far higher than if you don't. Nine out of ten people who develop lung cancer are smokers.

However sometimes your parent may not have had any of these risk factors, yet they still got cancer. Often there is no apparent reason for the cancer.

### **It's not like catching a cold**

You may worry that you will catch cancer (no, it's not a silly thought). You can't. It is not a contagious disease. So there are definitely no problems with hugs and kisses.

### **Can mum or dad pass it on to me (like my eye colour)?**

Most cancers are not passed down from parent to child. However there are some cancers that do have a genetic component. That is they are caused by a faulty gene that may have been inherited from your parents.

Only a small number of cancers (between 5-10% or less than 1 in 10) seem to be the result of having a faulty gene and these tend to be the cancers that affect older people. So, say your dad has bowel cancer and maybe your grandfather had it, there is a chance that it could be caused by a faulty gene. But it doesn't mean that you will get it as a young person.

If you are concerned about this you can talk to your parents, ask their doctor or check out one of the websites in the "Where to get help" section on page 78.



### **Will my parent die?**

While many people survive cancer, the reality is that people do die from it. There are many factors that affect what the outcome will be for your mum or dad including what type of cancer they have, where it is and how advanced the cancer is.

This is discussed in more detail in the chapter "If treatment no longer works".

**Seventy percent of people who get cancer are over 60.**





# GETTING THE RIGHT INFORMATION

Having the right information is an important way to help you cope with what's going on.

Not knowing what's happening may be more stressful. Everyone in your family will deal with things in their own way. For some people having all the information is important but for others just the key bits are enough.

You may not want all the information at the very beginning or you may not want it all at once. But as time goes on you may be ready to ask more questions.

Whatever you choose is OK but here are some questions that you may want to ask your parent, their doctor, the nurses or the social worker at some stage.

**Remember: You may need to remind them to speak in plain English, not doctor language.**

- What kind of cancer does my parent have?
- What part of the body does it affect?

- Will my parent get better?
- Is there a chance that I may get this cancer too?
- What treatment will my parent get?
- Will there be more than one type of treatment?
- How will my mum or dad feel while they are having this treatment?
- Is the cancer painful?

Head Stuff/Getting the right info

- Will the treatment be painful?
- How often do they get this treatment and how long will it last?
- Will it change the way my parent looks, feels or acts?
- How will we know if the treatment is working?
- What will happen if the treatment doesn't work?
- Where will they get this treatment and can I go with them?

There may be other questions that you have. Use the space below to write them down

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**Remember:**

**You may need to remind them to speak in plain English, not doctor language.**



**Information Overload**

When you are stressed, upset or scared, it's often hard to take in everything that is said. More than likely you will only remember a small amount of stuff that you are told, especially in the beginning.

So here are a few tips on how to get the right information and ways to remember it:

- Write your questions down beforehand (or use the list above).
- Write the answers down.
- Ask people to repeat things if you don't get it.
- Ask the doctor or the nurse to use a model (not a magazine one, but a plastic one) or draw a picture.

# what are they doing to my

## parent?



Knowing what is being done to your mum or dad and why, may help to take some of the fear out of this whole experience.

There are over 100 different types of cancer and each type is treated differently.

The aim of the cancer treatment is to get rid of the cancer cells.

What sort of treatment your parent receives will depend on a number of factors:

- the type of cancer
- whether the cancer has spread
- your parent's age and their general health
- their medical history
- whether the cancer is newly diagnosed or if it is a recurrence (the cancer came back).

The plan that the treatment follows is called a protocol. However, people's bodies react differently to treatments so even if two people have the same cancer and the same treatment, how they cope with it may be different.

It's important not to compare your parent's experience with another patient – we are all individuals.

One of the hardest parts of this journey is waiting to see if the cancer treatment is working. The situation can be changing all the time. One day your parent may be feeling really well and then the following week they can be feeling sick again.

Unfortunately, what side effects your parent gets or how severe they are has nothing to do with whether the treatment is working.

The most useful piece of information that I got was...

the pieces of paper about the process that mum had to go through.



The doctors may try one treatment and then try something new and the treatment can last for several months or even years.

This uncertainty can make things really hard for everyone.

When things seem really bad, try to focus on the fact that the treatment your parent is undergoing is working to stop the cancer and eventually make them better.

The charts on page 61 give brief overviews of the main types of treatments: their medical names, what they actually are, how they are given and what their side effects may be.

You may have a lot more questions to ask after reading this. Check out the recommended websites for more information or ask your parents or the medical staff treating your parent.

(See tips for talking to your parents and the medical team on pages 7 & 8.)

## Things to look for

When your parent is being treated for their cancer they can get infections more easily. That's because the white blood cells that fight infections in our bodies are often affected by the treatment, making it harder to fight things like colds, the flu or chicken pox.

An infection could make your mum or dad sicker, so they may need to stay away from crowded places or people who have an illness they could catch. You can help by:

- washing your hands regularly to avoid spreading germs
- letting your parent know if you've been in contact with someone who is sick or has a cold
- not coming in close contact with your parent if you get sick (this is another good reason for taking care of yourself)
- checking with the doctors or nurses if you are worried about infections or other stuff that may harm your parent.

# when to worry and what to do

Your parent may be really sick while they are being treated and sometimes it is hard to know what is a normal reaction to the treatment and what is something that you need to worry about.

Your mum or dad may also get sick after treatment is finished and you might be worried about that as well.

To help you work out when to worry and when not to, here is a list of questions to ask that can help to sort this out. You may want to ask another adult or the nurse who is looking after mum or dad to get these answers for you. You could even just give them the list and they can put in the answers for you.

- When do I worry about a temperature?
- How much vomiting is too much?
- Should I worry if they are a bit sleepy or vague – more than normal?
- What about going to the bathroom a lot?
- What if I notice blood on a towel, in the toilet or in their bed?
- Is it a problem if they cut themselves anywhere?
- What if I notice bruises?

There may be other questions that you have or that relate directly to your parent's situation. Use the space below to write others down.

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There is also a Don't Freak Checklist at the back of the booklet (page 77) so that you can write down the answers to these questions.

# Good G<sup>o</sup>o<sup>g</sup>ling

Without stating the obvious, the net is a great source of information but as we all know it is also full of some weird stuff. That's not always helpful when you are trying to get accurate and useful information.

Here are a few tips to make your Googling a bit more successful.

## **Always check the source of the information**

Much of the information on the net, while well meaning, can be misleading or out of date. Look at where the information is coming from. There are many reliable cancer organisations that have great information that is accurate and up to date. (See the list of some of these in the "Where to get help" section on page 78.)

## **Don't believe it all**

If the claims in an article seem too good to be true, then they probably are.

Living with cancer can make us all very open to promises of cures and miracle treatments.

It's a good idea to check out the claims made with your parents, their treating doctor or a reliable web source.



**At the start  
I really wish  
I knew...**

**how hard it is to make  
an accurate prognosis for  
cancer patients.**

### **Look who is behind the website you are on**

If it starts with something like “I cured my own cancer in three weeks” or “The facts the medical profession won’t tell you”, it is a good guess that it is not a reliable site.

People have all sorts of reasons for putting stuff up on the web.

### **What they don’t tell you**

Every treatment has risks and benefits. If the site doesn’t mention both the good and bad bits it may not be telling the whole story. If you hear about a treatment from one website look for other evidence that backs it up on another website.

### **Make sure you are searching the right stuff**

Each cancer is different but the treatments and outcomes for the same cancer can also be different depending on things like the stage and where it is in the body.

Before you head off into cyberspace, see if you can find out these things about your parent’s cancer. (Could save you from freaking over something that you don’t have to!)

### **Use the web information as a starting point**

Information found on the web can be a good way to start a conversation with your mum or dad. Having information can help you to feel a little bit more in control. It is possible that you are better at searching the net than your parents. This may be one way that you can provide some practical support.





No matter how much you hoped it wouldn't, life changed once your parent was diagnosed with cancer.

Living with a parent who has cancer can affect your life in almost every way. Some changes are really big while some are not as noticeable.

Often the focus is on how cancer affects your feelings but it can also mess with everyday life: routines change, it's not always easy to plan for things, people act weird and nothing seems certain anymore.

This can all seem very scary, challenging and at times even very unfair.

You may have to dig deep and find a strength that you didn't know you had.

You may also have to put up with well meaning people telling you how brave you are (when really all you want is for it all to go away).

People will deal with things in different ways as they try to make sense of this new situation. You may be unsure about the future, what is happening at home or even what's going on in the family now.

Do these things sound familiar?

- You're doing more around the house – have you had to find the washing machine?

- You're home alone more (and you thought that might be fun?!).
- You're looking after younger brothers and sisters.
- You get farmed out to relatives and friends.
- You don't get to spend as much time with your friends.
- 2 minute noodles get really boring after a week.
- You've had to move back home.

You may feel like your normal life has been stolen from you. This isn't fair and definitely not what you asked for. This reaction is perfectly OK. Most of us are happy with routines in our lives and don't like too many changes, especially when those changes feel out of control and life is not how you want it to be.

Although it is much easier said than done (aren't most things!?), try to be flexible and take each day as it comes.

Getting used to what this now means for you, your parents and the rest of the family may take a while.





# relationships; family and friends

A cancer diagnosis can put a strain on all of your relationships: parents, brothers, sisters and friends.

Dealing with these changes can be really hard.

## Parents

Whether your parents live together, are separated or you only have one parent, your relationship with them will more than likely go through some changes. Lots will depend on your age, whether you are still at school or working and whether you have moved out of home.

All of us have the 'normal' parent/child hassles and conflicts, and the bad news is that cancer can make these even tougher to deal with.

That's not to say that there isn't also a really big chance you will develop a better relationship with your mum or dad and come to appreciate things that you may not have been aware of before. Little disagreements may no longer seem so important.

Don't expect things to change overnight – if there were things you didn't agree on before it doesn't mean you will miraculously see eye to eye now that they have cancer.

You still want to be you but now circumstances mean that some things have to change.

Seeing your parent sick, in pain and maybe not even looking like they used to is really hard. It can make you feel guilty if you get angry with them or want to do things that they don't agree with.

There may also be a lot of focus on your parent who is unwell and you may feel a little left out of their lives. Things like birthdays, special events or school meetings may get forgotten.

This can be hard to handle but it doesn't mean they don't love you, just that they are dealing with a heap of stuff as well.

You will probably read a lot about the importance of talking about things and not bottling things up. That can be easier said than done. It is really important to learn how to do this.

See "Talking is tough" on page 23 for tips on how to communicate with your parents.

Your parents may also worry that you have no-one to talk to and may want to organise for you to meet with a social worker, psychologist or counsellor.

Whilst you may not want to admit it, they are probably right and are only doing it because they are concerned about how you are doing.

Let them know if you are talking to people and if you do feel like you have some support.

## Brothers and sisters

Best friends or biggest pains? Brothers and sisters often have a love/ hate relationship and when you throw a really sick parent into the mix things can get a bit tricky.



We are all individuals and will deal with things differently. You probably have set roles in your family: you know, the responsible one, the rebel, the quiet one, the one everyone blames.

Just like your relationship with your parents there may need to be some negotiations and lots of talking about the changes that are going on in the family.

If you are the oldest in the family you may take on some extra responsibilities – for some of you this may be fine but others may find it a big hassle. Younger brothers and sisters may also not like the fact that they think you are being the parent. You know the cry: "You're not mum/dad! Stop bossing me around!"

But the other side to this is that sometimes it really does bring you closer together. It puts you on the same team and you'll learn stuff about each other that you didn't know.

However just like the relationships with your parents, don't expect miracles.

**Remember: We all react to difficult situations and change differently. We all express our fears and pain in different ways.**

Go easy on each other – believe it or not your brothers and sisters do understand what you are going through – they're going through it as well.

## Friends

Friends are always important – you probably spend as much time with them (or more) as you do with your family.

You may act differently because of your parent's cancer, and your friends might find this difficult to deal with sometimes.

We know that for many of you this one is a biggie. You might wish your friends were better at being there for you.

**Remember: You may have acted the same way as your friends are acting before you had this experience.**

Some of the things your friends may be thinking include:

- What am I supposed say or do?
- How can I be a friend to someone whose parent has cancer?
- Should I still share things that are bothering me? They seem trivial compared to what my friend is going through.

As unfair as it may seem, you may have to help your friends to deal with what is happening for you. They might need help in getting over their fears. Often you will have to make the first move and to let your friends know that you are able to talk about your situation.

Below are a few things that you might want to think about concerning your friends.

### Friends don't know what to say


Your friends may be scared to say the wrong thing or to ask you a question. Often they will just say nothing.

It's not because they don't care, but more that they just don't know what to say.

If you want to talk you may have to start the ball rolling.

### Friends won't say things to deliberately tick you off

Sometimes your friends will say stuff that really annoys you and makes you angry. This can be really hard. But try to keep in mind they didn't try to tick you off on purpose, it's just that they don't understand. It's OK to let them know. You can start with "You know, that annoys me when....".



**The most useful piece of information that I got was...**  
to talk to other people and relax.

## **Friends may ask tough questions (or even questions that seem a bit silly)**

Be prepared for questions that may seem strange – remember all the things that you didn't know before all this started.

Sometimes you may not want to answer questions about your parent's cancer. It is OK to let your friends know that you don't feel like talking right now.

## **Your friends have their own lives**

It may seem that your friends are just getting on with their lives without you and you feel a little left out. Try to remember that they have their own lives too and they aren't facing the same situation as you are. Unfortunately, the world doesn't stop just because your parent has cancer (although for you it may seem like you have entered a whole different world).

Try to stay in touch and let your friends know that you still want to be part of what's going on even if you can't always go out and do things.

SMS, msn, on-line social networking sites (like FaceBook and My Space) are all great ways to stay in touch (if you have access to these). You could even use the old fashioned home phone.

## **Friends may change**

It's amazing how common experiences can lead to friendships. You may connect with other young people who are going through the same thing. It may be easier to talk to them about what is happening for you because they understand.

## **Top Tips**

**Don't push yourself beyond what u feel comfortable with,**  
*don't try and be what someone else expects you to be.*

Lots of young people say that this is often the best support.

You may also lose some friends along the way. Some people find it too hard and you may also decide that they are just not worth the hassle.

Having positive people in your life is important at this time.

Go to [www.nowwhat.org.au](http://www.nowwhat.org.au) and [www.canteen.org.au](http://www.canteen.org.au) to find ways to connect with other young people in the same boat.

Also check out the "Tear off tips for friends" and the "Talking cards" at the back of the book.



Dealing with your parent's cancer can throw up all sorts of different feelings. Some you may have expected and others may come as a complete surprise.

It may not always be so easy to pinpoint your actual feelings and they can also be hard to understand.

**Remember: There is no right or wrong way to feel.**

It may feel a bit like being thrown around in a washing machine (not that many of us have ever experienced

that, but just pretend) or the experience has been described as like being on an "emotional rollercoaster". Maybe this refers to the feeling of racing along feeling like you have no control or maybe it is the big ups and downs that you feel.

Many of you may not be comfortable sharing your feelings and sometimes you hope that if you just ignore them they will go away. (Guess what? They don't.)

Feelings are not good or bad, they are just feelings. Even if you hope that they will go away, try to ignore them, or even feel guilty about them, they will still just be there.

The problem is that when things get bottled up they need to get out somehow and this can lead to behaviour that is not safe, angry outbursts or a bit of a meltdown. As hard as it may be, finding some way to express what you are feeling is really important in helping you to deal with the stress of living with a parent who has cancer.

The list of emotions below may help you put a name to what you are feeling.

(These are what other young people have described.) You may experience all of these at some stage, or maybe only one or two. You may switch from one to the other depending on what is happening in your family and with your parent's treatment.

### **Shock/Disbelief**

More than likely you will feel shocked when you hear that your parent has cancer. You may also go through a stage of disbelief.

This can happen even if you thought that something was up. Cancer was probably not what you were expecting.



### **Scared**

Doesn't matter how tough, grown up or brave you are – finding out your parent has cancer can scare the crap out of you.

There is a lot of fear around a cancer diagnosis. Some of it may be based on facts but others may be about things that won't or can't happen. Some of the fear may go away as time goes on.

Admitting that you are afraid can sometimes be a big relief.

### **Angry**

Feeling angry when you first find out that your parent has cancer is pretty normal. You may think that it's not fair, want to know why it has happened to you (and your mum or dad). And then you may get angry at yourself for feeling that way.

It is OK to feel angry but learning some positive ways to express it is important. See "Safe ways to act out your feelings" on page 33.

Anger can hide other feelings like fear or sadness.

## **Sad**

There are lots of reasons to feel sad about your parent's cancer and it's all part of the reaction to it. However, if these feelings get really bad, don't seem to go away after a few weeks and start to get in the way of other things then you may be feeling depressed. (See "When it all seems too much" on page 31 for more on depression.)

## **Guilty**

Some of you may get "the guilts" big time about your parent's cancer. This can be about a number of things; you're healthy and they're not, you've wished bad things would happen to them or argued with them, you laugh and still have fun or you wish you didn't have to do the extra things that you may have to do.

## **Nothing**

Sometimes you may feel nothing. This can be connected to shock or disbelief. It can also be about being too busy in your own life – new boy/girlfriend, school etc.

It may take a while to feel something. Again, don't be hard on yourself, this doesn't mean you don't care – it's just that you may take time to deal with it.



## **Neglected**

With so much of everyone's energy and focus going into your sick parent it may feel like you are being left out or forgotten. It's not uncommon for the family's focus to change. It can be hard to accept that you don't get as much attention at this time.

## **Embarrassed**

Your parent may look different and perhaps act a bit differently because of the cancer. People may also ask questions that you don't know how to answer. Having a parent with cancer can make you feel different and that is not always easy to handle.



Cancer is a tough topic to talk about (no kidding!!!). You may have stuff that you want to know but you're not sure how to ask your parent. Your parent may not be ready to talk or perhaps your parent wants to talk but you are not ready to listen or talk to them.

While lots of pamphlets and videos show families all sitting around talking and sharing their innermost thoughts, the reality is not all families talk openly and honestly about things that are happening or their feelings. A cancer diagnosis isn't going

to miraculously change that. In fact it is probably only going to make it more difficult.

But difficult things can become more difficult if everyone goes around thinking about it, but not sharing how they are feeling and talking about what is really going on. The trick is to find ways that you can talk and communicate.

You may be surprised how much better it is when things are talked about.

You've heard it before but not talking about it won't make it go away.

Lots of things can get in the way of talking openly.

### **Things to think about**

There is no right or wrong way to talk about things.

Let your parent know that you want to know what is going on.

Your parent might not want to talk about their cancer because they don't want to worry you.

Maybe your parent doesn't have all the information themselves. Let them know that you would like them to share the information once they have it. Good or bad.

It can be difficult to talk about the situation if there is a big gap between what you want to talk about and what your parent wants to talk about.



## Heart Stuff/Talking is tough

It may be easier for you to talk to someone else in your family or even someone outside the family. This is OK. Think about people who you trust and feel comfortable with. (See "Getting support" on page 34.)

### Talking Tips

It may help to think about what you want to ask and what you want to say before you start.

It may be really hard to start with and there may be lots of silent moments. That's OK.

Try not to freak if you or your parent gets upset – this is not an easy thing to be talking about.

Talking can be easier if you are doing something else at the same time – driving in the car, cleaning up in the kitchen.

Try not to worry about it too much – this whole thing is strange and scary and it may take time to work out the best way to talk to each other.

### If talking is too hard

Sometimes talking is too hard but you still want your mum or dad to know how you are feeling.

These may help:

- Try writing a letter.
- Find cards that say what you may be feeling.
- Send an SMS.
- Find quotes that you find inspiring and share them with your mum or dad.
- Draw.

### When you want to know more

If it is information that you need, then you can do some research yourself or speak to the doctors, nurses or social workers.

However there is this policy called "patient confidentiality". Your parent's doctors are not able to tell you stuff about your parent's treatment or their prognosis (what the outcome may be) without your mum or dad's permission.

How to get around it? You can ask your parents to give the doctor permission to give you information. But be aware if your mum and dad has told the doctor that they do not want you know some things then the doctor has to obey those wishes.

For some parents not telling the whole story is a way of protecting you. Closing the gap between what your parents want you to know and what you want to know can take some delicate negotiating.

Expect a lot of mixed or confusing emotions



# Supporting your parent

You don't need to be a genius to figure out that having cancer can really mess with your life.

Knowing how your parent is feeling about it could help you figure out how to support them or at least understand where they coming from.

It may surprise you but your mum or dad is probably feeling many of the same things you are.

## **Sad or depressed**

Your mum or dad may not be able to do the things they used to do and they will miss these activities. Just as your friends may not know what to say to you, your parent may have the same issue with their friends.

Depression (as opposed to just feeling down) is not uncommon for people diagnosed with cancer.

This can be treated by a doctor. (See "When it all seems too much" on page 31 for some warning signs.)

## **Scared**

Your parent may be afraid of how their cancer will change their life as well as the lives of the rest of the members of your family.

Treatment can also be a scary thing; your mum or dad may even be frightened that they will die.

## **Anxious**

There are lots of things that could cause your parent to worry; how they are going to go to work, pay bills, how the treatment will affect them and how they will look. And like all other parents they are probably worried about how you're doing.

## Angry

Cancer treatment and its side effects can be very difficult to go through. Your parent's anger can sometimes come from feelings that are hard to express like frustration and fear. Try to remember that they are most likely angry at the cancer and not at you.

## Lonely

Having cancer can be a lonely experience and your mum or dad may feel a bit isolated. They may find that their friends have a hard time dealing with their cancer and don't visit, or they may be too sick to do things that they used to do.

They may also feel that no-one understands what they are going through and that they need to hide their feelings.

Does a lot of this sound familiar?

## How can you help?

Firstly, remember you are not responsible for making everyone happy or for solving everyone's problems. There are some things that you can do that will help and this might make you feel like you are better supporting your parent.



**One thing I have learnt from this experience is...**  
never assume the worst, always think of the positives and always look forward to the future.



## Be positive

This can be good for you and your family, but don't feel like you have to be upbeat all the time, especially if that is not how you feel. Looking for the positive in things can make a difference. Just being yourself is OK.

## Be patient

You and your parents are under a lot of stress. Routines may have changed and your parent

may not behave in ways that you are used to. Try and understand that and be patient with them and yourself. If you find it is getting too much, take a walk, listen to some music or just find some space for yourself.

(See "What's a coping strategy?" on page 36 for more ideas.)

## Help out at home

Depending on which parent has cancer, the extra things you may need to do could vary. They may involve helping out with younger brothers and sisters, cooking meals, doing the washing. You may also need to be around the house

more, especially if both of your parents are spending time at the hospital.

Often it is the really small things that can make a big difference. Sometimes it is just doing something without being asked.

### **Spend time with them**

Just hanging out with your parent can really help. You could watch TV together, read to them or find something to laugh about.

Things will change in your life and you may feel that you need to be around your mum or dad a lot more. But it is still OK to do the things that you did before they got sick.

**Remember: You and your needs still count.**

**Remember:**  
**You** and  
**your needs**  
still count.

### **Visiting your parent**

Hospitals can be freaky places at the best of times. (Well, maybe not for everyone.) They may feel even more so when your parent is having treatment.

Knowing what is happening to them and understanding what to expect when you go to visit can help make it less stressful.

Before you visit you might like to know a few things. You can get this info from another adult, the doctor, an older brother or sister or another relative:

- Will they be connected to any machines?
- Will they have tubes, drips or other stuff attached to them?
- What will it smell like?
- Am I allowed to touch them?
- Does the medication affect their speech or hearing?
- Will they seem a bit “out of it”?

**Remember: Your mum or dad is still the same person even though they are sick.**

Your mum or dad is still interested in what is going on with you and will still want to be your parent (they may still even expect you to clean your room or stay in on a Friday night).

Here are some things to make visiting easier:

- Take your homework to do while you visit – that way you have something to focus on other than all the medical stuff.
- If you have access to a DVD or video player in the hospital room you could take a movie to watch.
- Do the crossword together or take a board or card game.
- Catch up on some sleep in the visitor's chair – just being in the room can be a comfort to your parent.
- Take some music to listen to or the newspaper or a trashy magazine to read.

- Take in their favourite food or get take-away delivered. (Just check that they are not feeling sick because this could turn them off their favourite food forever.)

### When visiting is too hard

There may be practical reasons that make visiting hard: you have other commitments like sport training, too much school work, exams or work. Visiting hours in some hospitals make it hard to fit it all in. Don't be hard on yourself if you can't get to visit all the time.

Sometimes you just can't face visiting. This is OK. But you can still stay in touch by phone, sms or even by writing a letter.

If you find that you just can't visit at all, then you may need to find someone to talk to about this.

**Remember: Life doesn't stop when you have a parent living with cancer.**



**Remember:**

**Your mum or dad is still the same person even though they are sick.**



While everyone is worried about your parent who has cancer, it is really important that you take the time to look after yourself.

It's not selfish because if you don't take care of yourself then you can't take care of anyone else. You'll need all your strength to get through the tough times.

### **Taking care of your body**

You've probably heard it all before; eat and drink well, stay away from smoking, drinking and drugs and get enough sleep.

That all may seem easier said than done with everything else going on in your life right now. Plus you may not really get why it is so important.

Basically, your body needs the right fuel to keep it going. If you start to skip meals or don't get enough sleep your brain can get that foggy feeling and it just makes everything else harder to deal with.

If you've ever seen a baby scream because it's hungry or grizzle because it's tired, you'll get the picture. You might not do the same things but your body will still start to feel bad.

The idea is to make it easier – not harder – for yourself.

These things are a good starting point:

- Eating well throughout the day.
- Getting enough sleep.
- Having regular exercise.
- Taking time out to relax and unwind.
- Laughing.
- Seeing a doctor when you are not feeling well.

## Taking care of your mind

As well as having a healthy body, your mind needs looking after as well. Things to do:

- Learn how to relax.
- Take time to chill with your friends.
- Deal with things so that you don't spend time and energy worrying about them.
- Talk to people about how you are feeling.

- Write your thoughts and feelings down (check out the journal and other spaces to scribble in this book or start an online blog).
- Find others who are in the same situation as you at [www.nowwhat.org.au](http://www.nowwhat.org.au)



# when it all seems too much



When you are living with a parent who has cancer, it is normal for everyday things to seem hard and for you to have a whole heap of mixed emotions. However sometimes things can start to seem like they are out of control and it can feel like it is all too much.

It's really important to recognise some of these warning signs and to get some help.

## Depression

People experience depression and depressed moods in different ways. Some common symptoms are:

### Mood

- Feeling sad, moody or crap.
- Feeling guilty and blaming yourself.
- Feeling hopeless or helpless.
- Unable to feel good or enjoy things that you do normally.
- Poor concentration and memory.
- Believing that you can't cope and that things are out of control.



### **Behaviour**

- Not having motivation and energy.
- Crying a lot.
- Increased use of drugs or alcohol.
- Withdrawing from friends and family.


### **Physical**

- Losing your appetite or overeating.
- Changes in your sleep patterns – waking up during the night or sleeping more than normal.
- Having headaches or stomach aches.
- Feeling physically sick.

Many of these symptoms may be just part of dealing with the stress and a normal reaction to dealing with a parent who has cancer, but if these feelings last for more than two weeks and they start to interfere with things that you used to enjoy, then you may be depressed. Try not to panic – there is help out there for you. Check out the websites and phone numbers in the “Where to get help” section on page 78.

## **Unhealthy ways to deal with stress and tough times**

A lot gets written about positive ways to deal with stress, but we all know that there are other ways that you can try to cope that aren't exactly so healthy or helpful. Don't let the fear of people possibly judging you stop you from asking for help. No-one will judge you if you are doing any of these. Staying safe and healthy is more important.



**At the start I really wish I knew...  
that cancer can be cured.**

If you are into any of the following, you may be at risk of doing yourself some long-term damage. Find someone you can trust to share what is happening or use the “Where to get help” section on page 78.

### **Drugs and alcohol**

You may start using drugs and or alcohol to cover up the pain or try to make it go away. Or you may simply use them to wipe out or escape from what is happening for you.

Without the lecture, this is only ever going to be a short term fix.

As tempting as it may be for you to use this as a coping strategy, it will not help you in the long term and in fact will only do you harm.

## Hurting others

Feeling angry when your parent has cancer is OK. Anger sometimes covers up all the other emotions going on underneath. If you don't think you have a safe place to express yourself you may turn your anger on others.

Anger is a natural emotion but violence towards others is never an OK way to deal with it. There are better ways to express your anger that don't involve hurting others.

## Deliberate self harm

This is when you deliberately harm yourself, usually in secret. This can involve cutting, burning, pulling out your hair, scratching yourself or picking at sores on your skin.

Often it is used to cope with difficult or painful feelings.

It's also a way of trying to tell people that you need some support or feel out of control.

Ask questions even if you are scared to do so



Deliberate self harm can give you an instant sense of relief but it is only a temporary solution. You can be left with permanent scars and ongoing issues with your mental health.

## Safe ways to act out feelings (especially anger)

- Punch a pillow – use your hands, a stick or anything else you can get your hands on.
- Chuck a tantrum on your bed or in your room.
- Go for a run - pounding the pavement is better than beating up on yourself or someone else.
- Watch a sad movie – what a good excuse for a great big cry!
- Find a private space and SCREAM at the top of your lungs.
- Take a long shower (shhh.. don't tell the water restriction guys) and cry, sing or yell while you are in there.

**Remember: Having a parent with cancer sucks, but you are not alone and there are people who will understand and can help.**

# getting support

Asking for help can be a pretty scary thing to do.

It may mean having to:

- ‘fess up to not be doing as well as you would like to be (or are pretending to be)
- open up about what’s going on
- talk about things that are hard
- admit that you don’t have all the answers
- be honest and let your guard down.

But unlike lots of other stuff that you have to deal with, having a parent with cancer is off the radar for most young people. It’s not something that you may have ever thought about, let alone read anything about or chatted to friends about.

Faking the “I’m OK” thing is going to be a whole lot harder.

## What does a good support person look like?

Well they’ve got really big hair, wear long flowing skirts, burn candles and are as old as your grandmother.

No seriously, they will look different for different people but will probably have some things in common.

A good support person will:

- listen to you
- not judge you
- be there when you need them
- keep things private (if and when you ask)
- be honest with you
- have a sense of humour
- not always tell you that they know how you feel.

## Who can you get support from?

It may take a few shots at finding the right person, but it’s worth making the effort.

### Parents

You may find that your “well” parent is able to offer you all the support you need just because they know you and are around all the time. But remember they have a lot to deal with and you may have to be brave and ask for their support. The same goes for your parent who has cancer.

## **Remember:**

Asking for help doesn't mean you've failed. No-one expects you to get through this on your own and other people really do want to help.

### **Other relatives**

Sometimes you get on better with an aunt, uncle or grandparent than you do with your parents. (That's OK.) Maybe you have things in common, are closer in age (alright not with your grandparents) or they just get you. Use these people to get support.

### **Counsellor**

You don't have to be crazy to see a counsellor. They will listen to you and you can say things to them that you may not want to say to anyone else. The best thing is that you can't hurt their feelings or piss them off. They are skilled in helping to work out ways to cope with anger, sadness and fear.

### **GP**

Your family doctor may have known you and your family for a while, so they might understand what is happening for you. Doctors not only treat physical problems but can help with offering you support. You don't need your parent's permission to see a doctor if you are over 14.

### **Teacher**

Maybe there is a particular school teacher you have a good relationship with. Don't be afraid to let them know what is going down. They work with young people all the time and are usually great listeners and can be an advocate (someone who is on your side) at school.

### **Friends**

Some friends may be great at giving you just what you need but you may need to ask. Just having people know what is happening can help.

### **Religious leaders**

Priests, pastors, rabbis or other religious leaders are experienced in supporting people in their communities. You may already be involved in a youth group. They may be able to give you just what you are looking for.

### **Support groups**

Sounds lame? There are organisations that work with young people who are in the same boat. This might not grab you at first (others have said the same thing) but once you actually go you might change your mind. It is said that the best support comes from those who have been there and done that. CanTeen, the organisation for young people living with cancer, has great programs that offer support. Check out the website [www.canteen.org.au](http://www.canteen.org.au)

**N W H A T ' S V S  
B A A W G H O R F  
S C F D S F L H J  
G D O E Q S D S D  
D F F P V Y U I O  
I O P P I B F D B  
N R D G P N D N R  
S F D F P O G I Y  
S T R A T E G Y ?**

“Coping strategy” is a fancy term for those thoughts and actions that help you deal with the tough stuff that having a parent with cancer throws at you.

**Do I need one?**

Yep—in fact you may need a few and they may be different than the ones you have used for other things (like exams or hassles with friends).

We all deal with things in different ways but developing some good coping strategies can help you stay on top of things.

Here are a few that may help:

- Talk – expressing how you are feeling is better than bottling it up.
- Ask lots of questions and write the answers down.
- Get some time out (that doesn’t mean getting sent to your room!).
- Eat chocolate.
- Check stuff out on the Internet.
- Write a journal/blog.

- Find ways to have a laugh.
- Wherever possible keep doing the things that you like – playing sport, exercising, hanging out with friends.
- Learn how to meditate – you will be amazed at how good this feels.
- Tap into your spirituality – not just traditional religion but anything that may give you comfort.
- Get organised, especially if you have taken on extra roles. Things like a weekly planner and a to-do list can really make things more manageable (and no, it’s not a lame thing to do).
- Eat chocolate.
- Offload some of the things that you have to do – ask for help (this is really hard but really important).
- And finally eat chocolate (alright not too much and get some fruit and veggies as well).

# Not saint

There is a whole lot of stuff out there about how being “touched by cancer” can somehow make you into a saint, cause you to give up all your bad habits and find the answer to the universe.

It is true that many young people say that the experience has taught them stuff they didn't know, made them appreciate the little things more and helped them find a strength that they didn't know they had.

But for some of you, the expectation that this is how it should be is a really hard thing to live up to.

So...

- it's **OK** not to feel special
- it's **OK** to still get cross with your parent and have all the normal parent-child issues
- it's **OK** to not feel really brave and think that the whole experience will be good for you
- it's **OK** to think the whole thing sucks
- it's **OK** to come out the other end of this still being the same, faults and all.

## Remember

Everyone deals with things their own way and learns different things from the same experience.



There is heaps of grief and loss around living with a parent who has cancer.

Often we only think about grief and loss in terms of someone dying but in fact you could have these feelings even though your mum or dad is living with their cancer.

Loss is what happens; grief is how we feel about it.

You can think of loss as any event or thing that changes the way things have been. It is sometimes described as that point in time after which everything is different.

For many of you the first time this happens is when you are told about your parent's cancer. Life may never be the same again. Or it can happen at other times along the cancer journey.

Some losses will really knock you about while others may not have such a big impact.

It depends on what sort of changes it will mean for your life and how you feel about them.

Examples of losses that you may experience as a result of your parent's cancer:

- You lose contact with friends because you can't go out as much or you don't feel like doing the same things.
- Your school work is not up to the standard you are used to.

- Mum or dad can't work so there is a change in your financial situation.
- Going to uni or TAFE is too hard because you need to take care of your parent.
- Dad or Mum can't play sport with you because of their treatment.
- You feel that you have had to grow up a lot and you miss out on being just a regular kid.
- A planned holiday was cancelled because of cancer treatment.
- Your mum or dad is just not the same after their cancer treatment.

As you can see, there are lots of things that you can feel like you have lost because of what cancer can do to your family.

Grief is a personal thing and no two people experience it the same way. Just like feelings, there is no right or wrong way to do it.

What is important is to recognise when you may be experiencing grief and to learn positive ways to deal with it.

### **The most useful piece of information that I got was**

It wasn't my fault that the cancer happened. It's reassuring that you are not to blame for it.

These are some of the changes you may notice if you are experiencing grief and loss:

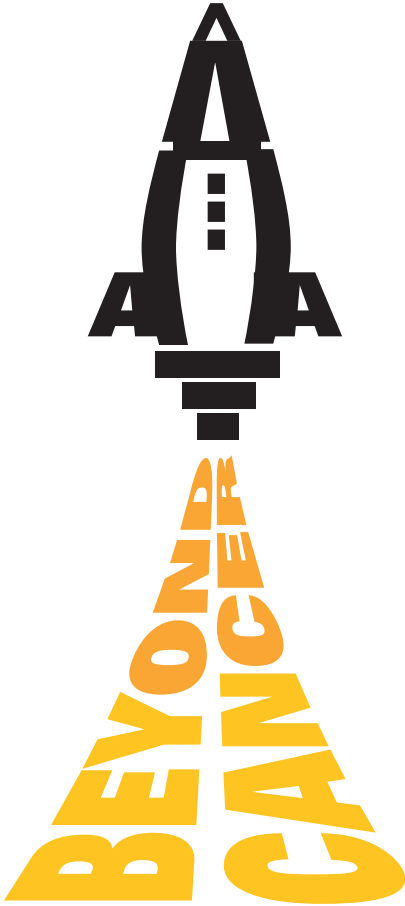
- Wanting to sleep lots or not being able to sleep.
- Dreams or nightmares.
- Eating heaps or not wanting to eat much.
- Headaches.
- Crying lots.
- Avoiding places that remind you of what you may have lost.

Putting a lid on it and hoping it will go away isn't always the best way to deal with it. (Have you gotten the message yet that this is the same for all sorts of things that you experience when living with a parent who has cancer?)

Check out these other sections in the book for ways to take care of yourself:

"What's a coping strategy?", "All about you" and "Getting support" will give you more info.





Thinking too far ahead is generally pretty hard when you are young, even on the good days. When mum or dad gets cancer, it probably gets even harder.

You have probably been so focused on doctors, drugs and getting by that you haven't had

much time to even think about what will happen when the doctors finally say that the treatment has finished.

The end of treatment can bring up a whole bunch of emotions, much like when your parent was first diagnosed.

You might be so relieved that it's over and then get mad when you realise that it really isn't.

Even when the cancer treatment has finished there can be short and long term side effects which can continue to have an impact on your family.

Getting over cancer treatment takes time. In general, it will take longer for your parent to recover than the time it took to treat them. This can be very frustrating for you and your mum or dad.

Cancer and its treatment can leave the body pretty beaten up (not to mention the mind). Your mum or dad may find they have to deal with:

- being tired – sometimes called “fatigue”, it's not just normal tired that sleep can fix. It can be “tired” for days and days
- “chemo brain” – memory and concentration problems. These can pop up months or years after treatment

At the start I really wish I knew  
That it can last for a long time.



- pain – ongoing from surgery, radiotherapy and chemo
- mouth and teeth problems – especially if they had radiotherapy to the head and neck
- changes in their weight and their eating habits
- lymphoedema or swelling – this is when an arm or a leg swells.

Some of the things that may become issues for you are:

- fear that the cancer will recur (come back)
- seeing your mum or dad still weak and sick

- dealing with your parent's physical changes; they may look different, have scars, be bald or their hair is not the same, or they may even be missing an arm, leg or breast.

For you, there can be a real sense of loss (and possibly anger) that your parent is not the same person they were before they got sick.

One of the hardest things after the treatment has finished is not knowing what happens next. There may be the expectation that things will just get back to normal – but what is normal and will things ever be the same?

There will certainly be a time of re-adjustment. You may feel that you have just got the hang of the new responsibilities and then suddenly you don't have to do them anymore. You may find that you have more time on your hands or that your mum and dad are around more because treatment has finished.

Just like all the other phases that you have gone through so far, it will take some negotiation, heaps of patience and above all communication to adjust to life after treatment.



Some of you may have to face the fact that your mum or dad's cancer has come back. This can be really tough and come as a big shock. Many of the emotions you felt when you first heard they had cancer will come crashing back. Understanding what it means can help.

### **What is a cancer recurrence/relapse?**

A cancer is considered to have recurred when the cancer returns after your parent has been in remission. (When there is no evidence of cancer in the body). This happens because sometimes some cancer cells were left behind despite the treatment that they received or brand new cancer cells develop.

A cancer recurrence can mean it's the same cancer coming back or in rare cases the cancer may be a completely new cancer.

### **Where does cancer recur?**

There are 3 types of recurrence;

#### *Local recurrence:*

The cancer reappears in the same place it was first found, or very close by. The lymph nodes or other parts of the body are not affected.

#### *Regional recurrence:*

This happens in the lymph nodes and the tissue in the area of the original cancer.

#### *Distance recurrence:*

This is when the cancer has spread (metastasised) to other areas in the body.

# Top Tips

**Do your best to be positive  
for yourself and your family**

## Can cancer recurrences be treated?

Local recurrences may still be curable however cancers that recur at a site distant from where the original cancer occurred may be more difficult to treat.

What treatments your mum or dad receive or choose to receive will depend on things like where the recurrence is and what they may be prepared to go through again.

This may be really hard for you as you may feel like you have no control over the decisions that your parent makes and you may be very scared about what will happen.

Like all the other stages you have been through with your parent's cancer, getting the right information is really important.

Ask people to be honest with you about what is happening.



# if treatment doesn't work

Sometimes it doesn't matter how hard your parent fought, how positive you all have been or how many different treatments the doctors tried, some people cannot be cured.

If this is the case, active treatment and testing will be stopped and your mum or dad will be given medicines for pain and to relieve other symptoms like nausea and vomiting. These medicines are aimed at making your parent as comfortable as possible.

This stage is called palliative care or palliative treatment.

It is important to remember that just because your mum or dad is receiving palliative care this doesn't necessarily mean that they are going to die soon.

This stage can last from as little as a week to a year or more. Each situation is different. Again, make sure you ask someone you trust to explain exactly what is going on for your parent.

During this time you and your family will have to face a lot of new challenges.

Some of the emotions and feelings that you had when you first found out about the cancer may come back but there are also going to be a whole bunch of new ones and they could be a lot stronger than before.

You might even feel despair – an emotion that you've never felt before. It is just a feeling of hopelessness, like you are completely lost and useless. This is a really tough one to cope with.

This time sucks so bad you might feel completely alone at times, really angry with the world, your parent, the doctor, the nurse or some random walking down the street – because they look healthy and it feels really unfair. Yep it feels like that because it is.

But don't let that stop you from spending time with your parent, having fun, laughing, crying and sharing your thoughts and feelings with them.

**Remember: There is no right or wrong way to feel or act when your parent is dying.**

What is really important at this time is to ask as many questions as you need to. Ask your mum or dad, doctors, nurses, social workers.

Ask people to be honest with you. They may think that you can't handle it, but you know that you can and they will see that.

Don't expect to get it right, everyone is trying to do their best in a really tough situation. Be patient with each other.

Just keep talking to each other and know that your mum or dad still love you and don't want to say goodbye and that the love will never stop.

Some of you may want to make something together with your parent, maybe a picture, a scrap book, a video or something that you will treasure and that is just between you two.

**Remember: Only do what feels comfortable and right for you.**

And at this stage you will start to wonder, "What happens when...". And there will be millions of "What happens when..." questions for you, other family members and your parent. But most of all, you are going to wonder "What happens when I don't have the person with me to love, and be loved by, anymore?".

**Remember:**

There is no right or wrong way to feel or act when your parent is dying.

“

**At the start I really wish I knew...**

how difficult this would be.

”

This could well be your toughest question ever. This is when a group like CanTeen (where you can connect with other young people who have faced the same crappy outcome), or a professional counsellor or psychologist could be of most use.

"What happens when..." is a really scary moment for everyone. You will need some help for yourself. You will need to be there to help others like your other parent and siblings. You will need to have space and time. Asking can be hard – not asking can be even harder.

All the tips and suggestions in the rest of the book are just as useful at this time. Get support, take care of yourself, and be aware of danger signs if it's all getting too much and remember to be easy on yourself.

For those of you who need more information about this stage in the journey [www.nowwhat.org.au](http://www.nowwhat.org.au) has more detail on this.

# SCHOOL + STUDY + WORK

You will have worked out by now that the rest of the world doesn't stop because your world seems to revolve around cancer. Things like school, other study and work don't go away, but trying to juggle it all may mean you risk dropping some of the balls.

## School

If you're in school it forms a big chunk of your life. Having a parent with cancer can affect you at school in lots of ways:

- You may have difficulty concentrating on stuff because you are worried about mum or dad.
- You may be tired because you are doing extra things around the house.

- You have less time to get your homework done because of these extra jobs.
- Motivation may be down.
- Your work might not be up to the usual standard.
- Friends and teachers may act weird.

While you might not want to be treated any differently, letting your teachers know what is going on may mean they cut you some slack. It will help if you don't have to pretend that everything is OK.

## Years 11 & 12

If you are doing your final school exams you may be able to get “special consideration” if you have missed work because you have been looking after your parent or younger brothers and sisters, or you have just had a hard time coping with it all.

You will need to speak to the school counsellor who can organise this for you.

**Remember: It's not bludging – just recognising that things are really hard.**

## Work

What you tell your employer or work mates about your parent's cancer is completely up to you. There is no law that says they need to know. However you may find that they are supportive and understanding, especially if you have to take time off or are just having a bad day.

Check with your supervisor, manager or human resources manager about your rights when it comes to taking time off.

You may be entitled to carer's leave or you can take sick leave, annual leave or time off without pay (this should be the absolute last resort) if you have to care for your parent or take them for treatment.

If you don't ask you won't know.

Check out “Where to get help” on page 76 for more info.

## Other study

If you are at uni or TAFE, talking to your lecturers, tutors or department heads should help you to work out a strategy to cope with your study work load and with recognition of what is going on at home.

Most campuses have a student services centre that provides counselling and support.

Don't be afraid to take advantage of whatever is on offer to help you get through these tough times.

**Remember: It is best to deal with things before they hit crisis point.**

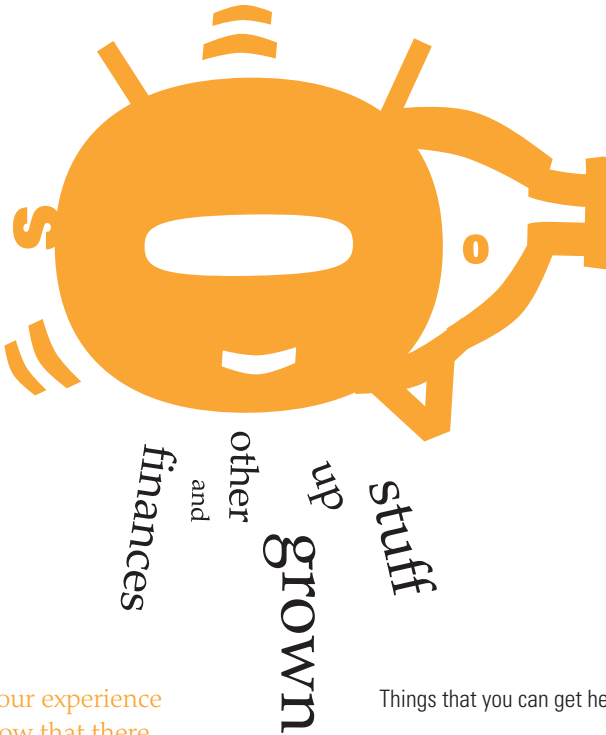


One thing I have learnt from this experience is...

that **life** is what **you** make of it.







From our experience we know that there are some of you who will have to deal with financial issues, banking, Medicare, private health funds, Centrelink and other exciting government departments.

This can be really overwhelming and stressful, especially when you are trying to deal with everything else, but there is all sorts of assistance available. It is just sometimes a matter of knowing what to ask and who to ask.

Things that you can get help with include:

- financial assistance – you may be able to get a Carer’s Allowance or Carer’s Payment
- rent assistance
- pharmaceutical allowance
- concession cards
- parking vouchers at the hospital
- accommodation during treatment
- transport costs to and from hospital.

Where to get more information:

- Ask the social worker at the hospital.
- Speak to the nurses on the ward or in the clinic.
- Check out websites and support services in the “Where to get help” section on page 78.

## Budgeting

Some of you may find yourself responsible for the household budget while your parent is being treated for cancer. This could be as simple as having to do the weekly shopping or it may mean having to look after all the finances for the family.

Knowing how much you have to spend and what you need to spend it on will make it a whole lot easier. That's what a budget is.

Here are a few tips that can help you tackle this.

- A good idea is to list all the things that you need to buy and pay for on either a monthly or weekly basis.
- Always put aside money for the essential things first, like food, rent/mortgage payments, electricity and health care.
- Get a calendar and write on it when the regular bills come in and need to be paid.
- When you are doing the shopping, make a list and stick to it. Having a trolley full of TimTams and ice-cream and then no money for meat and veggies (and no loo paper) isn't so smart.

- Another way to avoid the lots of food but nothing to eat trap is to work out what you are going to eat/cook for the week, make a list of all the things you need and then make sure you buy it all.
- Supermarkets are cheaper than convenience stores.
- Don't put the envelopes with those little see-through windows in the top drawer and forget about them. They are most likely bills and won't go away just because you didn't open them. (Or they could be offers for credit cards that you don't want or need – in that case, bin them.)

**Remember: You don't have to do all of this on your own and it is OK not to know how to do things. Don't be afraid to ask for help.**





If you haven't already got the message, then we will say it again **TO BE GOOD AT LOOKING AFTER SOMEONE ELSE, YOU HAVE TO LOOK AFTER YOURSELF FIRST!** That means you need to get healthy, and stay healthy by learning how to feed yourself some really good food. If you now have the job of feeding your whole family, then they will get a health bonus as a result of your new cooking skills.

Up to now, you probably yelled out "what's for dinner?" when strolling by the kitchen on your way to somewhere else. So now you might be the one getting texts from your siblings saying "wotz 4 dinr bro?" Yep, it'll be a pretty steep learning curve. But the thing is you will get good at shopping, cooking and serving food really, really fast because you will be doing it over and over again.

Here are some good ideas...

If cooking is new to you, then find someone to give you basic tips about food safety, knife skills, cooking techniques and reading recipes - ask a friend's mum or sweet-talk the Food Technology teacher at school.

Getting enough protein (from nuts, beans and lentils, eggs, fish, meats and dairy products) is

very important, especially when someone is ill. But, sometimes protein can be difficult to digest, so protein powder can be sprinkled on or added to most foods and non-meat sources like tofu are pretty easy to use.

The smell of food can sometimes make an ill person feel worse, and make eating more difficult, so try cooking and serving food outside or place a fan behind the table so the smells are blown away.

Some drugs and chemo can make food taste metallic, so serve dishes with plastic utensils, chop-sticks or porcelain spoons.

Fresh vegetables and fruits can be easier to eat when they are juiced, but some acidic juices (like tomato) can hurt if the person has mouth ulcers. Drinking with a straw or adding aloe vera juice (you can get this from health food stores) might help.

Clear broths and soups made with fresh organic ingredients can provide plenty of nutrition and are easy to eat. Make lots and freeze some for later.

Eating favourite foods when you are sick or nauseous can sometimes turn you off them, so serve these dishes on special occasions or celebrations with friends and family when your parent feels better.

Hospital food can be awful so prepare some homemade meals that can be reheated in a microwave or eaten cold.

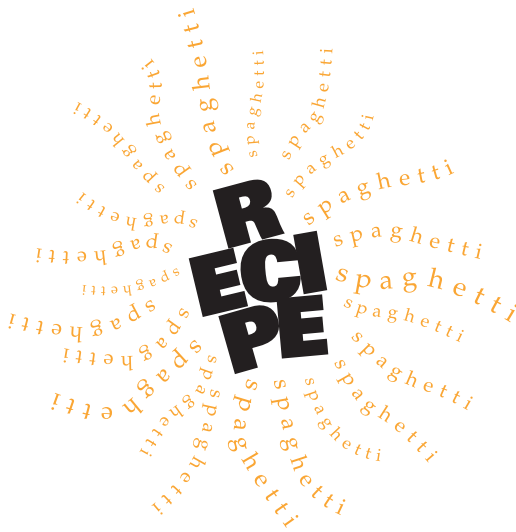
Reserve one 'cooking' day a week to make big batches of family food that can be frozen then reheated (or added to lunch boxes) without too much effort.

Small meals on a nice plate in a lovely setting can be less scary than a huge plate piled high.

Take the time to relax, eat well and look after yourself and always ask for help – even before you need it!

**Find a way to escape – be it reading, listening to music or do something like drawing or writing. Sometimes you just need to get away from everything**





## Easy Spaghetti Bolognese

Spaghetti bolognese is a dish almost everyone will enjoy – especially if the sauce is packed with great ingredients and cooked with love. Of course bolognese can also be used in different ways, so make a huge batch and use it for more than one meal. See more ideas at the end of the recipe instructions.

### Serves 4

**Preparation Time: 10 mins**

**Cooking Time: 30 mins**

### Tools

Sharp knife & chopping board

Heavy-based large sauce pan (for sauce)

Long handled stirring spoon and ladle

Large saucepan (for pasta)

Colander

Bowls, forks and spoons for eating

## Ingredients

2 teaspoons olive oil

1 brown onion chopped

400 g lean beef mince

1x 700g jar of bolognese pasta sauce

1 carrot finely chopped\*

1 celery stick finely chopped\*

375g spaghetti

\*(You can leave the veggies out and it will still taste good).

## Method

Heat the oil in a saucepan over medium heat and fry the onion until it is soft and changes colour.

Next add the mince and cook until it has changed colour – goes from red (raw meat colour) to brown. You will need to stir it to make sure that it all gets cooked and you break up any lumps.

Add the veggies and cook for another 3-4 minutes.

Pour in the pasta sauce and bring to the boil.

Cover and simmer (gently cook) for about 30 minutes or until the veggies are soft.

While the sauce is cooking fill a large saucepan with water, add a little salt. Bring to the boil and then add the spaghetti and cook until al dente. (See notes for explanation).

Drain in a colander. Add a little bit of oil to stop it sticking together.

When the sauce is cooked, check if it needs any salt and pepper.

To serve place some spaghetti in a bowl and spoon some sauce over the top.

Sprinkle with grated cheese.

## Notes

Al dente [al-DEN-tay] is an Italian phrase meaning “to the tooth,” used to describe pasta or other food that is cooked only until it offers a slight resistance when bitten into, but which is not soft or overdone.

Any leftover sauce can be frozen then reheated in the microwave for a quick pasta sauce or to put on toast for breakfast!

Use organic ingredients if you can to avoid any residue of chemicals or pesticides.

## Variations

**Chilli Con Carne** - add a can of kidney beans, 100g dark chocolate and 1 teaspoon of crushed chillies to the sauce when it has nearly finished cooking or to a batch you are reheating. Stir till the chocolate melts.

**Lasagne** – layer a baking dish with bolognaise, instant lasagne sheets, cheese sauce (and layer again in this order), top with grated mozzarella and cheddar cheese then bake at 180°C for 40 minutes.

**A Bigger Batch** – add 400g more mince, 1 more carrot and another jar of pasta sauce.

**Tacos** – leave the sauce as it is or add a sprinkle of cayenne pepper, spoon into heated taco shells and top with sliced fresh tomato, shredded lettuce and grated cheddar cheese.

**Quesadillas** – cover a tortilla with bolognaise then top with sliced red or green peppers, grated cheddar cheese, and another tortilla. Brown both sides in a non-stick fry pan or toast in an electric sandwich press (grill or snack maker).

**Nachos** – put a pile of plain corn chips onto a baking tray, dob over spoonfuls of bolognaise and grated cheddar cheese, then put in the oven or microwave till the cheese melts.

**A Snack** – leftover sauce can be reheated and eaten on toast or in a toasted sandwich.

Check out the website [www.nowwhat.org.au](http://www.nowwhat.org.au) for more recipe ideas.



## One thing I have learnt from this experience is...

how to do more things, because I help so much and I know more things than some of the girls in my class.



What **cancer** is that?



There are over 100 different diseases that are referred to as cancer. This table lists the most common adult cancers. If your parent's cancer is not listed you may need to ask your parents, the doctors or nurses or check out the websites listed on page 78 to find out more.

Type of cancer	Description	Incidence	Treatment
<b>Bowel cancer</b>	Bowel cancer can grow from either the inner lining of the bowel or from a small raised area called a polyp. Polyps are usually harmless, but some can become cancerous (malignant) and spread.	Bowel cancer is the most common form of cancer diagnosed in Australia.	Bowel cancer is highly treatable if found early even if it spreads to lymph nodes. If it has spread to other organs such as the liver it is more difficult to treat and cure. Treatment involves surgery and then occasionally chemotherapy or radiotherapy depending on the stage of the disease.
<b>Breast cancer</b>	Breast cancer develops when some of the cells in the breast begin to grow out of control. A cancerous growth then appears somewhere inside the breast. It is commonly detected by feeling a lump in the breast or surrounding tissue. Diagnosis is usually confirmed by a mammogram, ultrasound or biopsy.	Breast cancer is the most common form of cancer affecting women in Australia. It also affects men.	Treatment for breast cancer usually depends on where the cancer is, whether it has spread, the cancer's growth rate and the person's general status. Most breast cancers are treated either by surgery, radiotherapy, chemotherapy and hormone replacement therapy.

Type of cancer	Description	Incidence	Treatment
<b>Lung cancer</b>	Lung cancer is a cancer of the cells in the lungs. There are two types of lung cancer: small cell and non-small cell.	Lung cancer is the third most common cancer in men and the fifth in women in Australia.	Small cell cancer of the lungs is treated with chemotherapy and radiotherapy. Non-small cell cancer usually requires a combination of surgery, chemotherapy & radiotherapy.
<b>Prostate cancer</b>	Prostate cancer develops when the cells in the prostate gland form a tumour. (The prostate is a small gland the size of a walnut that sits below the bladder and surrounds the tube that carries urine from the bladder through the penis.) Most prostate cancer forms only within the prostate and it is slow-growing compared to other cancers. Therefore it can be detected earlier. It can spread to other parts of the body, and this is known as advanced prostate cancer.	Prostate cancer is the most common form of cancer in Australian men.	Treatment depends on age, how fast the tumour is growing and whether it has spread. The most common treatment includes surgery and radiotherapy. If the cancer has spread beyond the prostate then hormone therapy may be used.

**The most useful piece of information that I got was...**  
**what was going to happen, the side effects and where the cancer was.**



Type of cancer	Description	Treatment
<b>Leukaemia</b>	<b>Leukaemia is cancer of the white blood cells (WBCs). Bone marrow and other blood forming organs produce abnormal numbers of white blood cells, stopping the production of normal blood cells.</b>	
<b>Acute lymphoblastic leukaemia (ALL)</b>	ALL increases the number of WBCs called lymphocytes.	Treatment plans for ALL usually include chemotherapy and radiotherapy. This can be for up to 2 years. Some patients may also require a bone marrow transplant (BMT).
<b>Acute myeloid leukaemia (AML)</b>	AML increases the number of abnormal WBCs called myeloid cells.	Treatment plans for AML usually include 6 months of chemotherapy with 2-3 drugs in each course of treatment lasting 5-10 days. 4-5 courses of chemo are given on a monthly basis. Depending on the success of chemotherapy a BMT may be necessary.
<b>Lymphoma</b>	<b>Lymphoma is cancer of the lymphatic system, which is part of the immune system that protects the body against infection and disease.</b>	
<b>Hodgkin's lymphoma</b>	Cancer of the lymphatic system. Tumours affect the lymph nodes as lymphoma cells lodge in the system causing a lump. These are normally close to the body's surface, such as in the armpit and neck.	Treatment depends on the stage of lymphoma. Most people need a combination of chemotherapy and radiotherapy.
<b>Non-Hodgkin's lymphoma (NHL)</b>	Cancer of the lymphatic system that does not have the features of Hodgkin's disease. NHL affects the lymph nodes deeper inside the body. There are different types of NHL, the two main types being B-cell NHL and T-cell NHL. B-cell NHL usually affects the neck, head, throat and abdomen whereas T-cell affects the lymph nodes in the chest.	The most common treatment for NHL is chemotherapy and occasionally radiotherapy. There can be some short-term and long-term side effects from NHL treatment.



**Don't let others keep on giving you bad advice**

Type of cancer	Description	Treatment
<b>CNS Tumours</b>	<b>Cancers of the brain and spinal cord.</b>	
<b>Brain tumours</b>	There are many different types of brain tumours. The most common tumours grow from glial cells, which are the support cells in the brain.	Some brain tumours are more serious than others and require more aggressive therapy. Treatment usually involves surgery to remove the tumour, and then radiotherapy and possibly chemotherapy, depending on the outcome of the surgery.
<b>Other cancers or tumours</b>		
<b>Germ cell tumours</b>	These tumours develop in the reproductive organs (testicles and ovaries). They can travel to other parts of the body including the chest, abdomen and brain. The most common germ cell tumours are testicular, sacral, chest and ovarian.	Most commonly involves surgery to remove the tumour then chemotherapy.
<b>Melanoma</b>	Melanoma starts from melanocytes, the cells in the skin that produce the skin pigment or colour. Melanoma grows quickly which means it can spread to the lower layer of skin then into the body and other systems.	Melanomas are always removed by surgery. Radiotherapy may also be required depending on the stage of melanoma and whether it has spread to other organs.
<b>Thyroid Cancer</b>	Thyroid cancer affects the thyroid gland which is located in the neck. There are different types of thyroid cancer, categorised by growth rate, malignancy and type of cells affected.	Treatment may involve surgery, radiotherapy, chemotherapy and hormone therapy.

# stests and more tests

These are some of the most common tests that are used in the diagnosis and treatment of cancer.

Test	What for	What happens
<b>Biopsy</b>	Used to find out whether a tumour or abnormality is cancer. Benign means it is not cancer. Malignant means that it is cancer.	A doctor removes a sample from a person using one of two ways: with a long needle (needle biopsy) or by making a small cut (surgical biopsy).
<b>Blood test</b>	An examination of the blood to see whether the balance of the cells and chemicals is normal.	A nurse or technician inserts a needle into a vein, usually in the arm. Then he or she draws blood.
<b>Bone marrow aspiration</b>	Collects a small sample of cells from inside a bone to be examined under a microscope to assist in diagnosing leukaemia and other blood disorders. It can also help to see if the cancer has spread.	A needle is used to remove a small sample of tissue from a bone (usually the hip bone).
<b>CAT (computerised axial tomography) or CT scan</b>	Uses x-rays and a computer to produce three dimensional (3-D) images of the inside of the body so the doctors can look for tumours and can also guide the surgeon to the right spot for a biopsy.	The patient lies flat on a table, which moves through a large tube while a series of x-rays is taken.



Test	What for	What happens
<b>MRI (magnetic resonance imaging)</b>	Uses radio and magnetic waves to make images of organs and other tissues inside the body so the doctor can make a more definite diagnosis.	The patient lies flat on a table, which moves through a large tube while an MRI machine scans the body for several minutes.
<b>PET scan (positron emission topography)</b>	Uses computerised pictures of areas inside the body to find cancer cells.	The patient gets an injection and then a machine takes computerized pictures of areas inside the body.
<b>Spinal tap (lumbar puncture)</b>	Collects a sample of the fluid inside the spine to be examined under a microscope. The doctor does this to check for infections or the build up of white blood cells or protein.	A needle is used to remove fluid from the spine in the lower back.
<b>Ultrasound (ultrasonography)</b>	Uses high-frequency sound waves to make images of internal organs and other tissues inside the body.	A technician moves a small handheld device over an area on the patient's body. An image appears on the computer screen.
<b>X-ray</b>	Takes a picture of the inside of the body using high-energy waves.	The patient is placed in front of the x-ray machine or lies on a table.

# 7R347M3N75 D3-COD3D TR3ATM3NT5 D3-COD3D TREATMENTS DE-CODED

Y0u w1ll p1obably hear these terms used a lot while your parent is being treated.

You will probably hear these terms used a lot while your parent is being treated.

This chart explains what they are.

This chart explains what they are.

Treatment	What is it?	Side effects
<b>Chemotherapy or 'chemo'</b>	This is the most common form of cancer treatment. Chemo uses drugs, called cytotoxics, to kill or slow the growth of cancer cells. While these drugs stop the cancer cells growing and multiplying they affect normal, healthy cells in the process. That's why healthy fast growing cells such as the ones in your hair and inside your mouth are damaged by chemo.	Side effects vary from person to person, from one treatment to the next and depending on the type of treatment. The most common are nausea and vomiting, hair loss, mouth ulcers, loss of appetite and tiredness. These are usually temporary and disappear a few weeks after treatment stops. Some begin within 2-4 hours of the first injection and some happen a few weeks after treatment.
<b>Radiotherapy or 'radio'</b>	Radiotherapy uses high energy x-rays, gamma cells or electrons to kill cancer cells, or injure them so they cannot multiply, in a specific part of the body. It can be used to treat the original (primary) cancer and to treat symptoms of cancer which has spread. The radiation will affect all cells in the area, however, normal cells are better able than cancer cells to resist or recover from its effects.	The side effects of radiotherapy will depend on which part of the body is being treated. One of the most common is tiredness and lack of energy This gets worse as the treatment goes on but gradually improves after treatment has finished. Other side effects include; skin problems, hair loss, loss of appetite, nausea and diarrhoea and chest problems.

Treatment	What is it?	Side effects
<p><b>Hormone Therapy</b></p>	<p>Hormones are chemicals produced in glands that help regulate reproduction and growth. Examples of hormones include insulin, oestrogen and testosterone. Some cancers grow in response to hormones (or respond to changes in body hormones). Most hormonal therapies work by decreasing the amount of hormone in the body or by stopping the cancer cells from getting the hormones. By doing this, hormonal therapies can help reduce the size of the cancer and slow down the spread of the cancer.</p>	<p>Side effects from this treatment can differ for men and women. The most common ones are; tiredness, mood swings, weight gain, nausea and hot flushes.</p>
<p><b>Surgery</b></p>	<p>Surgery involves the cancer being removed while the person is under general anaesthetic or sometimes using just a local anaesthetic. Tumours are removed this way. For some people with bone or organ cancer it may be necessary to remove tissue from around the cancer to ensure that it is all removed. Sometimes the whole organ may be removed or a limb amputated.</p>	<p>The side effects from surgery are the same as any other operation; some pain and discomfort. Other side effects will depend on the type of surgery and what was done during the operation.</p>
<p><b>Complementary and Alternative Treatment</b></p>	<p>Complementary therapies are treatments that are not part of the conventional treatment routine for cancer (like the ones mentioned above). They are not scientifically proven, but complementary therapies such as relaxation, meditation, massage therapy and counselling, can help deal with the emotional and physical impact of the disease and treatment side effects. They can be used together with the other treatments.</p> <p>Alternative treatments are used instead of conventional treatment. Again they have not been scientifically proven to treat cancer. Examples include; high doses of vitamins, special diets, magnets or drinking large amounts of vegetable juices.</p>	<p>There are few side effects from complementary therapies.</p> <p>With alternative treatments it is not easy to know what the side effects will be. It may be best to check this out with whoever is recommending the treatments.</p>

# who is that person?

Your parent will be treated by a whole team of people. Sometimes trying to remember who does what can be a bit confusing. This chart will help. The blank column is for you to write in the names of the people who are looking after your parent.

There may be more than one person who is doing the same job or your mum or dad may not have all of these people on their team.

Who are they?	What do they do?	Their name
<b>Medical Team</b>		
<b>Medical Oncologist</b>	A doctor specialising in diagnosing and treating cancer patients.	
<b>Radiation Oncologist</b>	A doctor specialising in radiation to treat cancer. This doctor will decide if radiation is an appropriate treatment, will choose the best form of radiation treatment and then administer it.	
<b>Surgical Oncologist</b>	A surgeon who specialises in removing cancers via an operation.	
<b>Radiologist</b>	A specialist doctor who interprets X-rays, MRI scans and CAT scans to get pictures of the body.	
<b>Oncology Nurse Specialist</b>	A registered nurse with additional education and training in cancer.	

Who are they?	What do they do?	Their name
<b>Registered Nurse</b>	A nurse who provides regular care in the hospital or outpatient clinic.	
<b>Cancer Care Coordinator</b>	A nurse who is the main point of contact and helps patients and families communicate and deal with the different members of their treatment team.	
<b>Multidisciplinary team</b>		
<b>Social Worker</b>	A trained professional who helps patients and their families adjust to life with cancer and treatments. They can help with things like support services, financial assistance and other practical issues.	
<b>Clinical Psychologist</b>	A professionally-trained therapist who helps with emotional and intellectual well-being during cancer diagnosis and treatment.	
<b>Dietician</b>	A professional who provides information to patients and their families about nutritional needs related to their cancer and treatment.	
<b>Pharmacist</b>	A professional who is knowledgeable about drugs and medications that may form part of your parent's cancer treatment	
<b>Physiotherapist</b>	A professional who helps with recovering physical movement, like walking, bending and strengthening and may help with your parent's recovery after surgery.	



**The most useful piece of information that I got was...**

don't smoke, eat healthily, exercise – be healthy in mind, body, and soul, and smile.





# Glossary

## Glossary: (or what the... does that mean?)

Cancer has a whole language of its own. Some of the terms you may understand, some you may never need to know and some will become part of your everyday language.

Use this list to work out what the medical team is talking about (and to impress your friends).

The highlighted words are also defined in the list.

**Allogenic:** Tissue from a matched donor (often referred to with bone marrow transfusions).

**Alopecia:** The medical term for hair loss. Alopecia often occurs as a result of chemotherapy.

**Anaemia:** A condition where there is an insufficient amount of red blood cells in the body. It can cause tiredness and fatigue.

**Anaesthetic:** A drug given to a patient to stop them feeling pain during a procedure. It can be given as a local anaesthetic to numb the area or as a general anaesthetic to knock the person out!

**Analgesic:** A drug that relieves pain.

**Antibiotics:** Drugs used to treat or prevent an infection.

**Anti-emetics:** Drugs that help control and prevent nausea and vomiting.

**Aspiration:** Removing fluid from the body with a needle.

**Autologous:** Tissue from oneself (the opposite of allogenic).

**Benign:** Non-cancer or non-malignant. Can't spread to other parts of the body.

**Bilateral:** On both sides.

**Biopsy:** The removal of a small sample of tissue from the body. This sample is then viewed under a microscope. A biopsy helps doctors to diagnose disease.

**Blood:** Circulates around the body through arteries and veins. It carries all different substances such as food, oxygen and chemicals to the body's cells, and helps to fight infection. Blood consists of white blood cells, red blood cells and platelets suspended in a liquid called plasma.

**Blood count or full blood count (FBC):** Different numbers of the types of blood cells in the body.

**Blood transfusion:** Red blood cells given through the IV. The blood is from another person.

**Bone marrow:** The soft, spongy area in the middle of bones where red and white blood cells and platelets are made.

**Bone Marrow Biopsy:** The removal of a small amount of bone marrow, usually from the hip.

**Cancer:** A general term for a large group of diseases that have uncontrolled growth and spread of abnormal cells.

**Carcinoma:** Cancer that forms in the tissue at the base of the skin that lines the body's organs.

**Catheter:** A small tube that can be inserted into the body for removal or injection of fluids.

**Central line:** A catheter placed into a vein in the chest. It is used to give IV fluids, blood products and take blood counts.

**Chemotherapy:** The use of special (cytotoxic) drugs to treat cancer by killing cancer cells or slowing the spread of the cells.

**Clinical trial:** Research that involves giving medications to patients and studying the results. The aim of a clinical trial is to find better ways to treat or prevent disease.

**CT scan:** A procedure that takes lots of x-rays of the body from all different angles so that a good picture can be formed.

**Cytotoxic drugs:** Drugs that are given that damage or kill off cancer cells.

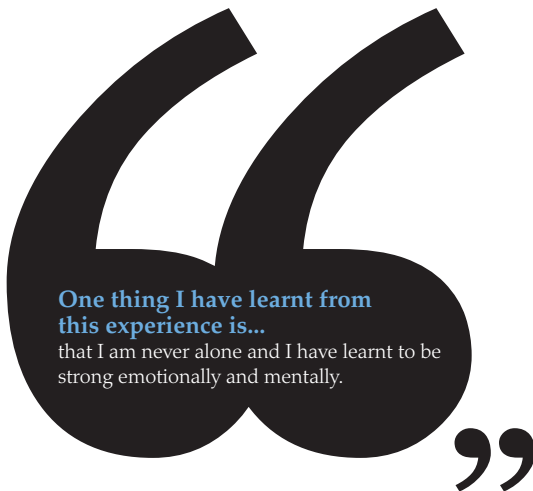
**Diagnosis:** The identification of a person's disease.

**Donor:** The person giving their tissue or organ to another person.

**External beam irradiation:** A common form of radiation treatment.

**Fatigue:** A feeling of tiredness that isn't fixed by sleep.

**Frozen section:** A sample of tissue is taken and then frozen quickly so it can be examined immediately under a microscope.



**Graft:** Healthy tissue is taken from a part of the body or from another healthy person and transplanted to replace diseased or injured tissue.

**Haemoglobin:** The component of red blood cells that carry oxygen.

**Haematology:** The type of medicine that studies the blood. The doctor that specialises in this is called a haematologist.

**Hormone:** A substance made by a gland that helps to regulate reproduction, metabolism and growth.

**Immune system:** The network of cells and organs that help to defend the body against foreign invaders like germs

**Immuno-compromised:** Weakening of the immune system often caused by disease or treatment.

**Infusion:** Slow injection of a fluid into a vein or tissue.

**Intravenous:** Giving fluids, drugs or blood directly into a vein.

**Limb salvage surgery:** When the original bone (or part of the bone) is replaced with an artificial (prosthetic) bone or bone from another part of the body.

**Localised cancer:** Cancer that has not spread to other parts of the body.

**Lymph:** A clear fluid that flows through the body carrying cells through the lymphatic system to help fight infection.

**Lymph nodes:** Small, bean shaped structures that filter the lymph to remove bacteria and other cells, such as cancer cells.

**Lymphoedema:** The swelling of an arm, leg or other part of the body because of an abnormal build-up of a fluid called lymph in the body tissues. This sometimes happens if the cancer blocks the drainage of fluid through lymph system. It can also occur when the lymph nodes have been removed by surgery or damaged by cancer treatments such as radiotherapy.

**Malignant:** Cancerous. A malignant tumour is likely to spread to other parts of the body if left untreated.

**Metastasis:** A secondary tumour that has spread from the primary site through the lymphatic or blood system.

**Neutropaenia:** An abnormal decrease in the number of neutrophils, a type of white blood cell.

**Oedema:** Swelling caused by an accumulation of fluid in the body or tissues.

**Oncologist:** A doctor who specialises in the treatment of cancer.

**Palliative Care:** Treatment that focuses on relieving the side effects or symptoms of a disease, but will not cure it.

**Plasma:** The fluid portion of the blood in which cells and platelets are found.

**Platelets:** Part of the blood that stops bleeding by aiding blood clotting.

**Prosthesis:** Artificial replacement for a body part that has been removed.  
eg. arm, leg, breast.

**Radiation:** Energy in the form of radio waves that can injure and destroy cells, particularly cancer cells.

**Red blood cells:** Cells that contain haemoglobin, which carries oxygen around the body.

**Relapse:** The return of the disease after treatment and a time of improvement.

**Remission:** The absence of signs and symptoms of active disease.

**Staging:** A way to identify the extent of disease. It is then used to determine treatment.

**Stem cells:** Immature cells found in the bone marrow from which blood cells are formed.

**Survival rate:** The percentage of people who are still alive after a particular length of time with a certain disease.

**Terminal:** When a disease cannot be cured.

**Thrombocytopaenia:**  
A decrease in the number of platelets in the blood, causing blood to take longer to clot.

**Total body irradiation:**  
Radiotherapy to the whole body, usually given prior to bone marrow transplants.

**Toxicity:** Harmful side effects caused by a drug.

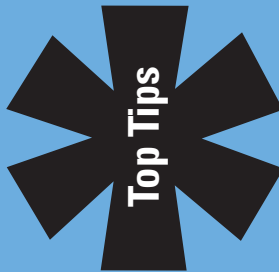
**Tumour:** An abnormal growth in the body.

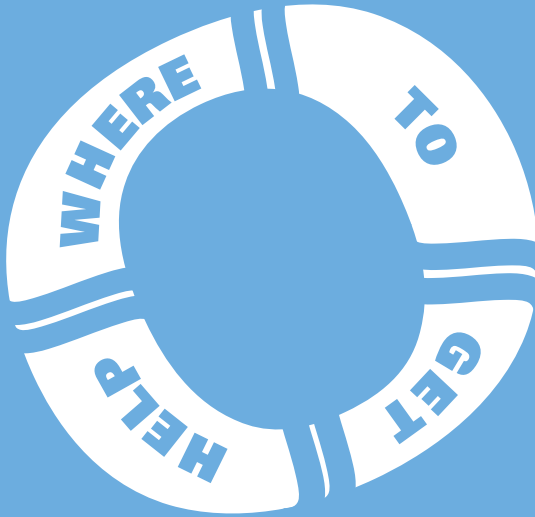
**Tumour marker:** A substance found in the blood produced by a tumour, which can indicate how treatment is working.

**White blood cells:** Cells in the blood that help to fight infection.

Ask questions even if you are scared to do so

Top Tips





These are organisations and websites that can help you deal with lots of things to do with living with a parent who has cancer. We have included some of the most well known and reliable sources for you.

Of course you can search for other resources on the net, but just remember the “Good Googling Tips” (on page 12) to make sure that what you find is going to help.

## Websites

### **[www.nowwhat.org.au](http://www.nowwhat.org.au)**

This website is designed for all young people living with cancer. You can access the information from the book as well as more detailed information on some topics. It also has other useful resources, stories, blogs and forums to support you.

### **[www.canteen.org.au](http://www.canteen.org.au)**

CanTeen is a fantastic organisation for young people 12-24 who have a parent who has cancer (or a brother or sister or they themselves have cancer). They run a whole lot of programs that are aimed at linking young people together who share similar experiences. They also work with bereaved siblings and offspring.

### **[www.cancer.org.au](http://www.cancer.org.au)**

The Cancer Council website has some really good, clear information on lots of things to do with cancer including different types of cancers, treatments and side effects. From this site you can access the Cancer Councils in your state

### **[www.leukaemia.org.au](http://www.leukaemia.org.au)**

The Leukaemia Foundation provides information and practical support for patients and families who are living with leukaemia, lymphomas, myeloma and other blood disorders.

### **[www.reachout.com.au](http://www.reachout.com.au)**

A site especially for young people going through tough times. Reach Out has fact sheets on depression, self harm, drug and alcohol as well as grief and loss.

### **[www.cancer.gov/cancertopics](http://www.cancer.gov/cancertopics)**

An American site that has lots of information on a wide range of cancer topics. It has reliable information on genetics and cancer and dealing with emotional stuff. Remember it is written more for adults.

### **[www.riprap.org.uk](http://www.riprap.org.uk)**

A UK site that is about supporting young people living with a parent who has cancer.

### **[www.myparentscancer.com.au](http://www.myparentscancer.com.au)**

This is mainly about young people who have a mother with breast cancer, but lots of the information is relevant for any cancer. A great site with information on things like healthy eating, drugs and alcohol, relationships and money and finances.

[www.kidshelp.com.au](http://www.kidshelp.com.au)

This has a free and confidential on-line counselling service as well as other helpful information on dealing with tough things.

[www.lifeline.org.au](http://www.lifeline.org.au)

This is a national organisation that has useful information on counselling, health, accommodation and a whole lot of other services.

[www.beyondblue.org.au/ybblue](http://www.beyondblue.org.au/ybblue)

This is the youth website of beyondblue: the national depression initiative. It has links to other support organisations and also has a list of doctors who have experience in dealing with depression. There are also fact sheets on depression.

[www.skylight.org.nz](http://www.skylight.org.nz)

A fantastic website with loads of stuff that is helpful and supportive for young people going through a rough time.

[www.youngcarers.net.au](http://www.youngcarers.net.au)

This organisation supports young people who are caring for a parent who is mentally or physically ill. They run support programs and provide information and links to other services. You can access the Young Carers Association in your state from this site.

[www.younggourmet.com](http://www.younggourmet.com)

This is a great website to do with food, cooking and all things to do with eating. There are recipes, tips and competitions.

[www.centrelink.gov.au](http://www.centrelink.gov.au)

This is where you can get all sorts of information on Government allowances and financial support.

[www.lawstuff.org.au](http://www.lawstuff.org.au)

If you have questions relating to legal matters this website provides lots of answers and also links other legal sites.

[www.workplace.gov.au/workplace/Programmes/WorkFamily/Carersleave.htm](http://www.workplace.gov.au/workplace/Programmes/WorkFamily/Carersleave.htm)

This is the link for information on taking leave to care for a parent.

## Telephone numbers

### Kids Helpline

1800 55 1800

### LifeLine

13 11 14

### Cancer Help Line

13 11 20

### CanTeen

1800 226 833



**One thing I have learnt from  
this experience is...**

**how strong my family really is and how we will  
do anything for each other.**





# BIBLIOGRAPHY

The following books, websites and publications have been useful in putting this resource kit together:

When Your Parent has Cancer – A Guide for Teens  
National Cancer Institute  
US Department of Health and Human Resources

Hipp, E. (1995) Help For the Hard Times – Getting Through Loss.  
USA: Hazelden

Vercoe, E., Abramowski, K. (2004) The Grief Book – strategies for young people.  
Australia: black dog books.

[www.riprap.org.uk](http://www.riprap.org.uk)  
A website developed by the team at the Sheffield Palliative Care Studies Group

[www.myparentscancer.com.au](http://www.myparentscancer.com.au)  
The National Breast Cancer Centre's website for young people with a parent who has breast cancer.

# Acknowledgements

**Now What?** Dealing with your parent's cancer.

Free copies of this book are available by calling CanTeen on 1800 226 833 or by going to [www.canteen.org.au](http://www.canteen.org.au)

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If you would like to support the work of CanTeen call the below number or go to the CanTeen website.

**CanTeen Australia**

GPO Box 3821, Sydney NSW 2000

Free Call: 1800 226 833

ABN: 77 052 040 516



This book is intended as a general introduction to the topic and should not be seen as a substitute for advice from doctors or other health professionals. All care is taken to ensure that the information contained here is accurate at the time of publication.



