



# Dealing with your brother or sister's cancer

Now what?





You've just been told that your brother or sister 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 may get lost in the whole picture as so much will be focused on your brother or sister who has cancer.

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 sibling'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 and downloads to support you through this tough time.

We have used the words brother or sister when referring to the person who has cancer in your family. However we know that for some of you reading this, that person could be a half or step brother or sister or could be another young person who lives with you that you have a connection to like a brother or sister. It doesn't matter who that person is, the journey is still the same.



We have also sometimes referred to ‘parents’ in the book, but are aware that families are all different and not all young people live with two parents.

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.

## Top Tips

Speak to people when you are feeling down.



OK, you now know that your brother or sister has cancer and your world has just been turned upside down.

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 young people survive cancer**

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 brother or sister 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 sibling who has cancer. It can help to know that others are experiencing similar things. See "Where to get help" on page 87, 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 brother or sister'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 straight facts

# up



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

Cancer is a disease of the cells. 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.

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.

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

There are over 200 different types of cancer. Some are more common in young people than adults, and some more so in men than women.

There are two main groups of cancers that young people get:

- Cancers of the blood cells (leukaemia) and lymph glands (lymphoma); and
- Solid tumours such as bone cancers and brain tumours.

The most common cancers in young people are explained in the “What cancer is that?” chart on page 61.

## Why do young people get cancer?

The causes of most cancers are unknown. Whilst cancer itself is quite common, cancer in young people does not happen that often.

## Will I get it as well?

You can't catch cancer from your brother or sister. So you can still hug and kiss them (if that's what you usually do). Most cancers don't run in families but if you are concerned about this you can talk to your parents and the doctors or check out one of the websites in the “Where to get help” section on page 87.

## Will my brother or sister die?

While most young people survive cancer, the reality is that for some their cancer can't be cured. There are many factors that affect what the outcome will be for your brother or sister including what type of cancer they have, where it is and how advanced the cancer is.

**Remember: Your parents and siblings are just as scared as you.**

**At the start I really wish I knew...**  
that cancer can change your life.

# GETTING THE RIGHT INFORMATION

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

We know that for many of you, feeling excluded from what is going on makes things harder.

Your mum or dad may not want to tell you everything as their way of protecting you or they may not have all the information.

Sometimes you might overhear stuff that frightens or confuses you.

If you can, check out what you have heard – you may be freaking for no real reason.

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.

Shutting it out and not wanting to know much about your brother or sister's cancer is OK. It can be a way of coping with stuff that is just too hard.

**Remember there is no right or wrong way of dealing with this.**

Asking questions can help you feel more involved in what is going on.

Here are some questions that you may want to ask your parents, doctors, nurses or the social worker at some stage.

- What kind of cancer does my brother or sister have?
- What part of the body does it affect?
- Will my brother or sister get better?
- Is there a chance that I may get this cancer too?

- What treatment will my brother or sister get?
- Will there be more than one type of treatment?
- How will they feel while they are having this treatment?
- Is the cancer painful?
- Will the treatment be painful?
- How often do they get this treatment and how long will it last?
- Will it change the way my brother or sister 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 ?



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

There are quite a few different treatments and therapies that are used to help get rid of the cancer.

They come in all different forms – from medication, to the use of x-rays and light beams, to surgery.

What sort of treatment your brother or sister gets will depend on a number of factors:

- What cancer they have.
- Whether the cancer has spread.

- Their 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. It's important not to compare your brother or sister'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 they may be feeling really well

and then the following week they can be sick again.

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

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 brother or sister is undergoing is working to stop the cancer and eventually make them better.

The most useful piece of information that I got was...  
you always have someone to talk to.

The charts on page 68 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.

If you have more questions to ask after reading this you can check out the recommended websites for more information or ask your parents or the medical staff treating your brother or sister. (See tips for talking to your parents and the medical team on page 28.)

### Things to look for

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

An infection could make them 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 parents know if you've been in contact with someone who is sick or has a cold.
- Not coming in close contact with your brother or sister if you get sick (this is a good reason for taking care of yourself).
- Checking with your parents, doctors or nurses if you are worried about infections or other stuff that may harm your brother or sister.

Always having to be careful about germs and infections can be a big drag. It may limit the activities you can be involved with and also make you scared that you might somehow cause your brother or sister to get sicker.

It's OK to feel angry about this.

### How long will the treatment last?

It is not always easy to put a time frame on how long the cancer treatment will last.

For some types of cancer the treatment may only last for a few months but for other types the treatment can last for several years.





# Stem cell DONATION

If your brother or sister has a leukaemia, lymphoma, myeloma or another blood disorder they may be treated with a bone marrow transplant (BMT) or a peripheral blood stem cell transplant (PBSCT).

(If they don't have one of these then you may want to skip this section).

## What are they?

Stem cells are cells that are born in the bone marrow and later develop into red blood cells (to carry oxygen), white blood cells (to fight infections) and platelets (to prevent bleeding) that circulate around the body.

Bone marrow is the soft, semi-liquid spongy material inside bones. Bone marrow is essential for the production of red blood cells, white blood cells and platelets.

## Why are they needed?

High doses of chemo and/or radiotherapy destroy both the cancer cells and the good cells and these need to be replaced.

So the cells are taken before the chemo and then transplanted back after the chemo has finished.

The cells will find their way back into the bone marrow eventually resulting in normal blood cell numbers. These new cells help your brother or sister recover from the cancer treatment.

## How do you donate your stem cells or bone marrow?

For a PBSCT the procedure is much the same as when you have a blood test except it takes longer. An intravenous needle is inserted into a vein and the cells are filtered out of the blood through a machine over about four hours. The cells are stored until they are given to your brother or sister through a transfusion, after they have finished their high dose treatment.

It is not painful (except maybe when they insert the needle into the vein).

A BMT is done under a general anaesthetic – the one that knocks you out. The doctor inserts a needle into your hip bone and collects the bone marrow. You won't feel anything as you will be asleep. Afterwards you may feel a little stiff and sore at the place where the needle went in.



## Who can become a donor?

Transplants can be autologous – where your brother or sister uses their own stem cells (which are collected before treatment starts) or allogenic where someone else donated their stem cells.

The most suitable donor is usually a brother or sister because their stem cells are the closest genetic match. In one out of four cases a brother or a sister is a good match.

To find out if you are suitable to be a donor the doctor will do a blood test that checks if your stem cells are a good match or not.

Finding out that you are not a match means that you don't have to make the decision to become a donor or not. You may feel disappointed that you aren't and can't help your brother or sister but there are other ways that you can help.

## Becoming a donor

Deciding to become a donor will more than likely bring up all sorts of stuff for you and you might have a heap of questions.

It's important that you get to ask all the questions you need to and as many times as you need to.

For a lot of you, becoming a donor is a way that you can do something for your brother or sister.

But it's your body and your choice. It is OK to say no and there are young people who decide not to be a donor even if they are a match.

A stem cell transplant is just one treatment option and there

are no guarantees that it will work. It is not a miracle cure. Remembering this might help you in making the decision to become a donor or not.

## What if it doesn't work?

It's pretty normal to have some thoughts that you have let your brother or sister down. This could not be further from the truth.

This could be a hard time for you and getting some good support is important. Check out "Getting support" on page 40 for how to do this.

**Remember: Stem cell and bone marrow transplants are just other treatment options. Not a guaranteed cure.**

Remember:

**It is *not***  
your fault  
**if you are**  
***not* a match.**

# Good G<sup>o</sup>g<sup>l</sup>ing

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 87.)

## **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...**

**what cancer was  
and what it can do.**

### **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, make sure you have as much information about your brother or sister’s cancer. Adult cancers, their treatments and their survival rates are different than those for young people. (This 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 parents about your brother or sister’s cancer. Having information can help you to feel a little bit more in control and included in the whole thing. 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 what your family situation is or where you are in the family, chances are things have changed in your life now that your brother or sister has cancer.

Living with a someone 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.
- The hospital becomes your home away from home.
- You don't get to spend as much time with your friends.
- 2 minute noodles get really boring after a week.

Because one or both of your parents will need to spend time at the hospital, who does what at home may change and things might not get done the same way.

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

All your relationships will be affected in some way by having a brother or sister who has cancer.

Dealing with these changes can be really hard.

Every family is different and things like whether you live with both parents or only one, how many brothers and sisters you have and the ages that you are will effect what happens.

## Parents

Your parents are dealing with a whole heap of stuff. They are dealing with their own emotions associated with the cancer diagnosis; they are also worried about you and the rest of the family. Things like how it is affecting you, the medical bills and whether they will be able to get time off work to look after your brother or sister, could all be worries for them.

Trying to keep it all together can put them under enormous pressure.

They are probably feeling the same things that you are but just express it differently.

They may also try to hide how they are feeling so not to scare or upset you.

Parents are used to being able to protect their kids and fix things for them. A cancer diagnosis can make them feel helpless as they can't fix it or make it go away. It may seem like they have no control over what is happening to your brother or sister.

Maybe it seems like they are only interested in your brother or sister who has cancer and have forgotten about you.

If you are used to sharing lots of things with your parents, it may feel like you are shut out by them now.

**Remember: They are not shutting you out on purpose.**

Even when your parents are around, their heads could be somewhere else. They will still be worrying about your brother or sister.

Your parents may be tired, stressed and cranky for a lot of the time.



This can be really frustrating and you may get angry with them (check out positive ways to deal with anger on page 39)

They might be trying to protect you and are not sure how much or what to tell you. Getting information from them about your brother or sister's cancer could be hard. Finding ways to ask is really important.

See 'Talking Tips' for ideas on how to get the information you want.

They may ask you to take on more responsibility than you have had before like extra work around the house or looking after younger siblings. This might make you really angry at your parents.

You may also feel like they are not treating you all equally any more and that your brother or sister with cancer is getting way too much attention and getting away with things that you can't. This is a very normal reaction.

Parents want to protect their children and make them better. When they can't, they sometimes become over protective and do things differently or seem like they are going easy on them.

Stress can do really weird things to people and your parents may not act like you are used to. This can have a big impact on your relationships.

## Missing them

Your parent or parents will need to spend a lot of time at the hospital. Not having them around will be hard. This may be doubly hard if you live with only one parent or are closer to the parent who is away a lot.

Being able to tell them how you are feeling will help get you through this.

There are some ideas for this in the tear out sections at the back of the book.

Just because this is the way that it has to be now doesn't mean you have to like it and no, that doesn't make you spoilt or selfish, just normal.

## Other family members

Cancer can have a ripple effect – it affects other family members like grandparents, aunts and uncles and cousins. So you may have to struggle with dealing with them as well as your immediate family.

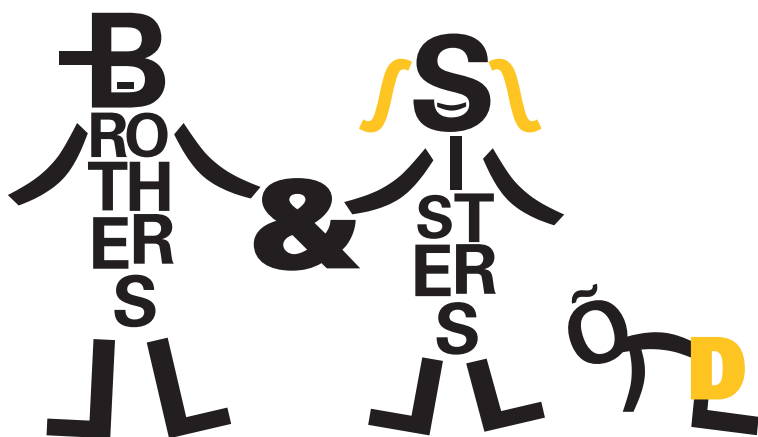
Instead of talking to you like normal they might start acting weird and either only want to talk about your brother or sister who has cancer or they may not want to talk to you much at all.

Sometimes grandparents and aunts and uncles step in to take on the jobs that your parents used to do. As with all the other things, for some of you it is no problem but for others it is just one more change that you have to deal with.

**One thing that I have learnt...**

family is the most important thing.

”



Best friends or sworn enemies? Well, probably both actually. And it can move from one to the other in just a few seconds.

Having cancer in your family won't make this go away. It's not like somebody waves a magic wand and says "now that cancer is here you will all love each other deeply and never fight".

But your relationship will change. You may take it a little easier on each other. You may stop arguing about small stuff like iPods, clothes and privacy. But you are probably still going to argue about some things. And there is something really healthy about this (still arguing).

Most people are busy being super nice, and super generous and super sympathetic to your brother or sister with cancer. Arguing with them can bring them back to earth and make things a bit more normal.

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.

The age of your brother or sister who has cancer will have a big impact on how you deal with it. If they are much younger than you, you may become very protective of them and you may understand their behaviour a bit more, but if they are older than you, being shut out and feeling jealous may be more of an issue.

How you got on before the cancer will have an effect on how you get on now.



## Top Tips Be patient

Long hospital stays will also impact on your relationship.

Not only are they not around but you might feel like you can't share things and don't have things in common like school, going out and just normal day to day stuff.

Even if you fought and annoyed each other, you might be surprised at how much you miss them.

Along with this you might become the link between them and their friends and school, uni or other places. As with all sorts of other things for some of you this role is OK as it is one way that you can feel involved, but for some it is just one more thing that you have to do.

You will need to get some new ground rules for pretty much everything. It is best not to have these negotiations when you're angry or tired or ready to snap. So timing is important.

### **Remember: We all react to difficult situations and change differently.**

We all express our fears and pain in different ways.

If there are more than two of you in the family, go easy on each other – believe it or not, your other brothers and sisters do understand what you are going through – they're going through it as well.

(See "Getting inside your brother or sister's head" on page 27 and "Helping you brother or sister" on page 30).

## Friends

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

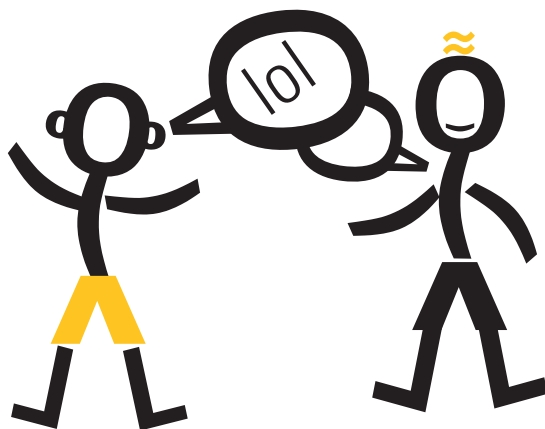
You may act differently because of your brother or sister's cancer, and your friends might find this difficult to deal with sometimes.

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 to say or do?
- How can I be a friend to someone whose brother or sister 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....".

## **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 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 brother or sister 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 MySpace) 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 to you because they understand. 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. You may even have to deal with friends bullying you or excluding you.

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

Go to [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 "Just one thing" card at the back of the book.

**Remember:**

*To let people know how you feel.*



Dealing with your brother or sister's cancer can bring 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 brother or sister who has cancer.

You, your parents and your brother or sister who has cancer may have a lot of emotions that are similar. 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 sibling's treatment.

### **Shock/Disbelief**

More than likely you will feel shocked when you hear that your brother or sister 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 brother or sister 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 brother or sister has cancer is pretty normal. You may think that it's not fair, want to know why it has happened to you (and your brother and sister). And then you may get angry at yourself for feeling that way. Being angry at your parents and/or your brother or sister at different times during this whole thing is also pretty normal. There can be lots of reasons to be angry.

It is OK to feel angry but learning some positive ways to express it is important.

Anger can hide other feelings like fear or sadness.

See "Safe ways to act out your feelings" on page 39.



## Sad

There are lots of reasons to feel sad about your brother or sister's cancer and its 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 37 for more on depression.)

## Guilty

Some of you may feel guilty big time about your sibling'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 brother or sister who has cancer, 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.

(See "What about me" for more on this on page 33).

## Embarrassed

Your brother or sister 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 brother or sister with cancer can make you feel different and that is not always easy to handle.





## Jealous

Your brother or sister may be getting a lot of attention and special treatment because of their cancer. Even if you understand why this is happening it can still make you feel a bit jealous. This is not uncommon and it is OK to feel like this sometimes. It doesn't mean you are not a caring brother or sister.

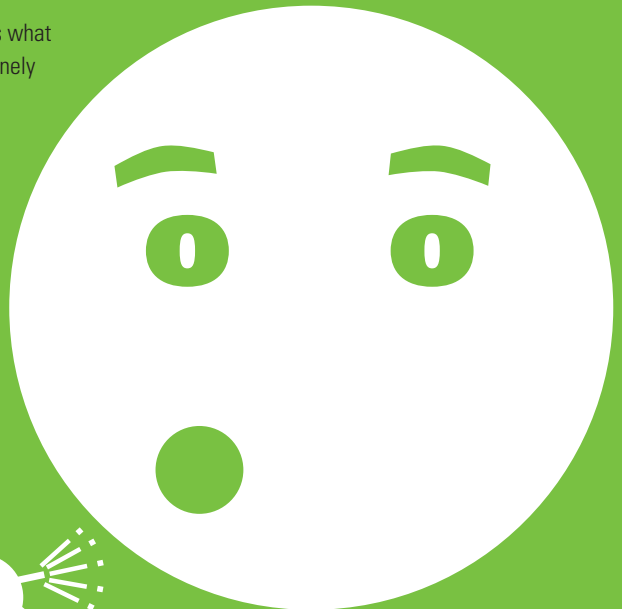
## Lonely

This may be a very lonely time for you. You may miss your brother or sister – either they are in hospital or you just can't be with them like you used to. Your friends might not be able to handle your brother or sisters cancer, so they stay away or you can't spend time with them. Your mum or dad will be spending a lot of time with your brother or sister who has cancer so you may not get to see them as often.

You may also feel like no-one understands what you are going through and this can be a lonely experience.

## Wishing it was you

Some of you may wish that it was you who had the cancer. This is really normal and it is to do with not wanting to see your brother or sister sick and in pain. There is a feeling of helplessness watching someone you love and care about go through a really rough time. It's also perfectly OK to be glad that it isn't you.



## How your parents feel

Your parents are dealing with a whole heap of stuff. They are dealing with their own emotions associated with the cancer diagnosis; they are also worried about your brother or sister who has cancer as well as you and your other brothers and sisters.

Trying to keep it all together can put them under enormous pressure.

They may be feeling many of the same things that you are but they may express it differently.

They may have an overwhelming sense of helplessness.

Parents are used to being able to protect their kids and fix things for them. A cancer diagnosis can often make them feel helpless as they feel that they can't fix it or make it go away. It may seem like they have no control over what is happening to your brother or sister.

It may seem that even when your mum or dad are around that their head is some place else. They may not be able to stop worrying about your brother or sister. This can be really frustrating for you and you may get angry with them.

Your parents may be tired, stressed and shitty for a lot of the time.

They are not shutting you out on purpose.

It is hard to always be thinking about everyone else all the time.

But having some understanding could just be a way of protecting yourself.

**Remember:**  
**Things** will  
not be like this  
**forever.**



**Getting inside your brother or sister's head could help you understand what it is like for them and also help you figure out what you can do to support them through their cancer experience.**

### **Scared**

Being diagnosed with cancer is a really scary thing (yes that comes from the Office of the Bleeding Obvious). They may be frightened about the treatment, about staying in hospital and they may even be afraid that they may die.

The age of your brother or sister may have an effect on what makes them afraid, but for all of them there will be some fear associated with their cancer experience.

### **Sad or depressed**

Cancer and its treatment can often limit the things that you can do. Your brother or sister may miss doing the things that they use to do and also miss spending time with their friends.

These feelings can range from just being down to depression. It is not uncommon for people with cancer to suffer from depression (for more information on depression go to page 37)

### **Guilty**

Your brother or sister's cancer diagnosis will have a huge impact on the entire family. They may feel guilty about the changes that have happened because of their cancer and may be really aware they are getting a whole lot more attention and special treatment. But remember this is not their fault.

### **Angry**

Cancer and its treatment can play havoc with moods and emotions. It may make your brother or sister moody and angry. Their anger may also come from feeling frustrated, sad or scared. If they have a go at you try to remember that they are probably angry at the cancer and not you.

### **Lonely**

Having cancer can be a lonely experience and your brother or sister may feel very isolated. They might spend a lot of time in hospital away from you and the rest of the family. Friends might have a hard time dealing with their cancer and so stop coming around. Often they feel like no-one understands and they have no-one to share with.

**“ At the start I really wish I knew... that the treatment can cause them to be moody and temperamental. ”**



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 or who to ask. There might also be things that you want to say to your brother or sister but just don't know how to go about it.

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 mum or dad know that you want to know what is going on.

They might not want to talk about your brother or sister's cancer because they don't want to worry you, find it too hard to talk about it themselves, or think that they are protecting you.

Maybe they don'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.

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 40).

### Talking with your sibling

What this looks like and how this happens will depend on a number of things including how old they are, how close you are, how comfortable they are with talking about what is happening to them and also how much you want to know.

It might take several go's to be able to ask the questions or share the stuff that you want to.

Being afraid or scared that you will upset people can often hold you back from talking about how you are really feeling or what is really going on for you.

### 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 any of you get upset – this is not an easy thing to be talking about.

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

Same for your brother or sister – doing something together can sometimes give you the chance to share what is going on.

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 parents or sibling 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.
- Leave Facebook messages.
- Download some music (if you have access to this stuff).
- Draw.

Writing about what happens can be very calming and releasing for the mind





Giving your brother or sister some support during their cancer treatment might be really important to you but knowing what to do is a little harder.

**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 brother or sister.

### **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**

Everyone in your family will be under a lot of stress. Routines may have changed and people 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 42 for more ideas.)

### **Hang out with them**

Just hanging out with your brother or sister can really help. You could watch TV together, read to them or find something to laugh about. Where possible see if you can still do some of the things that you did before they got sick – like annoy them and fight with them.

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

### **Help care for them**

Being involved in caring for your brother or sister might be important for you. Let your mum or dad know that you want to help and find ways that you can do this. It may be as simple as holding their hand while they are having a procedure done or if they are much younger maybe feeding and bathing them.

### **Help them stay connected with friends**

Spending long periods of time in hospital and stuck at home may mean your brother or sister loses contact with friends. They may appreciate being kept in the loop on gossip and other stuff that is going on.

“

**One thing I have learnt from this experience is...  
that I actually care about my brother more than I thought I did.**

# HOSPITAL VISITS

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

Your brother or sister may be treated in a children's hospital or if they are over 16 they may be in an adult's hospital.

These are very different places.

If they are in a children's hospital you will probably see lots of other sick kids. This might scare you as they could look worse than your sibling and there is a fear that this is what could happen to them.

Try not to compare them to your brother or sister.

Every patient is different.

You might spend a lot of time at the hospital.

If they are in an adult hospital then they will probably be in a ward with older people.

This can also be really hard to deal with.

There may not be a lot to do and the staff may not be all that geared up to dealing with younger people.

Knowing what is happening to your brother or sister 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 information from mum or dad, 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: You and your needs still count.**

### Here are some things to make visiting easier:

If your brother or sister is in a children's hospital then there is usually an activity centre that you can access. Check out what there is to do.

Other things to do:

- Take your homework to do while you visit – that way you have something to focus on other than all the medical stuff.
- Help your brother or sister with their homework.
- 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.)
- Take in DVD's to watch together.

### When visiting is too hard

Your parents may want you to visit all the time – especially if there is no-one at home to look after you. This may be hard and you might feel like you have no control over it.

There may be practical reasons that make visiting hard: you have other commitments like sports training, too much school work, exams or work.

Sometimes you just don't want to visit. This is OK. But you can still stay in touch by phone, SMS, Facebook or MSN.



**Remember:**

**Life doesn't stop when you have a brother or sister living with cancer.**



# WHAT ABOUT



Do you sometimes just want to yell “Hey what about me?”

Being the healthy brother or sister of a cancer patient is a really tough job, especially since you never actually applied for it.

It feels like everything revolves around them and the whole family has to make adjustments for them. It is possible that your whole life has been turned upside down.

No-one seems to be interested in you any more. People only ask about your brother or sister, everyone seems to be super nice to them and give them heaps of stuff.

You might also think that you have to hide your real feelings and be the “perfect child” cos you are worried about making things worse. This can put you under huge stress.

Do you wish that someone would just take the time to find out if you are OK and not assume that you’re doing OK?

These are perfectly normal questions and thoughts.

As hard as it may be, it is really important that you find ways to look after yourself and get some time for you. For some ideas on this check out “All about you” on page 35 and “What’s a coping strategy?” on page 42.



There are heaps of conflicting emotions going on for you and you can swing from one to the other in the space of about two minutes. That can make for a really confusing and frustrating time.

It can play out a bit like this:

I get angry because no-one is paying any attention to me, and then I feel guilty for getting angry in the first place. And then I get a little jealous and think to myself "I wish there was something wrong with me, just for one day, so that somebody had to care". I'm then happy that I really don't have cancer and I am not really sick like my brother or sister. And then I feel sad because my brother or sister is so sick that they might die. And then I feel guilty because I was happy a moment ago.

It is OK to think these things. It doesn't make you a bad brother or sister.

**Remember: Bad thoughts and feelings have no impact on what happens with their cancer.**

You can also use the "For my parents", "For my sibling" and the "Just one thing" cards at the back to help other people understand what it is like for you.



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

*how demanding the whole thing would be on me.*



**all about you**  
**(staying healthy)**

While it seems that everyone is worried about your brother or sister who has cancer, it is really important that you take the time to look after yourself and to get help when things are getting on top of you.

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. Go to [www.canteen.org.au](http://www.canteen.org.au).



# when it all seems too much



When you are living with a brother or sister 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 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 brother or sister 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 87.

### 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.

When it seems like you don't have control over things anymore, you might start to do things that you have control over. This can include things like stopping eating or getting in a car and driving fast.



If you are into any of the following, you may be at risk of doing yourself some long-term damage. No-one will judge you if you are doing any of these. Staying safe and healthy is more important.

Find someone you can trust to share what is happening or use the “Where to get help” section on page 87.

### 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 to 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 brother or sister 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.

Find a retreat – stay with a friend when things go haywire at home



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 brother or sister 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 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 brother or sister 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 mum or dad 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.





**Remember:**  
*It is never good to be negative.*

## 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. If you are at school you can try the school counsellor or you can try the Student Health Unit at uni or there are private counsellors that you can see. (Your local doctor can organise this and in some cases you won't have to pay.)

## 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).

**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.**

# 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 brother or sister 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.
- Find a safe place – somewhere you can go to

get away from it all like a friend or neighbours place.

- 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.
- Find something new that you can learn to do. Then you have something to focus on other than cancer.
- 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 brother or sister and have all the normal sibling rivalry stuff.
- 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: It's OK to feel jealous, angry or upset.**

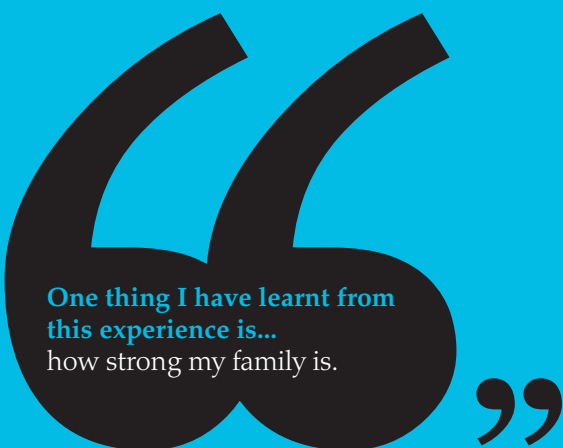
## Remember:

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



- Mum or dad spend a lot of time at the hospital and your relationship has changed.
- 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.
- 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.
- Important events like birthdays, school things, sporting matches get missed, forgotten or not celebrated the same way.
- Your brother or sister 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.



**One thing I have learnt from this experience is...**  
how strong my family is.

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.


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 brother or sister who has cancer?)

Check out these other sections in the booklet for ways to take care of yourself, and give you more info:

"What's a coping strategy?" on page 42, "All about you" on page 35 and "Getting support" on page 40.



# SURVIVING CANCER

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

Thinking about life after treatment is very hard as there is often a lot of uncertainty. But medical science is advancing on a daily basis and more young people are surviving cancer and entering a stage called survivorship.

## What is survivorship?

Survivorship is the state your brother or sister is in after treatment has been completed and when their cancer appears to have gone.

The transition from active treatment to survivorship can be both an exciting and yet confusing time for everyone.

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

Just because active treatment has finished, hospital and doctors will still be part of your brother or sister's life for a long time.

They will need to have regular check-ups. The lead up to these appointments can cause a lot of stress in the family as fear of relapse or recurrence is very common.

Cancer and its treatment can leave the body and mind pretty beaten up. There can be short and long term side effects which can continue to have an impact on your family.

Your brother or sister may look different or act differently after they have been treated for cancer.

“

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

*it was going to be such a long process.*

”

## Physical changes in your brother or sister:

- Being tired – sometimes called ‘fatigue’, it’s not just normal tired that sleep can fix. It can be ‘tired’ for days and days.
- 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.
- Stunted growth – they may not grow as tall as they would have or they may go through puberty later than others.
- Hair – their hair may not grow back the same.
- Scars – from surgery and other treatments.
- Amputation – treatment may have resulted in the removal of a limb and they might be fitted with an artificial arm or leg.

## Other changes

- Memory and concentration problems. Chemotherapy can play havoc with brains and this can last forever. This is often called “chemo brain”.
- Intellectual difficulties – depending on the cancer and the type of treatment they had, their brain may be affected and they may have problems with learning and may not be able to do things like they did before.

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?

Depending on the age of your brother or sister they may also go through a time of re-adjustment and this new stage might be filled with lots of soul searching questions and re-thinking about what they want to do and how they want to live.

They may look at life differently (as well as you and your parents).

You may have questions like:

What difference has cancer made to my life?

What have I learnt from the experience?

Do I somehow have an obligation to do something very special with my life because of this?

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

- Fear that the cancer will come back. There is more about this in “If cancer returns” on page 48.
- Seeing your brother or sister still weak and sick.
- A real sense of loss (and possibly anger) that your brother or sister is not the same person they were before they got sick.
- Your brother or sister continues to get special treatment and get away with things that you can’t.

There will certainly be a time of re-adjustment for everyone.

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 brother or sister's cancer has come back. This is called a relapse. 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 relapse?**

Your brother or sister is considered to have relapsed when the cancer returns after they have been in remission (when there is no evidence of cancer in the body). This happens because some cancer cells were left behind despite the treatment that they received or brand new cancer cells develop.

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

### **Where does the cancer return?**

It depends on the type of cancer that your brother or sister has. If it is a leukaemia or other blood disorder then the cancer reappears in the central nervous system or the bone marrow.

If they had a tumour then it can return in the;

#### *Primary site:*

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.

#### *Region of the primary site:*

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

#### *Secondary site or metastasis:*

When the cancer has spread to other areas or sites 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 or could be untreatable.

What treatments your brother or sister 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 parents and brother or sister make and you may be very scared about what will happen.

Like all the other stages you have been through with 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 brother or sister fought, how positive you all have been or how many different treatments the doctors tried, some people cannot be cured. This means that the person will die from the disease.

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

This stage is called palliative care or palliative treatment.

It is important to remember that just because they are receiving palliative care it 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 them.

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. There could also be a sense of powerlessness because people are making

decisions about someone you love and you feel you have no control over those decisions.

A lot of how you deal with this time might depend on how those around you are dealing with it.

This time sucks so bad you might feel completely alone at times, really angry with the world, your parents, the doctors, nurses, even your brother or sister who is dying 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 brother or sister, having fun, laughing, crying and sharing your thoughts and feelings with them.

What is really important at this time is to ask as many questions as you need to. Ask your mum or dad, doctors, nurses or 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 the love between you will never stop. Some of you may want to make something together with your sibling or as a family, maybe a picture, a scrap book, a video or something that you will treasure and that is shared by you.

For some of you, talking about your brother or sister dying is not done openly. There may be many reasons that families have for doing this, but it can make it very hard if you do want to talk.

If you can, find someone you can trust to share what you are feeling.

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



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

“

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

when things get tough we are always there for each other.”

”

And at this stage you will start to wonder, “What happens when...”. And there will be millions of “What happens when...” questions for you, your mum and dad and other family members. 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?”.

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 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 useful at this time. Get support, take care of yourself, 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, the website has more information. It also has answers to some of the questions you may find too hard to ask. ([www.nowwhat.org.au](http://www.nowwhat.org.au))

# 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 brother or sister with cancer can affect you at school in lots of ways:

- You may have difficulty concentrating on stuff because you are worried about them.
- 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.

For some of you school can be a bit of an escape and you don't want people to know that your brother or sister has cancer. If you want to keep it private then make sure your mum or dad or someone tells the school.

### Years 11 & 12

If you are doing your final school exams you may be able to get "special consideration" if you have missed work 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.**

### Bullying

Having a brother or sister with cancer can sometimes make you or them a target for the bullies at school.

Cancer and its treatment can really mess with what patients look like and sometimes with how they act.

Side effects like weight gain or weight loss, skin problems, hair loss and amputations, intellectual difficulties and mood swings can make them stand out.

Some people also have really weird ideas about cancer – like you can catch it - and they think this is a good reason to give you or your brother or sister a hard time.

You don't have to put up with it and even though you think it will make it worse, it is important to let someone know what is going on.

You may not want to cause any trouble but you have enough going on without having to deal with bullies.

### Work

What you tell your employer or work mates about your brother or sister'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.

Check out "Where to get help" on page 87 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. Keeping the balls in the air may be a whole lot easier than picking them all up off the floor!**





Have you become the new home cook? Do your cooking skills only consist of 2 minute noodles?

If your mum or dad are away looking after your brother or sister you may have to cook for yourself or the rest of the family.

This could be a bit of a shock to the system!

There is a lot to do at the moment and not much time with everything else going on, so there is a temptation to rely on ready-to-eat foods and "fast food".

The downside is that this is more expensive, not so good for you and won't give you the right fuel to give you the energy to deal with other things.

The following tips will help to make this job a little less stressful and mealtimes a little less boring.

- If cooking is new to you find some simple recipes that don't have too many ingredients or too much preparation. There is a simple spag bol recipe at the end of this section.
- Ask someone to show you some basic things to get started (like how to turn the oven on).
- Sandwich makers are a valuable piece of equipment.
- Stock up on things like pasta, bottles of pasta sauces, pizza bases, and other healthy pre-prepared meals.

- Buy some frozen meals to have as emergencies. In the freezer section of the supermarket you can find a variety of these.
- Try to get enough protein from meat, fish, eggs, nuts and beans. Tinned tuna or tinned baked beans are great ways to get this.
- If you have to cook for the whole family, 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.

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

There are a number of recipes on the website [www.nowwhat.org.au](http://www.nowwhat.org.au) that you can download.



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

how to be **self sufficient.**







# RECIPE

## Easy Spaghetti Bolognaise

Spaghetti Bolognaise is a dish almost everyone will enjoy – especially if the sauce is packed with great ingredients and cooked with love. Of course bolognaise 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

400g lean beef mince

1x 700g jar of bolognaise 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.

(With thanks to Young Gourmet [www.younggourmet.com](http://www.younggourmet.com))

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...

you need to work as a team.



What **cancer** is that?



This chart lists the most common cancers in adolescents and young adults. If your brother or sister's cancer is not mentioned here then ask your mum or dad or the medical staff to give you some information on the cancer.

Type of cancer	Description	Incidence	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.	ALL is the most common form of leukaemia that accounts for 6% of adolescent cancers.	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.	Almost as common as ALL in adolescents, although it usually occurs in people aged 20-29.	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.

Type of cancer	Description	Incidence	Treatment
<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, which you may find. These are normally close to the body's surface, such as in the armpit and neck.	Most common form of lymphoma, accounting for 16% of adolescent cancers.	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.	Accounts for 8% of all adolescent cancers.	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.

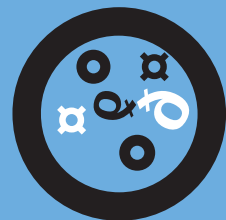
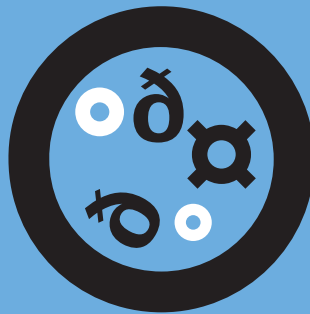
“ One thing I have learnt from this experience... my sister can bounce back. ”

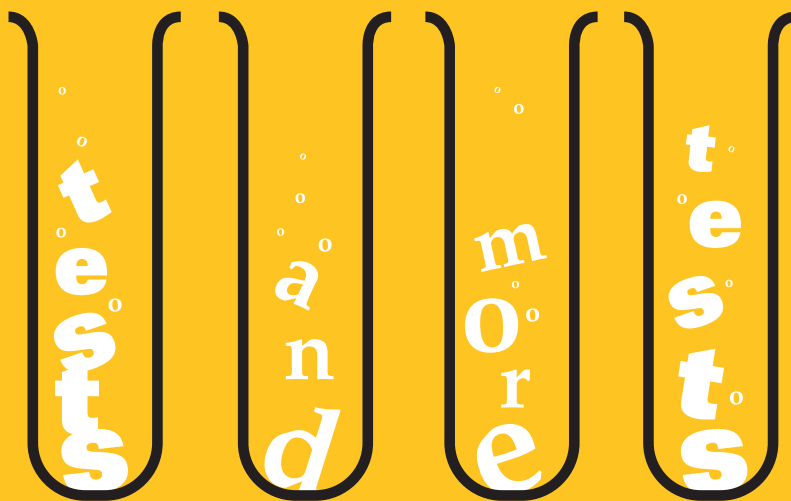
Type of cancer	Description	Incidence	Treatment
<b>CNS tumours</b>	<b>Cancers of the brain and spinal cord.</b>		
<b>Brain tumours</b>	There are many different types of brain tumours. The most common tumours grow from glial cells which are the support cells in the brain.	Most common in early childhood, but accounts for 10% of adolescent cancers.	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>Bone tumours</b>	<b>Cancer of the bones often starts in the ends of bones where the bone tissue forms as the young person grows.</b>	Occurs most often in adolescents.	
<b>Osteosarcoma</b>	Cancer that begins in the bone forming cells. It most commonly occurs in the arm and leg bones.	Commonly occurs between the ages of 10-25, accounting for 5% of all adolescent cancers. It is associated with rapid growth so it is rare to see it in early childhood	Treatment will depend on the size, position and stage of the tumour. Chemotherapy is usually given to shrink the tumour and then it is usually surgically removed. Sometimes this may involve amputation of the affected limb. Treatment usually lasts for 4-5 months.
<b>Ewing's Sarcoma</b>	A family of tumours found in the bone and soft tissues. It can develop anywhere in the body, but is usually found in the spine, hips, upper arm, long bones in the thigh or in the ribs	Most commonly occurs in teenage years, accounting for 2% of all adolescent cancers.	Treatment will depend on the size, position and stage of the tumour. Chemotherapy is usually given to shrink the tumour and then it is usually surgically removed. Sometimes this may involve amputation of the affected limb. Treatment usually lasts for 4-5 months.

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	Incidence	Treatment
<b>Sarcomas</b>	<b>Sarcomas are cancers of the body's soft tissue - muscle, fat, and blood vessels.</b>		
<b>Rhabdomyosarcoma (RMS)</b>	Develop from muscle and their surrounding tissues can affect any part of the body. They are commonly found in the head, neck, genital, urinary areas and the limbs.	RMS is the most common type of sarcoma. Children less than 10 years are most commonly affected, but adolescents are the second most likely group to get RMS.	There are 3 types of treatments depending on the size and stage of the sarcoma. Treatment mainly involves chemotherapy and radiotherapy, but can include surgery also. If RMS spreads beyond the primary site then high dose chemotherapy or a BMT may be given.
<b>Fibrosarcoma</b>	Cancer that develops in cells called fibrocytes that are usually found in the arms, legs or trunk.		Most people will need a combination of surgery, chemotherapy and radiotherapy treatments to get them back on track. The exact treatment plan will depend on your age, general health plus the stage and type of the cancer.

Type of cancer	Description	Incidence	Treatment
<b>Other cancers or tumours</b>			
<b>Germ Cell Tumours</b>	Develop in the reproductive organs: testicles for boys and ovaries for girls. 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 occurs in young adults and adolescents. Accounts for 15% of adolescent cancers.	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 can spread to the lower layer of skin then into the body and other systems.	Melanoma is more common in older people however it does affect young adults and adolescents.	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 is a cancer of 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.	Thyroid cancer is more common in older people however it does affect young adults and adolescents.	Treatment may involve surgery, radiotherapy, chemotherapy and hormone therapy.





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 computerised 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

You will probably hear these terms used a lot while your brother or sister is being treated.

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</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 side effect 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>Stem Cell Transplantation:</b> Bone marrow transplant (BMT) or peripheral blood stem cell transplant (PBSCT)</p>	<p>The use of stem cells found in either the bone marrow or the blood. This repairs stem cells that were destroyed by high doses of chemo or radiotherapy. The cells are transplanted back into the patient through an intravenous (IV) line.</p>	<p>The side effects are similar to those for chemo and radio but in some cases they can be even worse.</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>

# 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 underlined 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.

One thing I have learnt from this experience is... that I am never alone.

**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.

**Thrombocytopenia:** 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.

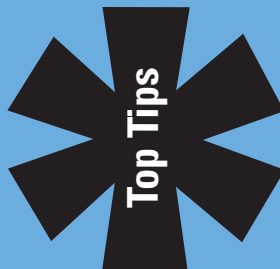
**Toxicity:** Harmful side effects caused by a drug.

**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





These are organisations and websites that can help you deal with lots of things to do with living with a brother or sister 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.canteen.org.au](http://www.canteen.org.au)**

CanTeen is a fantastic organisation for young people 12-24 who have a brother or sister who has cancer (or a parent 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.teamrevive.com](http://www.teamrevive.com)**

This site is aimed at young people aged 15-25 who have leukaemia, a lymphoma, 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, drugs 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.cyh.com](http://www.cyh.com)**

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 online 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.supersibs.org](http://www.supersibs.org)

This is an American site that is just for young people who have a brother or sister with cancer. The information is divided into different age groups and there is also useful stuff for friends and other relatives.

[www.cclg.org.uk/](http://www.cclg.org.uk/)

This is the site for the Children's Cancer and Leukaemia Group, a London organisation that offers support and information about childhood cancer. Has good information on treatments, links to other sites and useful downloads.

[www.childrenfirst.nhs.uk/teens/hospital/expect/siblings3.html](http://www.childrenfirst.nhs.uk/teens/hospital/expect/siblings3.html)

This link will take you straight to a page on this website that is especially for siblings. From there you can explore other parts of the site that has useful and easy to understand information on cancer and young people.

[www.click4tic.org.uk](http://www.click4tic.org.uk)

This is a UK site that is mainly for patients but has information on cancer in easy to understand language. It may also help you understand what your brother or sister is going through.

## 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

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have been useful  
in putting this  
book together:

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# Acknowledgements

**Now What?** Dealing with your brother or sister's cancer.

Free copies of this book are available by calling CanTeen on 1800 226 883 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 number below 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.



# HELP!

## WHO DO I CALL?

There may be a situation when you need to contact someone if you are worried or there is an emergency.

**Remember: Try not to panic (not always easy) and be clear about what the situation is when you call for help.**

Fill in the tear out table below and stick it on the fridge or somewhere you will be able to find it when you need it.

You don't want to have to search for it if you are in a panic.

If the information needs updating then you can download another from the website.

Who/What	Name	Landline	Mobile
Mum			
Dad			
Doctor – Specialist			
Doctor – GP			
Hospital			
Someone else in my family			
Neighbour			
Friend			

# Top Tips

Always remember the good times when  
the bad times happen

## In an emergency you can call 000

There are three important things to remember  
when calling Triple Zero (000)

1. When you call Triple Zero (000) the Telstra operator will ask you which emergency service you require.
2. Simply say "Ambulance". If you are calling from a mobile phone you will need to give them the state and the suburb or town that the emergency is in.
3. Once the operator has connected your call to the ambulance service stay on the line and provide as much information to the operator as possible.

**Triple Zero  
(000)**

