

When your
brother or
sister's cancer
can't be cured

Now what?



stuff

**Now What...?
When your
sibling's cancer
can't be cured**

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understandingstuff

dealingwith**stuff**

bigheavy**stuff**

handystuff

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introduction
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Since the moment your brother or sister was diagnosed with cancer, things might not have been easy for you. You have probably experienced a lot of change in your life and a huge range of difficult and confusing emotions.

Hanging on to the hope that their cancer will be cured and life will go back to the way it was before may have been the main thing getting you through.

If you are now finding out that your sibling's cancer is not going away – and facing the possibility that they may not get better – it can feel like the very thing that was holding you up is starting to wobble. You may be wondering: what am I supposed to do now?

This could be a time of great uncertainty and you may not know for sure what is actually going on. That's often one of the scariest things.

So this book is here to try and start the hard conversations and help you bring things out into the open. Because when you know and understand some of the things that may happen, it can help you "prepare" for them, as horrible as it may seem.

“The hardest things to deal with were not knowing what was happening and not understanding why my brother had cancer. **Emma**”

**“When my brother was sick
I was left in the dark.**
I didn’t understand what
was happening all the time
and I felt scared. **Emma**”

It can be heartbreakingly hard and painful to think about, but this book will talk openly about dying.

You might find some things very difficult to read, especially if you haven’t thought about this stuff much before and no one’s really talking about it. No one likes to talk about someone close dying. But that’s kind of why this book is needed. Because it really does help to talk if you can.

Dealing with this situation may not be easy. That could well be the understatement of the year. But that doesn’t mean you can’t get through this. You can.

Heaps of other young people have been through a situation just like this. We’ve tracked some of them down and in this book they share their stories with you. So hopefully, at the very least, you’ll find some comfort in realising that you are not alone.



It’s your choice

As the sibling, you’re a really important part of this story and you have a right to know as much – or as little – about it as you need.

Don’t feel like you have to read this whole book from cover to cover right now. Some things in this book may not be helpful, or you may disagree with some things. There might also be certain things you’re not ready to think about yet. That’s OK. This book will just be here for when you need it.

Thinking, reading or talking about the possibility that your sibling will not get better does not mean that you have given up on them or that you have to let go of your hope.



“ It wasn't that I didn't know that my brother could die from his illness but more that I didn't want to admit the reality. **Amanda** **”**

“ I acknowledged that my brother really did have cancer, but I refused to believe that there was any more than a small chance he wouldn't make it. **Ben** **”**

When young people are sick, most people – even doctors – expect them to get better. The idea that they might not seems unreal. It's the sort of thing that you often think happens to people in sad books or movies, but not to people you know. And definitely not to people in your own family.

You're not expected to know what to do.

Denial can be OK

You might feel that you don't really want to know the raw truth about your sibling's illness. Some people find that shutting it out and staying positive works best for them. What you don't know can't hurt you, right? This is your way of coping with something that's too horrible to think about and that's OK. Denial can give you some time to adjust to something really distressing until you're ready.

But denial can be tricky. It can also get in the way of you expressing some of the other things you might be feeling - like fear - and getting the support you might need.

“Yes, it was hard to know, but not knowing would have been harder in the long run. Sam”

Acceptance is OK too

If the treatment given to your sibling to try to reduce or control their cancer doesn't work and there are limited treatment options left to try, the doctors may say that it's no longer "curable". This means that your sibling will not get better and it's likely they will die from the cancer at some point.

"No way! I don't believe you!"
Even if you suspected deep down that things weren't looking good, you probably didn't expect this.

Your sibling may have already shown a lot of strength. They might have been really unwell in stages before, but they always bounced back. It might be extremely difficult to accept that they don't have any bounce-backs left.

Accepting that the treatments are not working does not mean there is nothing else you can do or that you are ready for your sibling to die.

"It's not really something that you can just accept straight away.

Eventually it gets better, but when it happens it feels like it never will." **Laura**

Palliative care is not giving up

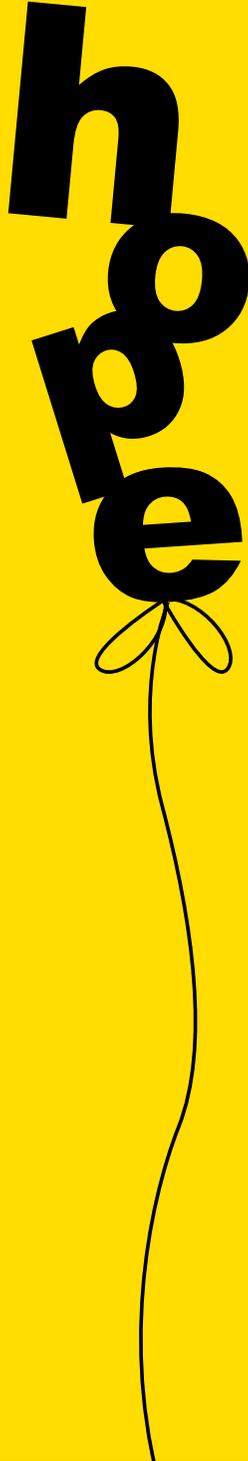
The doctors might say your family should consider your sibling starting “palliative care”. Huh? Is that like a cancer ward or something?

Most people have never heard of palliative care until someone they know needs it. It refers to the special kind of care and support provided to someone who has an illness that can't be cured.

The focus of treatment so far has been on fighting the cancer. With palliative care, the focus will shift towards relieving your sibling's symptoms so they can feel as happy and comfortable as possible.

It is about helping them (and your family) make the most of the life they have left, however long that is. Don't count the days, they say, make the days count.

(Skip to page 36 if you want to know more about palliative care.)



Hang onto hope

Hope is the belief that a positive result lies ahead. It can give you the courage to ‘just keep swimming’ in the face of bad news and disappointments.

Hope is flexible. As it becomes obvious that something you were hopeful for – like your sibling getting better – is probably not going to happen, you can shift your hope to other things. You might hope that your sibling will make it to Christmas, or that you will get to go away as a family, or that you will be able to go to the school formal with your friends, despite what's happening.

Hope and denial are different. Denial means avoiding the truth. Hope is about finding something realistic in the future to look forward to.

If you want to, hang onto hope. No one can take it away.



The problem with cancer is that it is really hard to predict exactly what is going to happen. A doctor will make a judgement about the likely outcome of a disease (called a “prognosis”) based on their knowledge and experience with patients who have had a similar condition. But cancer is different for every person and there is no way to know for sure exactly how quickly it will progress.

Being unsure about what will happen in the future can scare the pants off even the toughest and bravest of the tough and brave. You might think, “How am I supposed to deal with this when I don’t even know what I’m up against?”

“ **It’s like a waiting game, not knowing.**

When you’re kept in the dark your mind wonders... it’s pretty scary. **Laura** ”

What are you frightened about?

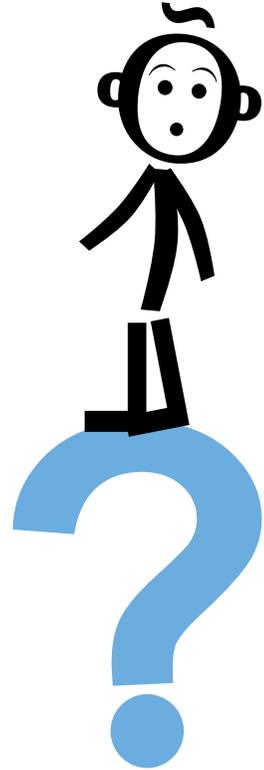
There might be so many worries tumbling around in your mind that they have joined together into a big, confusing clump.

It can help to try and put your finger on exactly what it is you are worried about. When thoughts and feelings have a name, it can be easier to know how to deal with them.

Here's an idea:

Write a list of all the questions that are too frightening to ask, your deepest darkest wonders. These were our questions...

- What am I supposed to be saying or doing?
- Should I talk about what's happening or is it better to 'stay positive'?
- Am I going crazy?
- Will I get cancer?
- How long does my sibling have to live?
- What will my family be like without them?
- Do my parents love my brother/sister more than me?
- When will my life go back to normal?
- Will I ever feel happy again?
-
-
-
-
-



News flash: These fears and questions are perfectly normal. Try to remind yourself not to avoid them or pretend they are not important. These kinds of thoughts are an unfortunate side effect of being human.

Although it's normal, we know that wondering and worrying can be exhausting. One step at a time, you will move forward through this rough bit.

Here's the plan:

1

Give yourself permission to be freaked out. Don't be embarrassed or ashamed of anything you are feeling.

2

Have courage, speak up and ask questions. You have a right to have as much information about your sibling's cancer as you need.

3

Accept that there are some things about this situation that you can't control. Worrying won't change what will happen, but it might get in the way of making the most of the time you have with your sibling.

4

Find someone you can talk to about what you're worried about. (There's more about finding the right person in the next section).

“

I learnt that it isn't your fault they are sick and you cannot make it better.

It's OK to ask for help and to need help dealing with things because it affects you too. **Emma**

”

GETTING THE RIGHT INFORMATION

“ I always felt Mum was keeping the seriousness of the issue from me. I’m sure she felt she was doing the right thing, but if I had of known the facts there’s so much more I would have done. Jess ”

People sometimes describe a big obvious problem that no one is talking about as an ‘elephant in the room’. You can just picture it: a massive jumbo plonked there in the living room while you’re trying to watch to TV. Um... anyone going to say something about this? Anyone?? Cancer can be a bit like that.

Families often try to protect each other by not talking about the really hard and hurtful stuff. Your family might not want to tell you everything about your sibling’s cancer because they don’t want you to stress. Or they may not have the answers either.

You might be feeling very confused or frustrated that, as the sibling, you might be the last one to get the memo.

“There were times when doctors would ask me to leave the room to discuss things with my family. This just made me feel excluded within the family.” **Amanda**

Ask as many questions as you want

If you want to understand more about what is going on or have more say in decisions being made, say so. Even if you are young you have a right to know what is happening in your family. (There are some tips on how to talk to people and get the help and information you need in the "Handy Stuff" section at the back of this book)

It's never too early or late to start asking questions. There is no question too trivial or too upsetting that it shouldn't be asked.

Spend some time thinking about your most important questions. Write them down so you don't forget.

Some tips on getting straight answers:

- Ask the same question a thousand times if you don't get it the first time.
- If someone tells you they will have to find out the answer, bug them until they get back to you.
- If someone says they don't know, ask how else you can find out.
- Ask people to use simple words.
- Ask people not to sugar coat things.

“ I felt like my mum didn't think I was adult enough to be trusted with the information about what was going on.

I felt like I wasn't important enough to be included. **Emma ”**

Who's the right person to ask?

Parents:

Some families hold family meetings and keep everyone updated and involved. But not all families are good at having conversations like this. If your family didn't talk openly much before cancer, they probably won't become great sharers now, especially when everyone is so stressed and tired. (There are some tips for dealing with this in the next section.) If your parents are really not willing or able to talk, make sure you ask someone else.



"Mum would say things like "I don't know".

Then she would get really aggravated and I'd have no choice but to drop the subject unless I was willing to get into an argument." **Jess**



Your sibling:

It is often the patient who knows best about what is happening to them. If you are close to your sibling, you might find comfort in talking directly with them.

"I was lucky enough to have a special relationship with my brother so predominately the information that I received was actually from him discussing it with me. Amanda"

Doctors, nurses and the palliative care team:

Spending time at the hospital can help you to feel more in the loop. You may not think that hospital is a particularly nice place to hang out. But you're welcome to be there, and you may find it's actually not that scary. You could ask to go to appointments with your sibling. Or just strike up a chat with the random nurse that comes to visit at 3:00 in the morning. You can ask them about all kinds of stuff that's bothering you, not just medical questions.

"The hospital staff were quite willing to be clear. I asked the nurses a lot of questions away from the room (and away from my parents and brother). Jane"

If you want to know more about cancer, treatments and other medical stuff, you can also speak to a cancer nurse on the Cancer Council Helpline (call 13 11 20). This might help if your sibling is being treated far from home and you can't get to the hospital.

Social workers or counsellors:

Social workers and counsellors can talk you through things that you are worried about, show you how to find more information and can help you figure out how to speak to your family about what is happening. For more on how to find a counsellor, see pages 63-64.

People at school:

There may be a teacher, school counsellor or nurse who can answer some of your questions – medical or emotional. The librarian might also be able to help you find information in books, magazines, videos or online.

“

I have wanted *more information since*, but at the time I had all the info I could handle. **David**

”

Beware of ‘Doctor Google’

We all know how wonderful, but also weird and huge the internet is. Here are some tips to make sure your Googling is successful.

- Make sure you’re searching the right stuff. There are over 100 different types of cancer. The likely outcomes are different for every cancer and different for every single person.
- Don’t believe everything you read. Print stuff out and check it with a doctor.
- Check the source of the information. A lot of stuff on the internet is out-of-date, wrong, or just trying to sell you something.
- Use websites you can trust. As a starting point, try www.nowwhat.org.au. There is a list of other recommended sites on page 63.

Information overload!

Give yourself a break. It’s hard to take in new information when you’re stressed. It can be easier to deal with little bits of info at a time rather than all at once. Wait for it to sink in before you go back for more.

Remember:

Google is not a doctor. No website can tell you how long your sibling will live.

messing

with the *family* dynamic



Every family is different. Each one has its own system (the famous “family dynamic”) for how things should be: who is the boss, what role each person plays, and how you get along with each other. They also have unspoken “rules” for what things are OK to talk about and for how family members “should” feel and think about things.

Add a stress like cancer to the mix and things can get tipped upside and stirred around a bit - for better, for worse, or a bit of both.

“

There were no family meals at the dinner table anymore as everyone was everywhere.

There was no real structure to our family life anymore. **Sarah**”

”

Some of these things might start to sound familiar:

- **There's not much of a routine anymore**

Some families are drawn together in a crisis. But in other families, communication gets tricky, responsibilities change and things can get a bit rocky and unstable. With everyone dealing with stuff in their own way, you might not feel like much of a family unit right now. There might be a crowd of visitors around wanting to help. It might have been a while since your life has felt 'normal'.

It can help to put some structure into your world. Try to keep doing your normal activities as much as you can.

“ **There was this sombre feeling that surrounded each single day as everyone was attempting to come to terms with what was happening to my brother. Amanda** ”



“ **My family didn't know what support each other needed.**
We all went down very different paths. *Jess* ”

- **You have to take on more responsibilities**

Your parents or sibling might think that you are really strong and independent and dealing with it all really well. They might start leaning on you a bit, expecting you to do more around the house, or become babysitter extraordinaire.

Most of the time, you probably just get on with it. But it's OK to take some time to chill out and get away from it all sometimes.

“ **I had to help Mum more with washing, cleaning, ironing, etc. I was only 16 and none of my friends had these responsibilities, so I did feel a bit hard-done by. Erin** ”

“ **Most of the time my parents weren't there. I had to look after my brothers so they could be at the hospital. David** ”

“It was difficult for me to understand that my parents just didn’t have the *emotional strength* to support me. I found myself being extremely angry at them and I didn’t even know why.” **Amanda**

- **Your parents are acting weird**

When parents are overwhelmed, they might find it hard to get the balance right. Sometimes they are overprotective; sometimes it seems they’re not interested in you at all.

As you know, your parents are really busy and distracted and they may not realise if you’re feeling hurt, lonely or smothered

It’s OK to tell your parents that you still need things from them and ask if you can make a time to talk. If it’s really hard to bring up difficult topics with your parents, try writing a letter/email or text.

“**Mum became very protective. She didn’t know how to leave me to be me. She wanted to know everything I was doing every minute of the day which was suffocating.** **Jane**”

“**I spent most of my time with my aunty and uncle and not really with Mum and Dad. *Everyone was sad* so we didn’t talk much.** **Zoe**”

- **Your relationship with your sibling who has cancer changes**

Just because your brother or sister is sick doesn’t mean that all of a sudden your relationship will be perfect. It’s likely that they will still make you cranky and annoyed sometimes, if they did before.

You might be drawn closer together as you share what is happening. Or you may find that you prefer to stay away and carry on with your normal things. This is OK, there’s no right way.

It’s very common to feel anger or resentment towards your sibling when they are sick; for taking away the normality of your family life and having the entire focus on them all the time.

A lot of people feel guilty for having thoughts like this. But these feelings are normal. If you find you are struggling a bit with how you feel, tell someone about it. It can really help to get it all off your chest.

Try not to put pressure on yourself to “be” or “feel” a certain way about your sibling and about the whole situation. You have to look after yourself, too, and think about what you really want or need - whether this is spending lots of time with your sibling, or spending lots of time doing the stuff you normally do.



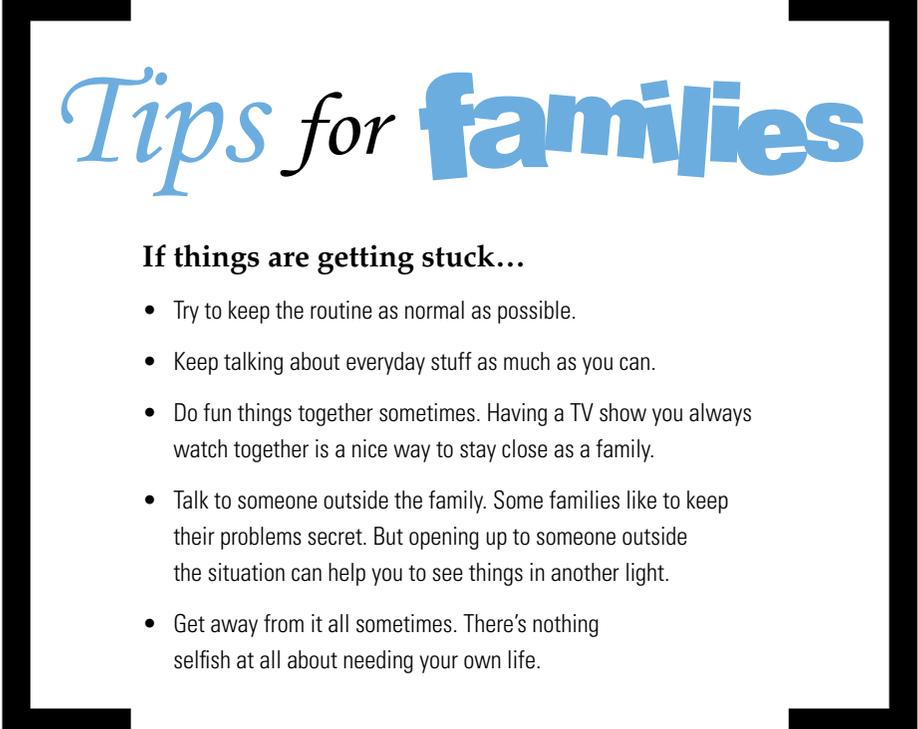
**I learnt that you don't
have to put the sick
person on a pedestal.**

They're not perfect. **Erin**



- **Nothing really changes at all.**

Every family is unique. Don't panic if none of these things - or completely different things - happen in your family.



Tips for **families**

If things are getting stuck...

- Try to keep the routine as normal as possible.
- Keep talking about everyday stuff as much as you can.
- Do fun things together sometimes. Having a TV show you always watch together is a nice way to stay close as a family.
- Talk to someone outside the family. Some families like to keep their problems secret. But opening up to someone outside the situation can help you to see things in another light.
- Get away from it all sometimes. There's nothing selfish at all about needing your own life.

Behind

the

mask

*(How are you
really feeling?)*

“I’m fine, thanks” Really?

Young people are very skilled at hiding stuff. And people expect you to be a bit moody sometimes. It might seem that you are doing just fine. It might not be obvious how you’re feeling behind that brave face – even to yourself.

“

No one ever asked how I was.

It was hard always being the “other one”. **Stacy**”

“ **I would have liked to know that my feelings were normal back then. I battled with the whole jealousy thing for a long time and the guilt from those feelings. Sarah**”

There is no right or wrong way to feel when your brother or sister has cancer that can’t be cured. Your feelings might rise up and strike suddenly like an electric shock. They might also be a constant nagging weight that you carry around with you all the time. Or you might not feel anything at all.

“

I remember feeling **numb** and spending my days just *going through the motions*. **Amanda**

”

It can help to give a name to what you are feeling. Here is a list of things other siblings have felt:

- Shock and disbelief
- Numb or empty
- Angry
- Guilty
- Confused
- Annoyed
- Jealous
- Left-out or ignored
- Selfish
- Sad
- Helpless
- Hurt
- Lonely
- Regret
- Heartbroken
- Uncomfortable
- Worried
- Embarrassed
- Ripped-off
- Scared
- Withdrawn (Like you just want to be alone)
- Ashamed
- Weak
- Nasty
- Panicky
- Crazy
- Over it
- Hopeful
- Calm
- Relieved
- Lucky
- Appreciated
- Proud
- Thankful

However you are feeling right now, chances are, there is someone else out there that has felt the same thing.

“Mainly I felt emotionally drained and put the rest of *my life on hold* because it just didn’t feel important.” **David**

Top tips from those who have been there done that:

- It's not your fault your sibling is sick. No one can give someone else cancer.
- Feel what you need to feel. If you want to cry, cry. If you want to scream, scream.
- You can't control what will happen. Try to focus on the present and take every day as it comes.
- It's not your responsibility to be perfect all the time. You can't make up for what your sibling can't do.
- Avoid the 'coulda, woulda, shouldas'. It doesn't help to dwell on the things you could have done differently.
- There ARE people out there who understand what you're going through.

“One thing I wish I'd known at the start was that *normality* does start to come back into your life.” **Lisa**



It's important to let yourself grieve. If you push it away, it can get stored up until years or even decades later.

Grief and loss

Some of what you are feeling might be grief. Grief isn't just about death. Grief is actually the reaction we have in response to the loss of anything that is really important to us.

You have probably already experienced lots of different losses since your sibling was diagnosed: loss of your old routine, loss of some friends, loss of your plans for the future. Any of these losses can be really upsetting and leave you feeling like your world has changed forever.

You can also feel grief when you know you are about to lose something important - before it happens. This is called "anticipatory grief" and often happens when someone you love is expected to die.

Waiting for the death to happen – and knowing you are helpless to stop it – can be just as painful and hard to deal with as the death itself. It can be really confusing, with heaps of mixed feelings and you might not be sure how you're supposed to act.

“ I learnt that everybody grieves in their own ways. You don't need to feel bad if you don't feel something. I wasn't sad, I didn't cry. You don't HAVE to cry. Jane ”

Grieving about what is happening does not mean that you have given up on your sibling. Grief is the way we get used to a new reality and the changes it will bring.

Grief is a natural part of life. But it can feel so difficult and scary. As much as it may not feel like it now, things will eventually settle down. Grief usually lessens over time.

What helps and what hurts

Imagine you are a volcano. Got that? Now imagine your feelings are all the gases and molten rocks bubbling away inside you. If they aren't released, the pressure will build up and eventually erupt!

OK, well that was all a bit dramatic. But you get the point. Bottling up your feelings doesn't make them go away. In fact, they will probably grow stronger and last longer. They might burst out in unsafe ways, or turn inside and leave you feeling drained and unwell.

Letting it out

There are heaps of things you can try that can get out some of your feelings and help you feel more relaxed and in control. The fancy term for these things is "coping strategies".

Different things work for different people. If you haven't yet found the thing that helps you feel better, keep trying: you will.



"Cry if you want to.

Don't worry about what people think, they'll deal." Amy





Things that might help:

- **Tell your story to someone you can trust.** You don't have to keep it all inside.
- **Write stuff down.** Write a journal, a blog, letters, songs or poems.
- **Take a break.** Go out with your friends, laugh and forget about things for a while.

“**For me it was playing guitar.**
Even just getting away for 5 minutes to have your own space and clear your head. **Laura**”

- **Exercise.** Make a playlist for your iPod and go for a walk or a run. Go and kick a footy. Exercise can release 'feel good' hormones in your body.
- **Distract yourself.** Watch a movie, do a crossword, play a game.

“**I watched a lot of movies and TV shows. Focusing on these fictitious stories somehow helped me escape reality.** **Chris**”

- **Get arty.** No one's expecting a masterpiece. Build something, knit a scarf, draw the cat.

“**Sometimes I would sneak down late at night and play the piano, just to try and get some of the things that I was feeling out.** **Amanda**”

- **If you're religious, pray.**
- **Punch a pillow or chuck a tanty on your bed.** Release that negative energy.
- **Find a special place.** Go fishing, ride your bike, browse the shops, stare at clouds.

“**I'd recently got my licence and my own car. I decorated the interior with neon lights and would simply sit in it and listen to music. It became a kind of sanctuary for me.** **Ben**”

- **Meditate.** Breathe in, breathe out. Try to focus only on your breath for about 15 minutes.

“**I used to drive out to the beach and just sit there.**
It was calming and so beautiful. **Sam**”

- **Write To-Do lists, set goals.** It can help to have things to look forward to. You don't have to dream up where you'll be when you're 65, but just think about something you'd like to achieve by the end of the month or year. Ever wanted to learn pottery? Salsa dancing?



One thing I know for sure is I wouldn't recommend the path I took to anyone.

I resorted to working very long hours, plus alcohol and substance abuse to *deal with my feelings*. It was self destructive and to be fully honest, a terrible place to be. Jess



Things that might hurt:

Cancer is majorly stressful and it's normal for things to get on top of you sometimes. But there are helpful and less helpful ways of releasing that steam.

- **Behaving badly or doing risky things:**

Swearing, biting your parents head off, wagging school, or running away can be a way of getting out your frustration or showing people you're feeling upset. But try to be patient with each other. It's not the best time to be pushing people away.

- **Using drugs, smoking or alcohol:**

This might seem like a way to block out the hard feelings. But without the lecture, it can actually make the stresses of cancer even harder to deal with. You might also look back with regret one day if you spend the time you have left with your sibling in a bit of a haze. Also, once the "positive" effects of drugs and alcohol have worn off, lots of people feel really down for days afterwards. This can make everything feel a little bit harder.

- **Hurting yourself or others:**

It's normal to feel p*ssed off when your sibling has cancer. But there are safe ways to vent it without taking it out on yourself or others. If you do hurt yourself, or have before and are worried you may do it again, tell someone you trust because there are lots of strategies that can help. A counsellor or social worker might be a good person to talk to.

- **Shutting yourself off from people:**

It's fine to need some time to yourself. But worries and wonders can grow into big fears if you hibernate away in a hole and refuse to talk to anyone.



"I went cuckoo. I ran away.

I was bitchy, like a brat.

I thought, 'I'll do what I want!'" Amy



“

I would tell someone else in my situation to relax and ask for help wherever you can.

Because I had lived with the situation for a while, I started to *forget it was unique* and be hard on myself for not coping. Lucy”

Don't worry, you're not crazy and you're not having a nervous breakdown. Be kind to yourself and let yourself make mistakes. No one is perfect in situations like this.

If you need to speak to someone right now, about anything at all, call Kids Helpline on 1800 55 1800 or Lifeline on 13 11 14.

You can also get help from websites like www.youthbeyondblue.com or www.reachout.com.au.

A bit about depression

It's normal to feel sad and down when your sibling is sick. But if you're feeling completely empty most of the time, hopeless and like nothing is worth it anymore, you might be depressed.

Depression is really common. There is nothing to feel nervous or ashamed about. It is not permanent, but it's not something you can just "snap out of" either. It's really important to tell someone about it and get some professional help. Your GP and your siblings treating team can help you find help.



Alone in a CROWD

Finding support



“ The friends who knew what was happening drifted away.
I stopped telling them what was going on and didn't really want to talk to them. **David** **”**

All this chatter of talking about it and getting help from other people...sounds good on paper, but it's not always that easy to know where to start.

There might be people all around you, but no one who really gets it.

Usually, you might turn to your folks to lean on when you need support. But your parents have probably got a lot going on at the moment and they may not have as much time to talk. So, who else...?

Friends

Some friends are great at saying the right things and picking you up when your feelings come and hit you like a bus.

But other friends don't really get the whole "cancer thing" and you might feel let down that they aren't as supportive as you wish they were.

“ You find out who your true friends are. Ignoring it is not good enough for your best friend. **Amy** **”**

It's normal to lose a few friends along the way. But it's likely your real friends do want to help you, but don't really know how. They may not know if it's OK to mention your sibling or the "c" word. They don't want to upset you and think it might be better to give you a bit of space.

This is new territory for everyone. There is a cut-out page you can give your friends to give them some tips on how they can help on page 61.

Other people in your life

“ Even if you are feeling alone, there is always someone there. You just have to find that special person that you feel comfortable sharing with. Ashley ”

This person might be in your extended family, a neighbour, a teacher, a doctor, a priest, pastor, rabbi, imam, elder, Scout leader, swimming coach, choir instructor, or someone you work with. It doesn't matter who it is. They just have to be a good listener.



Counsellors

If you feel like you want to talk, but are unsure who a good person might be, a counsellor is always a good option.

You might be thinking, “Nope, that’s not for me”. But counselling might not be what you think. Counsellors are trained people who are very good at listening to what you have to say and helping you to make sense of it.

You could find one through your local doctor or your school or uni. Your sibling’s hospital might also offer counselling services to family members. They don’t have to be part of your sibling’s treating team. You can ask a nurse or call the hospital and ask for the number of the counsellors yourself. Your parents and sibling don’t even have to know, if you would prefer.

There is also a list of organisations that provide counselling for people in your situation on pages 63-64.

“ With counsellors; go to a couple, shop around and find one that suits you. Andrew ”

“I really found talking to people through CanTeen SO helpful, because they helped me see that I wasn’t the only one feeling these things.

It’s important to know that the person sitting there listening to you *REALLY* understands your viewpoint because they have been touched by cancer too.” **Jane**

Support groups – other people in the same boat

There are also organisations that bring together other young people who are going through the same kind of stuff. It’s amazing how much it can help to talk to people who really, truly understand what it’s like.

CanTeen is one organisation that offers support to young people who have a sibling who has cancer or has died from cancer.

You might go away on overnight camps or just meet up for the day. You can share stories and tips for dealing with your sibling’s cancer. You also have time to just chill out and have fun. It might surprise you how fast and deep the friendships you form at these groups can be.

“ I had become a bit isolated, so coming into CanTeen was a good help - to meet other young people whose sibling had died and see how normal they still seemed. Lucy ”

Online support

If you’re feeling alone, you can also get in touch with other young people in cancerland from the comfort of your couch – online. There are online cancer support websites where you can read real-life stories, blogs and forums and read information written specifically for people like you.

The website www.nowwhat.org.au is a great website like this. It’s made just for young people in Australia who have a family member with cancer.

DUMB things people say



Sometimes people may say things to try and make you feel better, but they don't have the right words to use and it comes out sounding a bit unhelpful. They probably don't mean to be insensitive, but just don't fully understand what it's like for you.

You may not appreciate hearing some of these things:

- "I know how you feel."
- "I'm so sorry."
- "I understand, my dog died last year."
- "Stay positive. They'll be fine."
- "You're so inspiring. I couldn't do what you do."
- "Everyone dies sooner or later."
- "It's God's will. They've gone to a better place."
- "You're lucky you had them for this long."
- "At least you have another brother/sister."

Don't listen to the positive attitude police, or those who tell you to forget about it. It's important to let yourself feel however you feel.

What should I say should I do?

Do you want to be more involved in what's going on, but don't really know where to start?

To figure out what your brother or sister needs and how you can offer support, it can help to try and get inside their head and understand what living with an incurable illness is like for them. You might find that many of their thoughts and feelings about this situation are very similar to yours.

In your sibling's shoes

- They may be scared.
- They may be angry.
- They may be very lonely.
- They may be shocked or in disbelief.
- They may be thinking about all the things they'll never get to do. Or thinking of all the things they need to get done.
- They'll no doubt wish this wasn't happening to them.
- They may not like all the focus and attention on them.
- They may worry about your family and how you are coping.

- They may want to reflect on what's happened to them in the past – the good things and the not so good things. They may want to think about the 'meaning' of their life and the ways they have contributed.
- They may want to know what death will be like and worried that there will be pain.
- They may be wondering about their beliefs and spirituality and thinking about things like what (if anything) happens after they die.
- They may not want to talk or think about any of this stuff at all.

The best way to understand what your sibling is feeling is to spend time together. Even if you don't say anything at all, your willingness to just be there and share this time will let them know that they are not going through this alone.

“ I remember us lying on the bed having a chat and her saying, “The hardest thing Jess, is knowing that I won't be there when you get married or when you have kids. And not seeing Luke when he's all grown up. Jess ”

“

Peter and I didn't really talk directly about dying and I sometimes wish now that I had given him the opportunity to do so.

I know that he knew he was dying. Jane ”

Should we talk about dying?

Your sibling may want to talk about what is happening – or they may definitely NOT want to talk about it.

The best plan is to follow their lead. Don't force them to talk; give them permission to not have to.

Most people feel very scared and uncomfortable talking about death, especially when it is someone they love. Even though it will be hard, it can be important for your sibling to know they can talk about this stuff if they want, even if they don't take you up on the offer.

If your brother or sister wants to talk, listen. Try not to correct them and say things like, "Don't talk like

that". Knowing you will die can be an intensely lonely and frightening experience. Talking about it and knowing someone is there to listen can take away some of the fear. Talking about death with your sibling does not mean that you have given up hope or that you want them to die.

Just be yourself in conversations like this and only do what you feel comfortable with. You don't have to be cheerful and upbeat. You don't have to be their counsellor. You don't have to have the answers to the tough questions. It's OK to cry and let them know how you are feeling too.



If you don't get a chance to have an intimate conversation with your sibling, that's OK. You will have lots of precious memories of them and you can be sure that whether you do or not, they do know how much you care.

“ **I used to sleep next to my brothers bed in the hospital so it gave us a lot of time to talk. The comfort that we found within each other was something I will always treasure. Amanda ”**

Top Tips

Treat your brother or sister as you always have. They are still them.

“Only you know what you can handle.

You’ve got to look after you too.” Anna

How can I help?

Don’t let your fear of doing or saying the wrong thing keep you from being involved in this situation as much as you want to.

There is no rulebook that tells you exactly how many pillows you should plump or dinners you should make to be a helpful sibling. Every experience is different.

Try to let your parents and sibling know if you would like to be more involved in their care. Take some initiative and just do things. You may not be asked. But don’t take on too much. If there are things that you are not comfortable doing, you don’t have to.

Little things, like helping your sibling stay in touch with their friends by updating their Facebook page or sending out group texts can mean a lot to your brother or sister.

One of the biggest things you can do is just to hang out with them and keep them company. Think of things you can still do together even if they become weaker, like watching a movie or playing a board game. You will probably value the time you have with them later, even if you’re just sitting in silence.

“ I can’t really remember ever talking to my brother about what was happening. Looking back, I do wish had spent more time with him before and during his cancer experience. Zoe ”

Many ways to say goodbye

“ My advice to some one that has a terminally ill brother or sister is to *do it all, anything and everything*. Just be there for them. Call them, text them, talk to them, see them at every chance you get. Take a million photos. You can *never get enough time* with them, and after, it will never feel like it's been enough. Don't worry if you fight. Good times or bad times, it's all time. You will realise that the things that tick you off about them will be the things you miss most, so don't waste any time being upset. Laugh, joke, cry, do whatever to make them smile. Jess ”



Saying what you want to say and letting your sibling know what they mean to you doesn't mean you are admitting defeat or ready to let go. You don't have to think of it as "saying goodbye", but more like saying "you matter to me".

Don't wait and don't hold back. The future's a slippery little sucker. You don't know when the last minute will be.

“ I wish that I could have been brave enough to have thanked my brother for everything that he gave me within my life.

Or the care and security that he had always provided me. **Amanda** ”

In lots of different ways, a little bit at a time, let your sibling know how you feel...

- Thank you for...
- I'm sorry that...
- I forgive you for...
- What I'll miss most is...
- I'm proud of you for...

You can say a lot without even opening your mouth. Write them a letter, an email, a card, a story or a poem. Draw a picture, make a collage, find songs that say it for you. Give a hug, a wink, a smile. Hold their hand.

It might take a truck load of courage. You might feel embarrassed. It might be a bit uncomfortable. It will probably make you both cry. You just might be glad later that you did.

A farewell party?

If it's your sibling's style, and if they feel up to it, you could think about having a 'living funeral' - where the guest of honour gets to be there. Get their family and friends around and have a party, say nice things, eat some food, drink some drink and crank the iPod.

Don't worry if you don't get the chance

You'll never get to say it all. You'll forget things. Things will come out wrong, words will get stuck. You might not have the opportunity to say anything at all. The truth is, they KNOW how you feel. They know how much you love them. Even after they are gone, your relationship with them will still exist.





memories and *stories*

When your sibling dies, they will stay connected to you forever in your memories and thoughts.

The memories and stories you have about your brother or sister are really precious. You can never have too many. So it's never too early or too late to start collecting them. Here are some ideas on how to do that...

Get to know them

Looking back in the future, you'll probably find it's the little details you remember about your sibling that mean the most to you. There's no such thing as too much information.

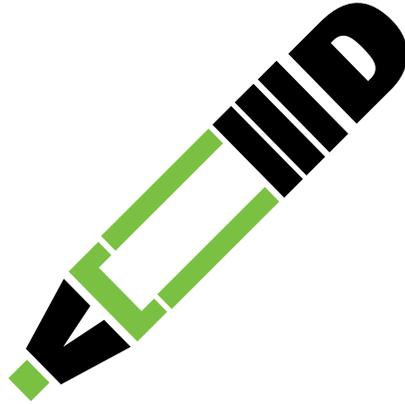
There might be lots of things you'd like to know about them:

- What are your dreams?
- What are your hopes for me?
- What do you remember about when we were kids?
- What did you want to be when you grew up?
- What is your favourite memory?
- What is your favourite place?
- What is your favourite colour?
- What is your favourite movie?
- What is your favourite food?
- What is your favourite song or band?

Get it all down

Memories can fade no matter how hard you try to hold on to them. Don't trust your brain. Get this stuff down onto paper, onto a disk, or into the computer. You could add to it over time as you recall bits and pieces. Get collecting:

- Put together a photo album. Write little captions about what you remember about each picture.
- Make a video or voice recording of stories and shared memories.
- Make a memory box or scrapbook. Collect things that are special to your sibling and remind you of them – like photos, concert tickets, cards, clothes or jewellery.
- Make a CD or playlist of their favourite songs.
- Make a cookbook of their favourite recipes.
- Let them live on, online. Create a website and put up photos, videos, stories, messages.
- Draw around their hand, record how tall they are, cut a lock of hair.
- Collect their smell. Smells are really powerful in bringing back memories. Find out what perfume or hair product they use. Or write down that their room smells of football socks.



Everyone approaches end of life differently

Your brother or sister might like to look back over their life and tell stories, make video recordings, or scrapbooks, write letters and answer these kinds of questions. They also might not. Or they may not get an opportunity.

You can prepare memories on your own later. Or you could talk about stuff with other people that know them. It can be just as special to record what their friends or other people in the family remember about them too.

**You'll never forget your sibling.
You wouldn't be able to even if you tried.**

Not just *alive*, but *living* Palliative care

When it no longer seems likely that your sibling's cancer can be cured, the focus of treatment shifts towards helping them feel as comfortable as possible, so they can make the most of the life they have left. This type of care and support is called "palliative care".

What type of support does palliative care provide?

Each palliative care team is different. But usually it is a team of professionals who work together to improve your sibling's quality of life and help your family to cope. It might include some or all of these things:

- Nursing or medical care - to control symptoms and side effects of cancer, like pain and nausea.

“

As a family we spoke about Lara stopping her treatment so she could live out the last of her time as full of energy as she could.

She was tired of the treatments and being in hospital feeling sick all the time. Jess”

- Counsellors and social workers – to help your sibling and family make the right decisions and cope with the stress.
- Loan of equipment – like special beds and chairs.
- Therapists skilled in music, massage, aromatherapy or colour.
- Dietary advice – about what your sibling can eat when most food tastes like mud and cardboard.
- Spiritual support and pastoral care from different cultural and religious backgrounds.
- Volunteers to help your family look after your sibling.

How do we know if it's time to consider palliative care?

Your sibling's treatment team will probably recommend if it is time to consider palliative care.

It might be your sibling's own decision to stop treatment. Often the patient knows before anyone else that they are not getting better and have had enough of treatment and side effects for thirty lifetimes. Far from giving up, this might just mean they want to have the energy to do things that are important to them while they still can.

But it looks like they are getting better...?

Sometimes when people stop cancer treatments and start palliative care, they start to look better than they have for a while. Their hair starts to grow back, they get some colour back in their cheeks and they may even have more energy. This can be confusing.

Cancer treatments are powerful and have some pretty nasty side effects. When they are stopped, the body starts to recuperate. But unfortunately, the cancer will still be there.

Is palliative care just for people who are about to die?

If your sibling is referred to palliative care it does not necessarily mean that they are about to die, although end-of-life planning is part of palliative care. A lot of people avoid palliative care as long as they can because they are afraid it means they have given up hope. But the palliative care team is there to make things easier for your family. It can really help to meet them sooner rather than later, to get to know each other and hear about all the ways they might be able to help.

It's not a one-way door. If your sibling's illness stabilises or improves, palliative services can be stopped.

Is palliative care like euthanasia?

No. Euthanasia is assisting the death of someone who would prefer to die. This is illegal in Australia. Palliative care is about helping your sibling have the most comfortable and pain-free life they can.

If I have questions, who can I ask?

The palliative care team is there to help you too. Ask anything you like; there is no question too small or silly to ask. Lots of siblings want to ask questions like, "What should I expect?" Or "What should I say if they ask if they are dying?"

End-of-life planning – Final wishes

We all know that eventually we are going to die, but who wants to think about it before you really have to?

Like lots of families, your family might avoid talking about your sibling's death, thinking that if you accept it it will somehow happen sooner.

But if your family can have a conversation about end-of-life while your sibling is still alive, it can give you an opportunity to share and discuss your hopes and wishes for what will happen when the time comes.

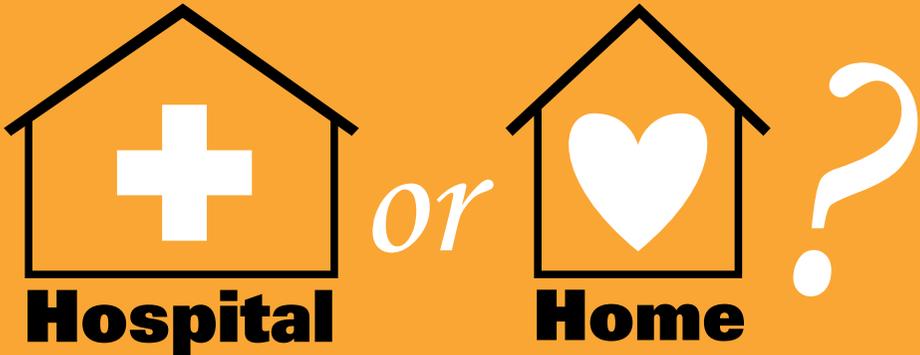
If you get a chance, you could discuss things like:

- Making an “advance care plan” to tell the hospital team what kind of treatments are or are not wanted, no matter what happens. This will include things like whether or not they want to go on life support if it comes to that.
 - Where would they like to die if they have a choice?
 - Who would they like to be there, or not be there?
 - Would they like to donate organs if they can?
 - Would they like to be buried or cremated?
- Do they have a “will”? A will tells people what your sibling wants to happen to their things when they die. They could think about who's going to get their bike or the PlayStation, or who's going to look after the dog now.
 - Do they have any ideas for their funeral? Maybe they don't want flowers placed on their grave, but a bowl of Twisties? Anything goes.

It can help to start talking about these things sooner rather than later if you can. Write the decisions down and make sure everyone gets given a copy to be sure they get followed when the time comes. Things that are written can be changed at any time if necessary.

“I really thought that he would recover and everything would go back to normal.

When the doctors told us they'd tried every drug combination they could think of and it hadn't worked and that we should begin looking at palliative care, the *denial finally ended*. It was a shock.” **Ben**



A major decision your family will have to make is where your sibling will be at the end: at home, hospital or a special hospice.

There are lots of things to consider, such as what care they need, where you live, what support is available in your local area and what your family feels comfortable with.

There is no right or wrong place. And you can change your mind at any time.

Home

Lots of people prefer to die at home. With the support of community palliative care services, this might be possible. It can be a really special time to have your sibling at home, surrounded by their family and their own things. Nurses and the GP might be able to make home visits and there might be a 24/7 phone number at the hospital you can call for advice.

But caring for someone at home can be really difficult, tiring and stressful and it's important your family doesn't take on more than they can handle.

“ Because he came home into palliative care, Mum had to be his full time carer. We had nurses visit, but Mum was involved in connecting drugs to his central line during the night etc, so she had very broken sleep and was pretty much house bound. I wasn't living at home, so I had to really push Mum to get help and not feel guilty about taking some for herself. Jane ”

There may be changes in the way your sibling looks, feels and acts when they are approaching the end of their life. It can be heartbreaking to see someone you care about become weaker and sicker and be helpless to do anything about it. It's really important to get enough sleep, eat properly and make time to get out of the house. You need to take care of yourself too.

It's not always possible for a young person to die at home, for lots of different reasons. It's no one's fault or failure if your sibling cannot be cared for at home.



Hospital or hospice

It's very common for young people to die in a hospital. Your family might feel more comfortable that they are cared for by trained staff, or there might be other reasons why hospital is the most appropriate option. There may also be a hospice or special palliative care unit that they can go to.

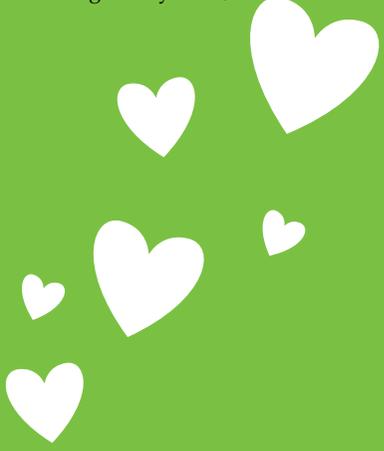
“ I really struggled with watching my sister's condition slowly deteriorate right in front of me while knowing there wasn't anything I could do. **Jess** ”

If your sibling goes into hospital or a hospice you might feel worried that they might not be able to come home again. But patients often move between different places of care as their condition and symptoms change.

Feel free to visit your sibling in the hospital as much as you would like. It can help you feel more involved in what is going on. You might even be able to stay overnight.

“As I was his little sister he always took the responsibility of looking after me.

Suddenly though in those final days I became the person who really had to be the *strong one* and take care of him. By focusing all my attention and care towards my brother I didn't really have to think or feel what the whole situation was doing to me.” **Amanda**



when the *end* is *near*

There is no way you can be fully prepared for what will happen and how you will feel when your sibling dies. But it can help to know a bit about what it might be like.

Firstly, there is no such thing as a normal or typical death: it's different for every single person. Sometimes, death is sudden and unexpected. In other cases, it may seem like the person will die soon and they are still around for weeks or months.

What does dying look like?

There are some signs that death is near, although it is impossible to know the exact moment that it will occur. These changes might start weeks, days or just hours before death.

- Weak and lacking energy. Your sibling's body will start to wind down and they might drift in and out of consciousness. Or they may stay alert until the end.
- They might not feel hungry or thirsty and find it hard to swallow.
- Their skin might feel cool and change colour as their circulation slows down.
- Their breathing changes, with periods of fast breathing, then shallow breathing and short periods of no breathing. Sometimes fluid in the lungs makes a bubbling noise. It's likely the patient does not find this distressing, although you might find it frightening.
- Hearing is one of the last senses to be lost, so keep talking, even if they don't respond.

Remember: For many people, dying is peaceful. Ask the medical and nursing staff about anything you are worried or unsure about.

Will they be in pain?

Not everyone who dies from cancer gets pain. But for those who do, pain can almost always be effectively controlled. There are lots of different types of painkiller drugs, plus other ways to relieve pain such as massage, meditation, using heat or cold, acupuncture, aromatherapy or with counselling or psychological treatment.

Will I be there when they die?

This is a very personal decision and something you should talk about with your family. Let your family know if you want to be there at the end if you can and make an agreement that you will be woken up or taken out of school if it happens then.

It's perfectly OK if you don't want to be there. There will be plenty of ways you can say your goodbyes to your sibling.

Stories of the end by other siblings...

“ My brother Peter’s death was quite sudden. He had been quite well and cheerful for the week before. On the Saturday morning he got up and asked my father to take him out for a ride on his motorbike. When they got home around lunch he said, “OK Dad, I need you to take me to hospital now”. He passed away in hospital early on Sunday morning. He was 14 years old. Jane ”

“ We were really well informed as to what would happen if we left the machines on and what would happen when we turned them off and we all agreed that it would be much kinder for Melanie’s sake to end her suffering by turning the machines off. Her body had given up. Sarah ”

“ In August, it got very serious very quickly. Tay woke up at about 3am but he couldn’t move. The poor kid had had a stroke. Off to hospital again. This time he’d had enough. He was paralysed on his left hand side and his eyes said it all. He was done. He slipped away at 8am on the 28th of August. Megan ”



when your sibling

dies...



“When he died, it was
still a shock, even though
he was in palliative care.”

Jane

There are some signs that someone has died:

- Their breathing stops.
- They have no heartbeat.
- They don't respond to anything.
- Their skin feels cold and looks pale.
- Their eyes stop moving and may stay open.
- Pupils of the eyes stay large, even in bright light.
- They might lose control of the bowels or bladder.

What do we have to do?

There is nothing that has to be done straight away. This is a very personal time to be with your sibling and say goodbye. Take as long as you need.

It's your own individual choice to see, touch or talk to your sibling after they die. Do whatever you feel comfortable with.

But even with the best planning things can change when the actual moment arrives. If things don't go exactly as you would have liked, there are plenty of other ways to say goodbye to your sibling.

If they die at home the care team doctor will tell your family what you need to do. Usually, a doctor will have to come and sign a death certificate and give it to your family or a funeral director. If your sibling dies during the night, you can wait until morning before calling the appropriate people if you want. You can keep their body at the funeral home, or possibly in your own home.

If they die in a hospital or hospice you are welcome to stay with them for a while after they die. It may be possible to take their body home for one last visit. Or the funeral director may come to collect your sibling's body from the hospital or hospice.

“The hardest thing to deal with for me was to deal with having to go home without him. It wasn't until then it really hit me. Zoe”

What happens now? The first few days...

No matter how long you have known this was going to happen, how much you have thought about it and how ready you think you are, nothing will ever prepare you for how you will feel when your brother or sister dies.

“When my parents sat me down to tell me that my brother passed away I tried to run away. I didn't believe them. I went to school that day to take my mind off everything. Emma”

The first few days might feel strange. You might feel numb, just going through the motions, more empty than sad. This is your body's normal reaction to shock.

You may not feel like you can really take in what has happened. It might feel like your sibling will just come back in the door any minute.

You might also feel relief. This is natural and very common, but it can be a confusing feeling. It doesn't mean that you are relieved your sibling died, just that they are no longer in pain or suffering. You might also be relieved that your family can start to move forward through this difficult time.

“I felt the *lifting of a burden* and I felt guilty for that. I was just glad there was room for me in this world again.” Lucy

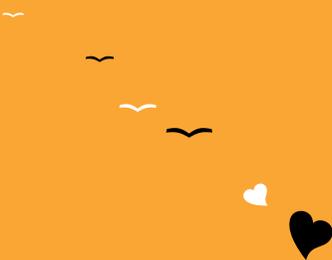
The first few weeks...

There might be lots of people around and lots of things to do and you don't really have much time to yourself to take in what has happened.

When things eventually settle down, it might feel eerily quiet and calm. For ages, everything might have been focused on hospitals, appointments, treatments and test results. Then suddenly, it's all over. What are you supposed to do now? It can take a really long time for things to feel 'normal' again.

You don't have to rush to pack away your siblings things. This can make it feel very final. You can leave things just the way they are until you feel ready.

“There were lots of people around just after Melanie died. There were lots of flowers, lots of cards and lots of food. The people came and left, the flowers wilted, the food got eaten...Then for a few seconds it was like we were normal again, and it was like Melanie was just in the hospital. Then I remembered that she wasn't in the hospital and I couldn't go and see her whenever I liked... Sarah”



Funerals

Some people say that a funeral is for the living. It can bring together the family and friends of the person who died and give everyone a chance to share their thoughts and feelings about that person, laugh and cry together and say goodbye.

What is a funeral like?

There is no 'right' way to do a funeral. It can look really different for every family. Your family's cultural or religious traditions and wishes, as well as the wishes of your sibling, can all play a part in how it goes.

Your family will probably start to plan a funeral a few days after your sibling dies. But there's no rush. It doesn't have to happen straight away.

Most families choose to use a funeral director to help plan the day. They can help you decide things like:

- Where will the service be? It can be anywhere – like the beach, a footy field or your garden.
- Will it be a burial or cremation*?
- Will there be a viewing*?
- Who will be invited?

- Who will speak? It doesn't have to be a religious service if that's not you. You can read letters from your sibling, poems or bits from the books or movies they liked. Don't be afraid to make people laugh.
- What music will you have? You could make a playlist of your sibling's favourite songs. Even get a live band or DJ.
- What personal touches can you add to show your sibling's personality? Cover their grave in cricket balls instead of flowers. Dress them in their ripped jeans if that's what they would have preferred. There are no rules.
- Will there be a "wake" after the service? This is a gathering that could be anything from a cup of tea and a biscuit to a raging party.

(* These words are explained in the Glossary on page 53.)

Should I go?

You can choose whether to go to the funeral or not.

Many young people find that it helps to go, to share your feelings and celebrate a life that was important to you in some way. It also helps you to acknowledge that they have really and truly died, so that you can eventually start to move forward with your grief.

“ I was 16 years old when my big sister Melanie died. I have learned not to feel guilty for what I did or didn't do or for things that I did or didn't say. Sarah **”**

But if you don't want to, or can't go, there are other ways you could say goodbye to your sibling. You could plant a tree, or tie a message to a balloon and let it go, or visit a special place you used to go together.

This may be one of the biggest and hardest things that will ever happen to you. Don't put pressure on yourself to be or feel a certain way.

Tell your family if you would like to be involved in planning the funeral.

Top Tips



the road ahead...

“ It doesn't end with them dying...That just opens the door. Jess ”

The grief may take a while to hit you, but at some point it probably will. When the initial shock wears off and it gradually sinks in that your brother or sister really has died, it can feel like the bottom has dropped out of the world.

The grief can strike unexpectedly, like when someone calls to speak to your sibling on the phone.

Or when you accidentally set one too many places at the table. Or when their favourite song comes on the radio.

“ For several months, I found myself struggling with 'what now?' kinds of thoughts; I had little idea of how to entertain myself. I'd spent 19 years having an older brother to do stuff with. Ben ”



I still miss him every day, but the worst of the grief is long gone.

Sometimes I still find it hard to believe that he's gone, but for the most part I've learned to live without him. **Ben**



What is normal grief like?

Your grief is your own. Whatever you experience is normal. It could show itself in you in really strong emotions or by feeling no emotion at all. You might have physical reactions, like not sleeping or having stomach aches. You might feel like going out all the time and partying, or hiding in your room and not going out at all. You might cry, or you might not.

Everyone will react differently. The people around you might be showing their grief in different ways.

How long will it last?

It takes as long as it takes. That may not sound very helpful, but it's true. Grief is a really important part of adjusting to a huge loss. You don't have to move on straight away. You just have to ride with it and let it run its course. Yes, it sucks. But most people find that over time, things do get easier.

“It has been a few years now since my brother died, and I can't tell you when I found 'acceptance' of that, but I did. Now I remember him and the good moments and the pain and sickness sort of blurs away. Jane



Permission to backslide

Feelings will come and go, they are like waves. You could think about grief sort of like a game of snakes-and-ladders. Some days you'll go one step forward and feel a bit better. Other days, something will trigger the painful feelings and it's like you're back at square one.

Over time, there will be more good days than bad days. You just have to be really, really patient with yourself and remind yourself that things won't feel this hard forever

The grief of your family

Some families who lose someone want to continue family traditions and keep things the same. Some families want to start new ones, move out of your home and change things. The tricky part comes when different people in the family want different things.

With everyone dealing with grief in individual ways, it's not uncommon for people to say or do careless things, for people to get snappy and feelings to get hurt.

This can be super hard to deal with, especially if your parents are not there for you at the moment in the way you need them to be. But eventually, like the feelings inside you, things in your family will settle down into a new pattern.

Some real stories...

“ My parents are divorced and had held it together in “the crisis”, but following Peter’s death they couldn’t be near each other without yelling. There was a lot of blame...I had to move back in with Mum because she wasn’t coping with his death. I was mad that I had to take care of her, when no one was taking care of me. Jane ”

“ My whole family changed. My father moved away after Shayne died as he said that the town just had too many memories of my brother. My mother really has never been the same but she is coping at least a little more these days. Amanda ”

“ The arguments became much more frequent and way more emotional in the months after his death. None of us knew how to deal with our grief, so unfortunately we often took it out on each other. Family relations did improve gradually and are now the best they’ve been in years. Ben ”

Your grief rights

No matter what anyone else says or does, you have the right to:

- Grieve in your own way, for as long as it takes.
- Talk – or NOT talk - about your thoughts and feelings.
- Be involved in memorials and rituals about your sibling’s death.
- Know the truth about your sibling’s illness and death.
- Keep things and photos that remind you of your brother or sister.
- Talk about your sibling and use their name.
- Ignore people who say insensitive things.
- Have your own personal beliefs about life and death.
- Remember your sibling as they really were, faults and all. Just because they died doesn’t make them a saint.
- Be helped, supported and cared for.
- Have your own life.

Some thoughts^o to carry with you



Things will get easier with time

At first it might feel like you'll never get through this or you'll never feel happy again. But you will. Time has a way of healing.

You will always have memories

You will never forget your sibling. They will always be a part of your life, they will just move to a different part of it. You don't need to feel guilty for going 20 minutes without thinking about them, or if you catch yourself having fun with your friends.

You have done your best

Most likely, you've been flying blind through this situation. No one teaches you what you're supposed to do in times like this. Be proud of yourself and try not to dwell on the things you could have done differently. It's natural to make mistakes. If you want, you could think of your "mistakes" more as valuable life experience.

Your sibling would want you to be happy

Don't be afraid to move forward in life when you're ready. Moving on is not the same as forgetting. Your sibling would want you to continue to live your life to the fullest. It's OK to make some changes in your life and stay open to new experiences.

It's OK to take some positives away from this

This experience will change your life. Not all the changes have to be bad. You might feel that you are stronger or wiser, or appreciate life and family more.

You don't have to think everything happens for a reason

You don't have to search for deeper meaning or think about what lessons you've learned from this experience if you don't want to.

It's perfectly OK to just think the whole thing sucks and to come out the other end being the same, faults and all.

We know the journey doesn't end here. We have written a book like this that focuses on the next stage – how you deal with your grief and start to move forward after someone you care about dies.

It's called Now What...? Living with the death of your parent or brother or sister from cancer. You can order a free copy at www.nowwhat.org.au/resource-order.

who DOES what

(They might be called something slightly different in your sibling's team ...)

Cancer Care Coordinator	A nurse who is the main point of contact and helps patients and families communicate and deal with the different members of their treatment team.
Dietician	A professional who provides information to patients and their families about nutrition and dietary choices.
GP (General Practitioner)	A medical doctor, sometimes called a family doctor. They are usually the first person you see for your physical and mental health care.
Oncologist	A doctor who specialises in the treatment of cancer.
Oncology Nurse Specialist	A registered nurse with extra education and training in cancer.
Palliative Care Nurse	A nurse with special training in caring for people with a life-limiting illness. They provide care, advice and support for patients and their families - in hospital, in hospices or at home.
Palliative Care Specialist	A doctor who has special training to be able to assess the needs of a person with a life-limiting illness. They prescribe medical treatment for pain and other symptoms, advise the other members of the palliative care team and support the patient and their family.

Pastoral Care Worker	A person trained to provide spiritual and emotional care as a part of treatment. They include counsellors, chaplains and other religious ministers or elders.
Pharmacist	A professional who is trained to know about drugs and medication.
Physiotherapist	A professional who helps with recovering physical movement and muscle strength.
Psychiatrist	A doctor who specialises in the diagnosis and treatment of mental health problems.
Psychologist	A professional therapist who helps with emotional and mental wellbeing.
Radiologist	A doctor who looks at X-Rays and other images of the body to diagnose and treat health problems.
Registered Nurse	A nurse who provides regular care for patients in a hospital or outpatient clinic.
Social Worker	A trained professional who talks with patients and their families and help them find support services.
Surgeon	A doctor who removes or repairs a part of the body by operating on the patient.

“ My whole family now has a better outlook on life and the importance of the little things. Zoe **”**

glossary

Advanced cancer Cancer that is unlikely to be cured. It might be the original cancer or cancer that has spread or come back.

Bereaved A person who has a loved one who has recently died. The period of time after their death when you are grieving their loss is called “bereavement”.

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

Carer A carer is someone, usually a family member or friend, who looks after a person who has a chronic illness or disability. You might be a carer if you help to provide support for your sibling with cancer – it could be for a few hours a week, or all day every day.

Chemotherapy The use of drugs to treat cancer by killing cancer cells or slowing their growth. It is also used in palliative care to control pain or other symptoms of cancer.

Chronic illness A medical condition that is permanent or lasts for a long time.

Complementary therapy Treatments that may be used as well as medicine to help your sibling feel more comfortable. Examples are: yoga, mediation or nutrition.

Coroner A government officer who investigates any death that is not obviously from natural causes. There does not have to be anything suspicious about a death for a coroner to be involved.

Cremation The process where the body of a person who had died is exposed to intense heat so that it is reduced to bone fragments commonly called “ashes”. The ashes may be kept by the family in a sealed container, buried or scattered outside.

Diagnosis The process of identifying a disease by its signs or symptoms.

End-of-life care The end stage of palliative care where the patient is very close to death.

Euthanasia The assisted death of someone who would rather die than suffer from the effects of their illness. It is illegal in Australia.

Funeral Director A professional person who can organise the practical and legal requirements of a funeral.

Holistic care An approach to care that combines different types of therapies and services to make sure that all of your needs (emotional, practical and spiritual) are met, not just your physical needs. Palliative care services are often holistic.

Hospice A place that provides care for people with a life-limiting illness. Patients might go in for a short time to bring their symptoms under control or to give their carers a break, and then go home again. They may also choose to die there.

Life-limiting illness An illness that is unlikely to be cured and will cause the person to die at some stage. A person may live with a life-limiting illness for weeks, months or years.

Malignant Another word for cancerous. A malignant tumour is capable of spreading to other parts of the body if untreated.

Metastasis Also known as secondary cancer. A cancer that has spread from another part of the body.

Morphine A strong and effective painkiller, which is commonly used to treat people with cancer who have pain.

Oncology The study and treatment of cancer.

Palliative care The care of people who have an illness that cannot be cured. The main aim is to help the patient feel as happy, comfortable and pain-free as possible so they can make the most of the life they have left. It is not just for people who are about to die, although end-of-life care is part of palliative care.

Palliative care team A multidisciplinary team which may include nurses, doctors, social workers, volunteers, chaplains, psychologists, physiotherapists and other kinds of complementary therapists.

Pastoral care Care provided by a person trained in giving spiritual and emotional support for a patient and their family and offering prayers and religious rituals if requested. It is usually provided by counsellors, chaplains and other religious ministers or elders.

Primary cancer The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

Primary carer A person who takes the most responsibility for looking after the patient. The primary carer of your sibling might be your parents, another relative or even you. There are many support services available to help the carer.

Prognosis The likely outcome of a person's disease. Doctors make their judgement based on their knowledge and experience with patients with similar medical conditions.

Radiotherapy A cancer treatment involving high energy X-Rays to kill cancer cells, stop them growing or to reduce the pain from cancer.

Relapse (or Recurrence) The return of the disease after a period of improvement.

Remission When there are no signs or symptoms of active disease.

Respite care A service which provides temporary care for the patient, to give the carer and the patient a short break from their usual situation. Respite can be in a hospital, hospice or at home.

Resuscitation A medical action that aims to return someone to life when their heart or breathing has stopped. Resuscitation may or may not be successful.

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

Symptoms Signs of an illness. This includes things such as pain, fever, nausea, fatigue and breathing difficulties.

Terminal When a person who has an incurable disease is showing signs and symptoms that suggest their death is about to happen.

Tumour A growth or lump, which may or may not be cancer.

Viewing A time and place for people to come and see the body of a person who has died to say their personal goodbyes if they wish. A viewing may be held in a funeral home, a religious building or at home. A viewing can be different in different cultural or religious traditions.

glossary



Useful websites...

Cancer info and support groups

www.nowwhat.org.au

This is our website for all young people who have cancer in their lives. There are lots of real-life stories, blogs, forums and heaps of information. You can also order free copies of the other "Now What..." books from this site.

www.canteen.org.au

CanTeen is an organisation that supports young people aged 12-24 who have a sibling with cancer or sibling who has died from cancer (it also supports people who have a parent with cancer or have cancer themselves). They run a range of camps and activities that bring together young people in a similar situation to share their experiences and get away from it all for a while. Call 1800 226 833 to find out more.

www.cancer.org.au

The Cancer Council website has lots of good, clear information on cancer and can direct you to Cancer Council support services in your state. These include counselling, support groups and practical assistance. Call 13 11 20.

www.redkite.org.au

Redkite provides emotional, financial and practical support to young people with cancer as well as their families. They also provide bereavement support to families if the young person dies. Call 1300 722 644.

www.campquality.org.au

Camp Quality runs programs for children and young people who have cancer, and their families. They provide camps, activities and education aimed at helping you have fun and stay optimistic.

www.macmillan.org.uk

UK website gives information and advice on how to deal with the practical and emotional and effects of living with and after cancer.

www.youthcancer.com.au

YouthCancer.com.au is the home of information, treatment and support services for young Australians with cancer. You can find info and services that will help you deal with your sibling's cancer.

Counselling and emotional support

www.kidshelp.com.au

Kids Helpline is a free phone or online counselling service for people aged 5-25 (not just for cancer-related stuff). Call 1800 55 1800.

www.lifeline.org.au

Lifeline is an organisation that has useful information on counselling, health, accommodation and many other services to help you. Call 13 11 14.

www.youthbeyondblue.com

Youth Beyond Blue supports young people dealing with depression, anxiety and other mental health problems. They provide tips on how to talk about depression and get help.

Dealing with grief, loss and death

www.grief.org.au

The Australian Centre for Grief and Bereavement is an organisation that provides information about grief – and how to get through it. It also has links to other resources and information that offer support when someone is dying.

www.skylight.org.nz

A great website with lots of tips and helpful articles to help young people who are experiencing grief and stress.

www.reachout.com.au

Reach Out is a website to help young people help themselves through hard times. Find stuff out, understand more about mental health and wellbeing, get help and connect with other young people.

www.winstonswish.org.uk

This is a UK website that provides services to bereaved young people and some great tips and living with someone who is seriously ill and talking about death and dying.

Palliative care and help for carers

www.pallcare.org.au

Palliative Care Australia includes information about palliative care services. You can access the palliative care organisations in your state from this site. The state sites have directories of services in your area, plus information for families and carers.

www.youngcarers.net.au

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

www.caresearch.com.au

This website brings together resources and information about palliative care and how to find services in your area. It gives really good suggestions about how to care for someone who is ill, and how to look after yourself as a carer.

www.homehospice.com.au

Home Hospice offers free support for people who are caring for a loved one living with a terminal illness at home. They can send a trained Community Mentor to offer your family guidance, information and support so that your ill sibling can continue to live at home until they die, if possible.



Practical assistance

www.centrelink.com.au

If you need financial assistance, you may be able to receive payments through Centrelink if you are a carer, a student, unemployed, in a remote area or bereaved.

www.afda.org.au

The Australian Funeral Directors Association provides information on what to do when someone dies and a directory to help you find a funeral director.

www.lawstuff.org.au

This site for under 18's can answer any questions you may have about the law.

www.australia.gov.au/life-events/death-and-bereavement

This is Centrelink's bereavement support page. It gives information about payments and services that may be available to your family after your sibling dies. Plus information about who you need to tell and other legal requirements.



HELPFUL phone numbers

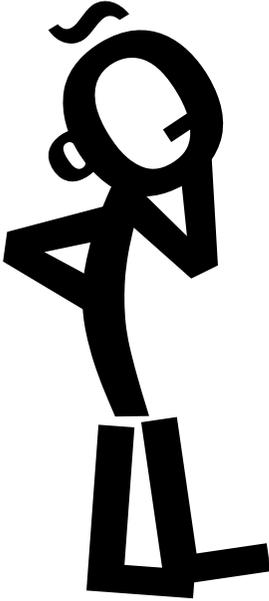
CanTeen
1800 226 833

Kids Help Line
1800 55 1800

Lifeline
13 11 14

Cancer Council Helpline
13 11 20

Young Carers
1800 242 636



REFERENCES

Adams, D. and Deveau, E. (1987), "When a brother or sister is dying of cancer: The vulnerability of the adolescent sibling", *Death Studies*, Vol. 11, pp. 279-295.

Cancer Council Victoria (2008), *When Cancer Won't Go Away: For people whose cancer has advanced* Melbourne: Cancer Council Victoria. Available at www.cancervic.org.au.

Cruse Bereavement Care (2004), *After Someone Dies: A leaflet about death, bereavement and grief for young people*. Available at www.rd4u.org.uk.

The Dougy Center for Grieving Children (2000), *Helping Teens Cope with Death*. Available at www.dougy.org.

Ganz, P. (2003) *Hey! What About Me? A personal journal for teens whose brother or sister has cancer*, SuperSibs! Available at www.supersibs.org.

Livestrong (2010), *Hope*. Available <http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Hope#s>

Macmillan Cancer Support (2010), *Let's Talk About You: A guide for young people caring for someone with cancer*. Available at www.macmillan.org.uk.

McEvoy, O. (2009), *Teenage Mental Health: What helps and what hurts? Report of the outcome of consultations with teenagers on mental health*, Minister for Health and Children, Dublin, Ireland. Available at www.dohc.ie.

National Cancer Institute (2005), *When your Brother or Sister has Cancer: A guide for teens*. USA, National Institute of Health

Palliative Care Australia (2010), *Journeys: Palliative care for children and teenagers*. Available at www.palliativecare.org.au.

Palliative Care Victoria (2007), *About Palliative Care*. Available at www.pallcarevic.asn.au

Pilotlight (2007), *Dying to know: Bringing death to life*. Hardie Grant Books, Victoria.

Skylight (2006), *Supporting children and young people who are living with anticipatory loss and grief – when someone they love is dying*. Available at www.skylight.org.nz.

White, P.G, *Surviving Siblings and the Four Basic Emotions*, The Sibling Connection, www.counselingstlouis.net.

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Now What? When your brother or sister's cancer can't be cured.

Free copies of this book are available by calling CanTeen on 1800 226 833 or by going to www.canteen.org.au

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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.

