GUIDES TO THE FL!PSiDE

canteen

DEALING WITH YOUR SIBLING'S CANCER

ACKNOWLEDGEMENT OF COUNTRY

Canteen acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of this land. We pay respect to Elders past, present and future. We are committed to providing inclusive and appropriate support for Aboriginal and Torres Strait Islander young people, their kin and community. Indigenous Australians are respectfully advised this resource may contain images, names or stories of people who have passed away.

Ngalaya (Dharawal for ally or friend in battle), is an artwork commissioned by Canteen created by Kamilaroi and Jerrinja woman and artist Jasmine Sarin.

ABOUT THIS BOOK

When a family member has cancer, it can affect the whole family. Life may change quickly and in many ways. It's natural to have lots of questions and feelings – you might be thinking, now what?

This book is specifically aimed at young people whose sibling has been diagnosed with cancer, it could be something you want to read on your own or could also be helpful to go through with a family member together. This book intends to help you understand some of what has or may happen and what challenges you and your family could be facing, it could even be useful to read if your sibling has finished their treatment.

The booklet contains cancer specific information, practical tips and suggestions for how Canteen or other support services may be helpful. Getting the right information and support can make a big difference when cancer enters a family's life.

For ease of writing, in the booklet we have used the word 'sibling' when referring to the person who has cancer in your family. It may be that you call your sibling something differently, we hope you can think of and use the information below in a way that works for you and your family.

When cancers in your life, Canteen is in your corner. Visit our website **canteen.org.au** for more information how Canteen might be able to help.

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GETTING SUPPORT

GETTING SUPPORT

Getting the right sort of information and support when your family member has cancer is very important. Your sibling's cancer experience may last for a long time and the kind of information and support you need may change overtime.

We hope you have people in your life that are in your corner, that you trust, and that will try to be there for you as best they can. These people may come from all different places:

- Parents
- Other siblings
- Your partner
- Other relatives
- Friends
- Psychologists, counsellors
- Social workers
- Teachers
- GP
- Spiritual, religious and community leaders
- Support groups
- Online support

Support services

Through your sibling's treatment you may hear about different places, like Canteen, that work with and support young people facing a cancer experience.

They may also tell you about other services that are more specific to the type of cancer your sibling has or related to their age (Canteen only works with young people above the age of 12).

Different support services offer different things, for what you and your family are needing help with there is likely a service that can help. A challenge can be knowing where to look.

Cancer Hub – an initiative by Canteen, Camp Quality and RedKite – is a one-stop shop to help you access all the different practical and emotional support you and your family may need. Visit **cancerhub.org.au** or call 1800 945 215.

Online support

There are online communities for young people impacted by cancer, such as Canteen Connect (**canteenconnect.org**). You can chat with others who get what you're going through, attend events from the comfort of your couch and online counsellors are available six days a week.

Canteen Connect is set up in a way that allows for young people to easily engage in support and to make it much less of a big deal to get support. For example, we only need limited personal information to have you jump in to start chatting to a Canteen team member.

How Canteen can support you

Getting the right information, advice and support can really help. Canteen is in your corner. We can put you in touch with a team member who will support your time at Canteen including offering individual counselling support if you would like this and connecting you with other young people through our programs and events who will have their own cancer experience.

Find out more at **canteen.org.au/young-people/sibling-cancer**.

HEART STUFF

FINDING OUT

You may have found it hard to focus or concentrate since you found out your sibling has cancer; this could be because you are having more thoughts related to worry about your family or other things are more on your plate that weren't there as much previously; your parents may be busier focusing on your sibling. Here are a few things that might be helpful to know to reduce some of the initial stress or worry:

People do survive cancer

Some people will have medical treatment for their cancer and can get better relatively quickly. When we write about treatment, we mean things that you may have already heard about, like Chemotherapy ("Chemo") or Radiotherapy ("Radiation"). Treatment can be very tough with the side-effects that people experience (low energy, possible hair loss).

There are other people with cancer who will need to have treatment for a longer time. Although the plan is for them to have longer treatment, there should still be periods where things feel more ok where the side effects may not be such a problem despite the treatment continuing.

Many factors will affect the outcome of your siblings' cancer (you may have heard the word "prognosis" being used to explain this), including the type or stage of cancer and whether the cancer has spread in their body ("metastasis").

There are new and better ways of diagnosing and treating cancer being discovered all the time, it may be reassuring to remind yourself when you're feeling uncertain or afraid that people can get better and do survive cancer.

Shared experience with others

While no-one will feel the same way as you and each cancer experience is different, it could be helpful to know that cancer is a common experience in families. For example, around 22,000 young people each year find out a family member has cancer.

Peer connection and knowing that other people share a similar experience as you can be a powerful thing, it can also be that other people who have been through a similar thing can share their ideas about what was helpful to get them through.

Canteen has a long history of promoting the importance of peer connection and support, one of the main things we offer young people is getting to know and share experience with other young people. Canteen has an online community where you can chat with other young people who get what you're going through. To join the Canteen Connect community, visit **canteenconnect.org**.

If you choose to become a client of Canteen we have day events and overnight programs that you can join with other young people to have a shared experience and develop connection around your experience with cancer - We have found with other young people that this can be an empowering and helpful experience for them, some young people have stayed with Canteen for many years.

You haven't caused your family member's cancer

Lots of things cause cancer, many of which doctors and researchers don't yet fully understand. But we do know that your sibling having cancer has nothing to do with anything you said, thought, or did. You may wonder or feel that it is your fault; something as big as cancer can bring up lots of tricky thoughts or feelings for people. When these types of thoughts or feelings come up it could be helpful to gently remind yourself that it is not scientifically possible that you caused the cancer for your sibling.

(Correct) knowledge is power

Learning more about the type of cancer your sibling has and its treatments from a trustworthy source can take some of the fear out of it and offer comfort.

If you're wondering about anything at all, try asking with your family, it could also be that your sibling's medical team may be able to answer questions. See **page 52** for a list of suggested questions.

Trying to find knowledge and information from known or trusted sources is important, your family may have been given information that you are unaware of so it could be worth asking them.

Cancer Council has a lot of up-to-date information about cancer types and treatments - **cancer.org.au/cancer-information**

Processing your feelings

Having feelings is ok. Knowing that a family member has cancer can be one of the hardest things you'll ever have to deal with. Every family member will react to the diagnosis in their own way. Your thoughts and feelings may be overwhelming, but we do know that these things do come and go for people like waves at the beach. Feelings and thoughts rarely stay the same for long periods.

It's okay to feel what you are feeling. You may feel scared or sad. It can be that when feelings are hard to get out, or it's hard to find the words to explain how you're feeling, that trying to speak to somebody who you think may help can be super important rather than keeping it all inside. This may be your parent or other family member; it could be a friend or other trusted person in your life. Your sibling could also be the main person you feel most comfort going to.

You can get support

Health professionals like social workers or psychologists are trained to listen and can help by talking and linking you with support if this is needed. If your sibling is in hospital or a medical team is coming to your home, most major hospitals and medical teams should have support people available to you, just ask whoever the family's main contact person is for the treatment (often this is a nurse).

Canteen provides a free and confidential counselling service (check out **canteen.org.au/counselling**). You can also ask your family doctor/ GP to recommend a counsellor or psychologist near you, there may also be low-cost youth specific counselling or support services in your area, these will come up on an online search.

A GP can also write you something called a Mental Health Treatment Plan to see a counsellor or psychologist that can make sessions more affordable under Medicare. Speak to your GP or look at the Medicare website for further information.

WHAT IS CANCER ANYWAY?

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 process helps to keep the body healthy, replace worn-out cells and heal after an injury. However, sometimes this process doesn't go according to plan and some cells grow abnormally and form a mass of tissue called a growth or a tumour.

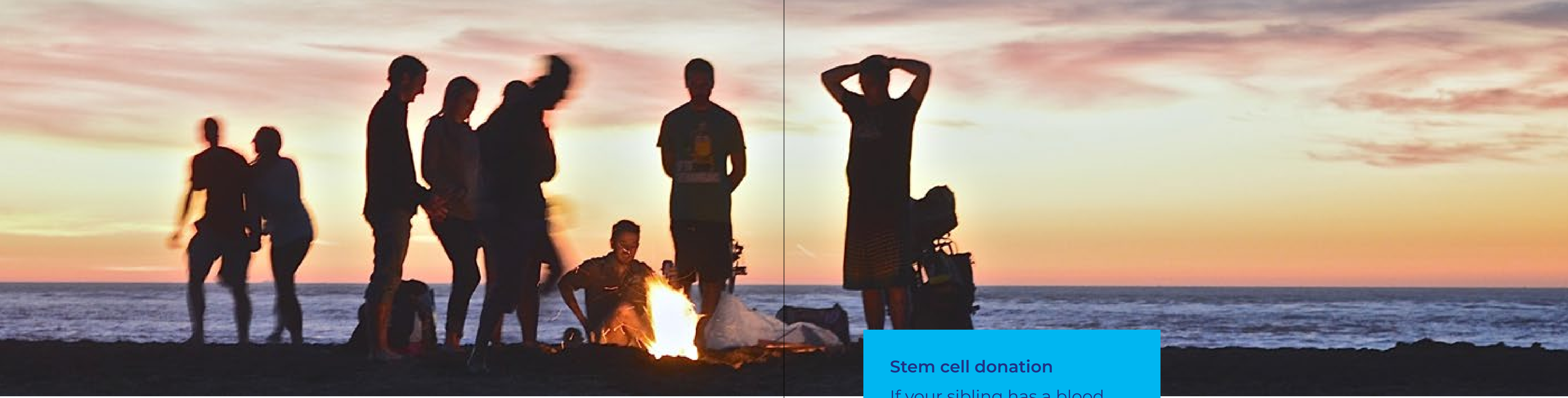
Tumours can be benign (not cancerous) or malignant (cancerous). Benign tumours can often be removed and don't spread to other parts of the body. Malignant tumours can also often be removed, but they can also invade and damage nearby tissues and spread to other organs in the body. The spread of cancer from one part of the body to another is called metastasis.

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

There are more than 200 different types of cancer. Some are more common in young people than adults.

Cancer Council (**cancer.org.au**) has detailed information about the causes, diagnosis and treatment of specific cancers.

> **"At the start I really wish I knew that cancer can change your life."**
>
> **Canteen young person**



Common questions

Why do people get cancer?

Cancer is quite common – about one in three people in Australia will be diagnosed with cancer. But getting cancer when you're young is rare. Each year in Australia about 1,100 young people aged 12 to 25 are diagnosed with cancer.

The causes of most cancers are unknown. You can't catch it from another person and you can't give it to anyone else. And cancer is nobody's fault.

Will I get it as well?

No. You can't catch cancer from your sibling. If you want to hug and kiss them, you still can. Most cancers don't run in families but if you are concerned talk to your parents and the doctors or check out one of the websites in the 'More information and support' chapter on **page 93**.

How long does treatment take?

There are lots of different treatments for cancer including surgery, chemotherapy (chemo) and radiation therapy. Treatment can last a few weeks, months or even years. Some treatments involve a number of phases – the first phase may last for a few months and the next phase may last for a few years.

Some people may have more side effects than others. This may depend on the type of cancer and the type of treatment.

Can they cure it

Most young people survive cancer. If cancer cells reduce or disappear after treatment, this is called remission. Remission may last for a few years. The likely outcome of a cancer diagnosis is called prognosis, which is different for every person. The doctor can explain more about the prognosis.

Stem cell donation

If your sibling has a blood cancer such as leukaemia, lymphoma or myeloma, they may be treated with a stem cell transplant. (You can skip this section if they don't have one of these).

What are stem cells?

Stem cells are blood cells at their earliest stage of development. They are made in the bone marrow, which is found in the centre of bones. Stem cells develop into red blood cells (to carry oxygen), white blood cells (to fight infections) and platelets (to prevent bleeding).

Stem cells can be collected from the bloodstream (called peripheral blood stem cell transplant or PBSCT) or bone marrow (called bone marrow transplant or BMT).

Why are they needed?

High doses of chemo and/or radiation therapy destroy both cancer cells and healthy cells. A stem cell transplant replaces your bone marrow with healthy cells.

Who can become a donor?

There are two main types of stem cell transplants:

- Autologous – when the person uses their own stem cells
- Allogenic – when the stem cells are collected from another person (a donor).

As a sibling, you have a 1 in 4 chance of being a good donor match. This is because your stem cells are the closest genetic match, but there's no guarantee you'll be a match.

How do you donate your stem cells or bone marrow?

A PBSCT is similar to having 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 4 hours. The cells are stored until they are given to your sibling through a transfusion, after they have finished their high-dose treatment. This procedure is not painful (except maybe when they insert the needle into the vein).

A BMT is done under a general anaesthetic, which makes you go to sleep. 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.

How do I become a donor?

If you're considering becoming a stem cell donor, you'll probably have lots of questions.

For many siblings, becoming a donor is a way of helping their sibling. To find out if you can be a donor, you'll have a blood test to check if your stem cells are a good match.

If you find out that you are not a match, you may feel disappointed that you can't help your sibling. You can still help others by registering to donate your stem cells to the Australian Bone Marrow Donor Registry.

There are young people who decide not to be a donor even if they are a match. You may find saying no difficult and feel pressure from your parents to donate. This could be a hard time for you and it's a good idea to find support. Check out 'Getting support' on **page 9**.

What happens if treatment doesn't work?

Cancer can sometimes come back after treatment ends. This is called a recurrence or relapse, and happens when some cancer cells were left behind after treatment or new cancer cells develop. A relapse will mean that your sibling will need to have more treatment.

Sadly, sometimes cancer cannot be cured. This may depend on many factors, including the type of cancer, where it is and how advanced it is when diagnosed.

TALKING ABOUT CANCER

Cancer can be hard for anyone to talk about. Your sibling and other family members might find it difficult to know how to talk about the cancer diagnosis or treatment, they might be worried about upsetting themselves or other family members.

How your family talks about cancer can depend on how they have communicated or related to each other before cancer entered the family's life. Cancer is unlikely to suddenly change this, but we do know that trying to find out new ways of talking together within families can be helpful when tough problems like cancer enter a family.

If you are a young person who hasn't previously wanted to ask a lot of questions about your sibling or how they are doing, it may be that your family is assuming this hasn't changed for you despite the cancer. Asking questions can be tough, but it could be a signal to your family that you are wanting to know more about what is happening. If this is something you find tough, we hope that it becomes something you can start at least trying out.

These talking tips may be helpful for you and your family:

Tips for talking about cancer

- Think about what you want to ask and what you want to say before you start. You could even write it down and then read it out.
- It may feel hard and uncomfortable at first and there may be some awkwardness. It could be helpful to try to sit with this and remind yourself in the moment that it's normal.

- Send a text message or email letting them know that you'd like to talk, there may be a best time for this to happen.
- If it's getting too hard to talk, it could be helpful to not feel that you must bring up everything in the one conversation. It is normal that you and your family members could cry or show other emotional responses in the conversation, you may need to take breaks.
- Checking in with each other at points in the conversation can be helpful to see if the person is happy to continue talking, the other family member can also hopefully help guide this.
- Do something at the same time as talking, e.g. going for a walk together or doing something that you like doing together, like watching TV. This can sometimes take some of the pressure out of stressful conversations.
- It could be hard to do in the moment but try not to worry too much about saying the wrong thing. It can take time to work out the best way to talk to each other

> **"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**

But what if talking is too hard?

Sometimes talking is too hard. Maybe it's not the right time or you don't know what to say. If you still want your family to know how you're feeling, you can:

- send a text message, email, or letter
- share songs that say it for you
- find quotes or cards that say what you might be feeling
- draw pictures, write, or play music
- keep a journal; it can be private, or you can share it with your family.

If you or your family can't talk about cancer, it may help to speak to a support service or person like a Canteen team member or family counsellor. They could help by giving you ideas on how to communicate with each other, this could particularly be helpful where there has been a lot of difficulty before now in your family relationships.

Contact Canteen (**canteen.org.au/counselling**) for information about our counselling services, which includes parent support that can help parents' problem solve how to talk to their children about cancer. If the communication problem feels too large, it could be that searching for a family-specific psychologist or therapist in your local area could be important for your family to start getting more specialist help.

LET'S TALK ABOUT FEELINGS

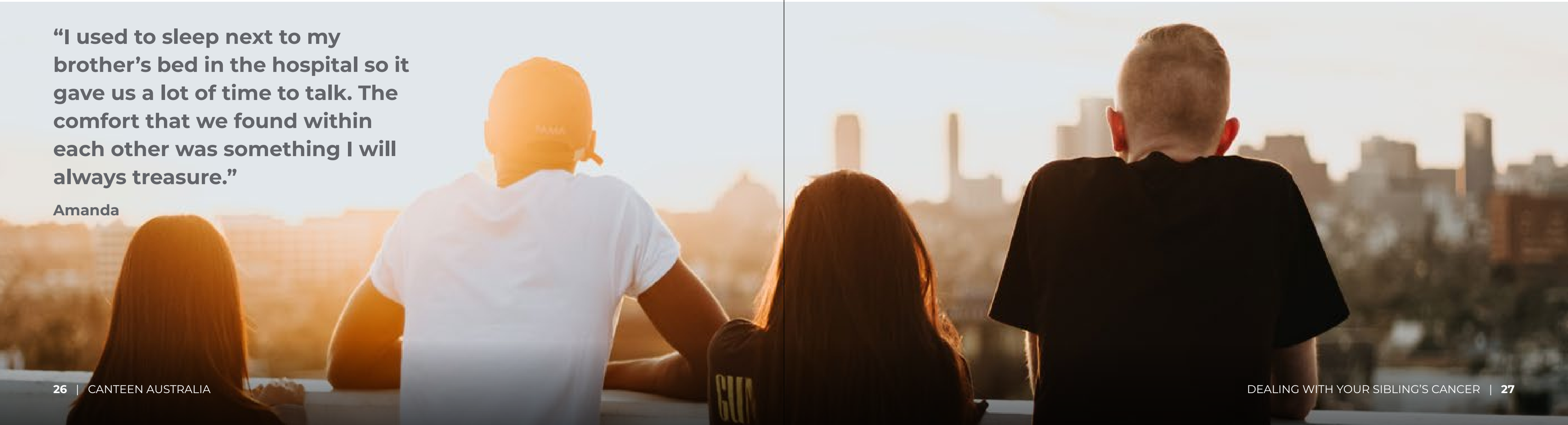
Cancer in the family is tough for everyone and relationships may change. Every family will react differently to a cancer diagnosis. Living with a sibling who has cancer can affect your life in many ways such as changes to your routines and roles.

How the changes affect you and how you deal with them may depend on your age, whether you have moved out of home and other responsibilities you're juggling (like school, study or work).

Your relationship with your parents

Your parents will be obviously concerned about your sibling and the impact of cancer on the family. Parents generally want their kids to be happy and healthy, and to protect them from harm. Your sibling's diagnosis may make them feel helpless as they have no control over it and cancer is not something they can make go away.

If you're used to spending lots of time with your parents, you may find this has changed or is changing in the family. Things may feel more lonely at home. It may feel like your parents are too busy or distracted to spend as much time as you used to together. You might be tempted to keep your feelings and worries about these changes to yourself because you don't want to upset your family. Talking to your parents may help, they they may not realise how you feel and may be able to make some adjustments. Even them just knowing this is your experience may make things feel not so lonely.



> **"I used to sleep next to my brother's 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**

Other family members

When your sibling is diagnosed with cancer, it's natural for grandparents, aunts and uncles and cousins to also be worried. They may be in constant contact asking for updates or how they can help.

Sometimes other family members take on some of the jobs that your parents used to do such as driving you to school or cooking meals. You may be okay with this or find it difficult having other people being around more.

It could be they are only wanting to talk about your sibling and the cancer, this might be hard to keep hearing about. Gently offering to people you are not feeling up to talking about your sibling or the cancer is ok.

Your relationship with your sibling

Sibling relationships can have their ups and downs. Some siblings are close, others don't really get along. And some are in-between.

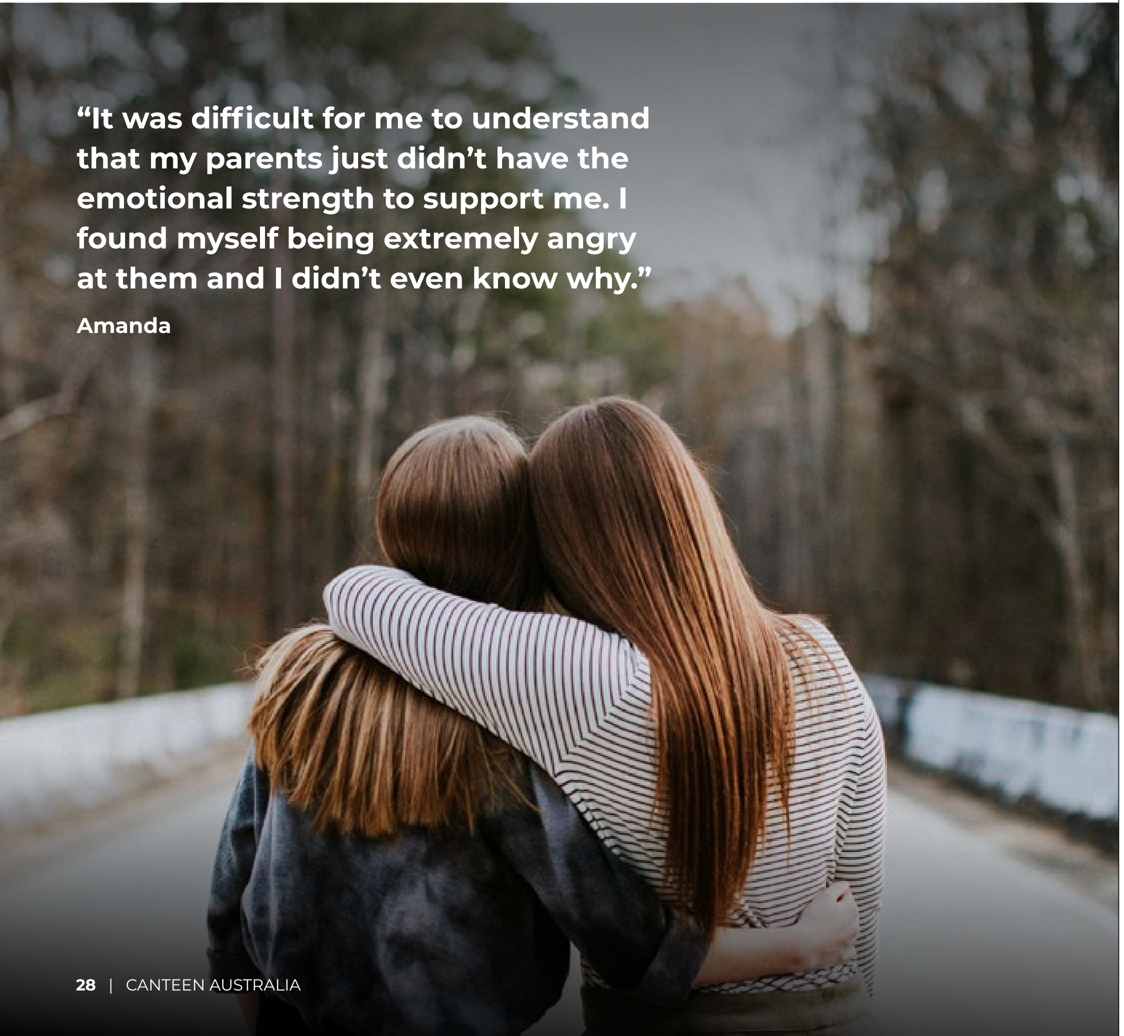
The diagnosis may mean your relationship with your sibling changes – you may find that the experience actually brings you closer together. But don't expect miracles, you're probably still going to argue about some things – and this is okay.

The age of your sibling who has cancer may impact on how you deal with it. If they are younger than you, you may become more protective of them, but if they are older, you may feel excluded from what's happening.

Your sibling may need to be in hospital for a while and this may impact your relationship. You might feel like you can't talk about what's happen in your life and other just normal day-to-day stuff. You might be surprised at how much you miss them not being around, even if you fought and annoyed each other before now.

If you have other siblings, they may be coping with the diagnosis differently to you. If you're the eldest, you may be asked to take on extra responsibilities – you might be okay with this or may find it tough. It can be okay to set some boundaries for what you're prepared to do. If it ever feels like it's getting too much, you would hope your parents are open to listening to this.

See 'How other family members may feel' and 'How can I help?' on **page 33**.



"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

"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

Friends and/or partner

Your friends and/or partner are an important part of your life – you could be spending as much time with them (or more) as you do with your family. When you're going through a difficult situation, you may find you want to lean into your friendships or withdraw from them.

Some may provide great support, others may find it difficult to know how to respond. You might feel like your friends or partner don't understand what you're going through.

Some things to keep in mind include:

They don't know what to say – Your friends or partner may be scared of saying the wrong thing, asking silly questions, or be talking about something trivial. Or not talking about the cancer. If you want to talk, you may have to start the conversation or let them know that it's okay to ask about your sibling's diagnosis. Canteen has a range of resources that can help – check out **canteen.org.au/friends**.

They won't say things to deliberately upset you – If friends or your partner say stuff that feels blunt or not understanding what you're going through with your sibling, it's okay to let them know how you feel. It may help to use 'I statements'. For example, 'I feel upset when…' instead of 'You make me upset when…', this can help to make things sound less blaming of the other person.

They may ask what seem to be tough or silly questions – Be prepared for questions that may seem strange – remember all the things that you didn't know before the diagnosis. Your friends or partner may be curious about what your sibling is going through, but sometimes you may not want to answer questions. It's okay to let them know that you don't feel like talking right now or there are some things you're not ready to talk about.

They have their own lives – Your friends or partner may talk about what's happening at school, uni or TAFE or work and this may make you feel left out. It might feel like they're ignoring what you're going through, it could be helpful to gently remind yourself that other peoples' lives are continuing and that's okay.

How you may feel

Finding out your sibling has cancer is likely to bring up a lot of different feelings for you. Some you may have expected, and others may come as a surprise. It may not always be easy to explain how you feel.

The main thing to remember is that there is no right or wrong way to feel.

Many young people describe the experience as an 'emotional rollercoaster' – you're going through huge ups and downs and feeling like you have little control over things.

Common emotions other young people who've found out their family member has cancer include:

- feeling scared
- angry
- sad
- guilty
- jealous of others
- or lonely

All these emotions are natural, and it's common to feel differently from one moment to the next. If you think you're 'stuck' in one, you could try talking to a Canteen clinician, by phone or face to face. **canteen.org.au/counselling**

Particularly when you first hear that your sibling has cancer, it is important to know that you could experience something called shock. Shock is a response in the body when a sudden illness or injury has been experienced, it can also be a mind-thing that happens when sudden or unexpected news is heard, and your brain and body becomes really overwhelmed.

Shock can include things like feeling shut off from reality or the world around you, it may lead to your heart racing fast, short breathing, or dizziness.

If this is something you had experienced when you first head about your sibling's diagnosis, it could be helpful to know that just because it's happened once doesn't mean it will happen again, it is just that your body got really overwhelmed when hearing the news.

If it happens again or returns, it could be something more anxiety related, and it could be helpful to start getting help with this through a mental health counsellor or psychologist through your GP. It could be something that a team member clinician at Canteen could also help with.

> **"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**

If you're finding things hard, you're not alone. Do any of these thoughts seem familiar?

This can't be happening.

Will they be okay?

I don't understand their diagnosis.

I wish I could make it all better.

I feel guilty when I have fun.

I'm worried I'll get cancer.

Nobody understands what I'm going through.

I feel angry all the time.

How other family members may feel

It's common for people to describe the days and weeks after the diagnosis as a whirlwind. Your parents will obviously be pretty worried about what the diagnosis means for your sibling, as parents they are already likely to be juggling a lot in looking after the family. If they are spending lots of time at the hospital and attending lots of medical appointments, they may feel guilty about this and worry about how to look after everything.

You and other family members, including the sibling with cancer, may have similar emotions to you about the diagnosis, they may try to not show how they're feeling to avoid upsetting you. They could seem more tired than usual, or seem more moody or withdrawn.

How can I help?

You probably want to support your sibling but don't know how. Tell your sibling that you want to help and ask them what they need.

These suggestions are a good place to start.

- **Be flexible** – Expect that family routines and schedules may change. Try to be understanding and patient but if you find it's getting too much, take a walk, listen to music or just find some space for yourself.
- **Spend time together** – Being stuck at home or in hospital can be boring if this is something your sibling has to do. Just hanging out with your sibling can give them something to look forward to. You could watch a film, TV or play a video game together.
- **Talk about normal things** – It's okay to talk about everyday things and laugh together. Let them know what's going on at school, uni or work, or with your friends. These conversations can be a good distraction from thinking about cancer.

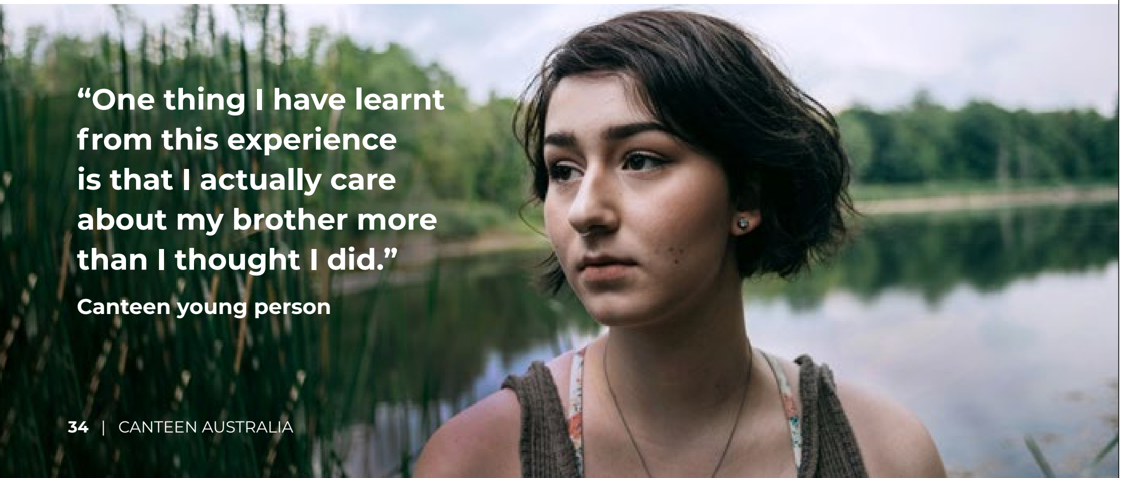
> **"There were times when doctors would ask me to leave the room to discuss things with my family. This just made me feel excluded within the family."**
>
> **Amanda**

- **Help care for them** – Being involved in looking after your sibling might be important to you. Let your parent 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, reading them a story or, if they are much younger, maybe feeding and bathing them.
- **Help out at home** – Depending on how old you are, you may be able to do more around the house. This may include looking after younger siblings, walking the dog, cooking meals, doing the washing. See **page 48** for tips on cooking.
- **Help them stay connected with friends** – Spending weeks in hospital and stuck at home may mean your sibling loses touch with friends. Maybe you could play a role in helping your sibling's friends know that it's okay to visit, your sibling may appreciate you reaching out to them.
- **Keep your distance if you're sick** – When someone is being treated for cancer they can get infections more easily. That's because treatment can reduce the number of white blood cells that fight infections, making it easier to catch colds, the flu or chicken pox.

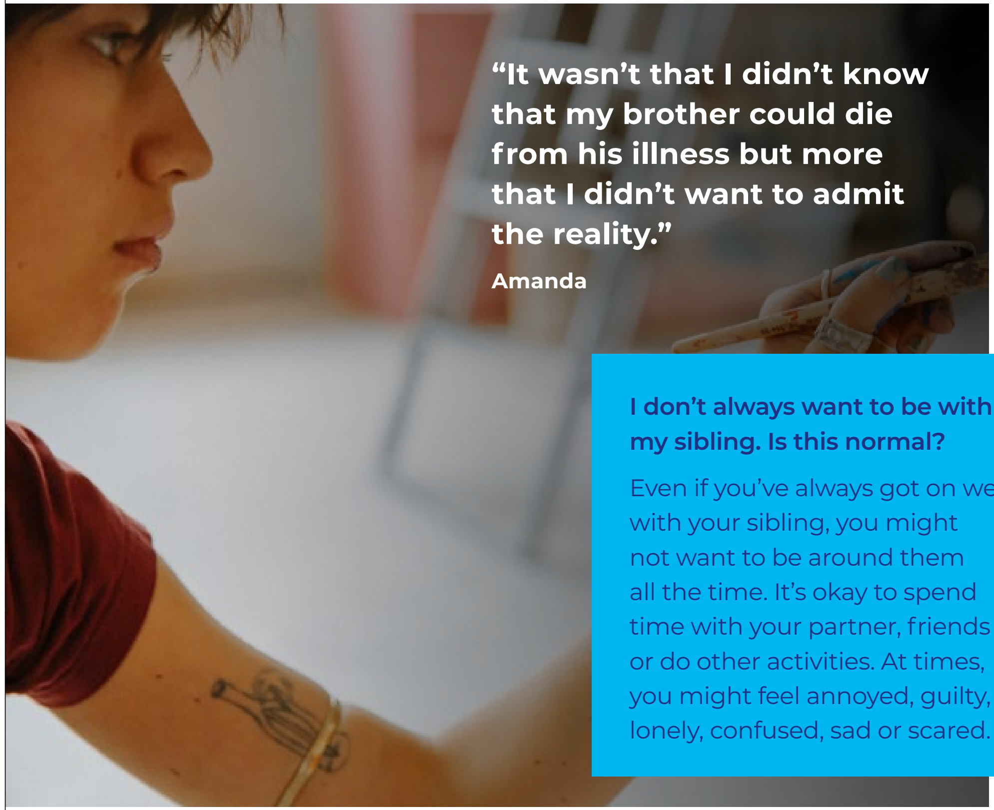
An infection could make them sicker, so they may need to stay away from crowded places or people who have an illness they could catch. You can help by:

- washing your hands with soap and water 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 sibling if you get sick
- checking with the doctors or nurses if you are worried about infections that may harm your sibling.

Having to be careful about germs and infections can get stressful. It may mean limiting the activities you can do. It's okay to feel angry about this.



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



> **"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 don't always want to be with my sibling. Is this normal?

Even if you've always got on well with your sibling, you might not want to be around them all the time. It's okay to spend time with your partner, friends or do other activities. At times, you might feel annoyed, guilty, lonely, confused, sad or scared.

When your sibling is having treatment

Having treatment for cancer usually means going to hospital. This may be for surgery, chemotherapy (chemo) or radiation therapy (radiation). Some people may also have a stem cell transplant – see **page 21**.

Hospitals can be busy and noisy places, which can feel overwhelming. Knowing what to expect can help make visiting the hospital less stressful. Your sibling may be treated in a children's hospital or, if they are over 16, in an adult hospital. These are very different places.

Treatment for cancer can be a long process. Some people are in and out of hospital for months, or even years. This may mean that you also spend a lot of time at the hospital.

If your sibling is in a children's hospital, you will see lots of other sick kids. You might find this scary especially if they look worse than your sibling – you may worry that this is what could happen to them. Try not to compare them to your sibling. Everyone is different.

If your sibling is in an adult hospital, then they could be in a ward with older people. You may feel awkward visiting them in the adult ward.

Before the visit

Ask your family or the medical team what to expect:

- What machines, tubes, drips or other equipment will they be connected to (e.g. a bag or urine hanging on the side of the bed)?
- Am I allowed to touch them?
- Will the treatment change how they may look (e.g. drowsy from the medicines)?

During the visit

If visiting the hospital feels boring or stressful, these tips may help:

- study – this will give you something to focus on other than all the medical stuff
- help your sibling with their homework or study
- watch a movie on a laptop or iPad
- play a video game, cards or a board game
- listen to some music or read a book or graphic novel
- bring in their favourite snack or get takeaway delivered (just check that they are not feeling sick because this could turn them off their favourite food.)
- get involved in the activities your sibling is doing in hospital (e.g. music therapy, etc).

When visiting is too hard

You may not want to visit because you're juggling sports training, music lessons, study or work. Hospital visiting hours may make it hard to fit it all in. Try not to worry if you can't visit all the time.

> **"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**

Sometimes visiting the hospital can feel difficult. This is okay. You can stay in touch with your sibling in other ways – try texting or using video calling. If you continue to feel like you can't visit, it may help to talk to someone about what you're feeling and why you're not visiting.

Changes at home

Chances are that family life has changed now that your sibling has cancer.

Routines – Frequent visits to the hospital for tests and treatment can affect your family's normal routines. It's natural if you find these changes challenging to take up. Your parent might try to keep your routine as normal as possible, but sometimes this might not be possible. They may need to ask family or friends to drop you off or pick up you from activities.

More responsibilities – Your parent may ask you to help out more at home, which may include looking after siblings, cooking, housework, looking after pets.

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

Travelling for treatment

The major hospitals for cancer treatment are usually in large cities. This means your sibling may need to travel for treatment and be away from home for a while. One parent may travel with your sibling and the other parent may stay home to care for you and your siblings, or to work. Travelling for treatment may be more complicated if you're a one-parent family. Your sibling may feel lonely being away from home, and miss hanging out with you..

Roles – Because one or both of your parents could be spending more time with your sibling or at hospital, who does what at home may change (or it may not!).

Others helping more – Some families rely on support from family and friends to help them care for you while they are at the hospital. They might do practical things like housework, cooking or taking you to activities. Or if you're younger you may need to stay with relatives or friends while your parent is at the hospital.

Possible ways to look after yourself

We all have things we do to look after ourselves and try to deal with difficult situations when they come up for us. This may be things you're aware that you're doing, or even unaware. These things we do can also be called other things like "Coping Strategies", "Relaxation Strategies", "Self-Care" or "Emotion Regulation Strategies".

When your sibling is diagnosed with cancer it could help to have a clear idea about what makes up your "Toolkit" for looking after yourself and facing tough times.

Some people are aware of what their toolkit is, other people may not be. At the least it could be helpful to be thinking about what these things are, sometimes writing up a list can be helpful, an idea might be to stick it up on your bedroom wall.

"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

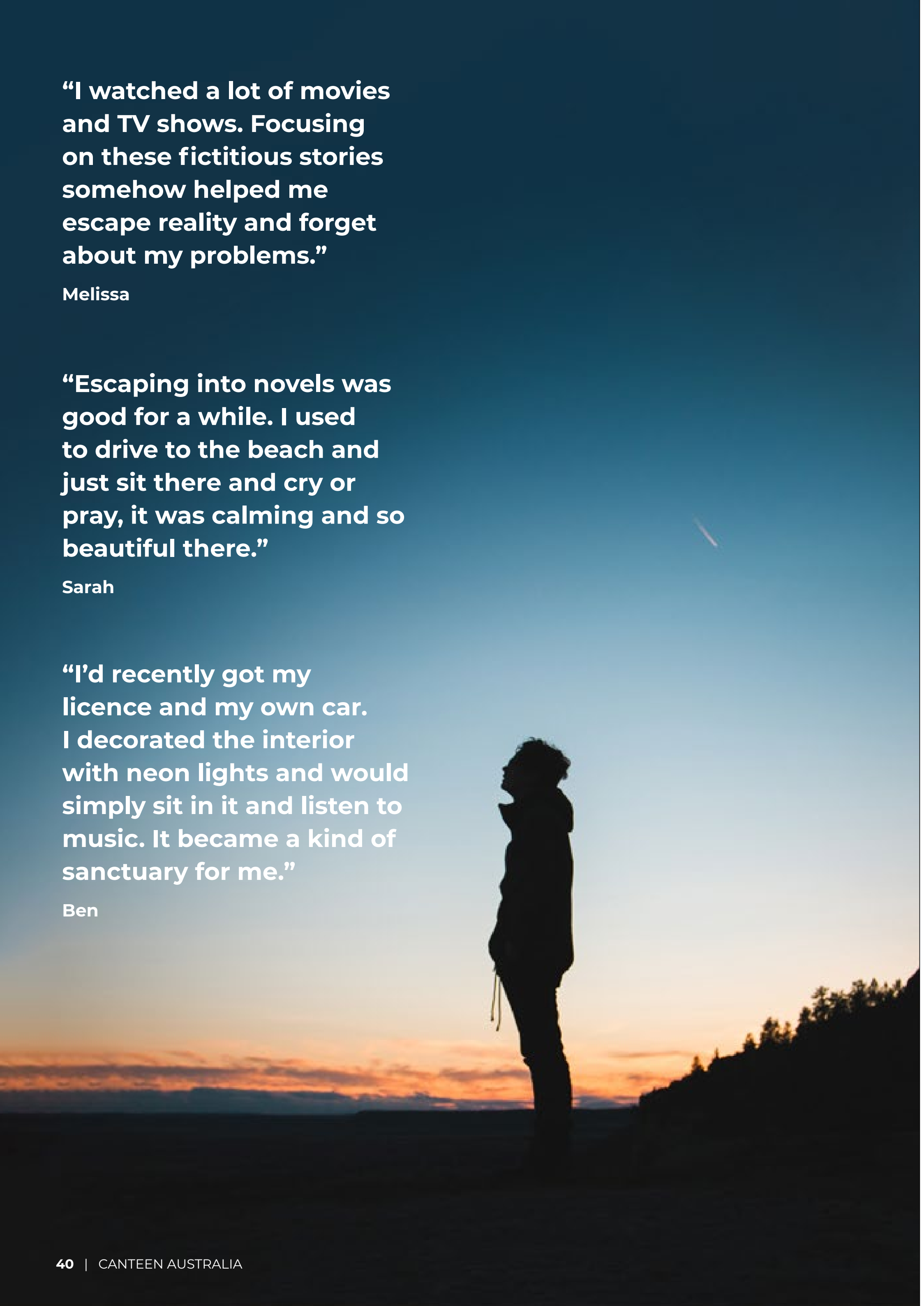
If it's possible, try to do things together as a family. It can be watching a show together or going on a picnic.

"Cry if you want to. Don't worry about what people think, they'll deal."

Erin

If you're unsure of ideas, or want some more, here are a few things you could try:

- **Talk to someone** – Talking can help clear your head and reduce worries, it can be a great way to think through problems out loud with somebody else.
- **Exercise AND rest** – Exercise and activity is proven to reduce stress, it releases a chemical in your body called endorphins that are proven to improve people's moods, it doesn't matter what the exercise is – It could be a walk or even a mountain climb! On the other hand, rest and sleep are both also super important to keep things on track with your body and how you're feeling.
- **Get creative** – Things like writing, drawing, painting, photography, scrapbooking, collaging are all great ways to let out how you're feeling, it can make our minds less cluttered when they feel jumbled or too fast, it can slow things down.
- **Keep doing things you enjoy** – Doing things you enjoy may help keep things feeling as normal as possible.
- **Try something new** – What could this be?



> **“I watched a lot of movies and TV shows. Focusing on these fictitious stories somehow helped me escape reality and forget about my problems.”**
>
> **Melissa**

> **“Escaping into novels was good for a while. I used to drive to the beach and just sit there and cry or pray, it was calming and so beautiful there.”**
>
> **Sarah**

> **“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**

- **Join an online community** – You might want to check out Canteen Connect (**canteenconnect.org**), it could help to chat with other young people going through something similar to you.
- **Try mindfulness** – This is all about being in the moment and can help you manage stress. There are several apps that can help you get started with mindfulness, including headspace (**headspace.com**) and Smiling Mind (**smilingmind.com.au**).
- **Sensory toys or tools** – Play with a pet or squeeze a stress ball, there is a lot of science behind sensory play and tools are effective in calming our bodies. It could help to develop your own sensory toolkit, to make your own toolkit you could base ideas on each of the 5 senses: touch, smell, hear, see, and taste – you may also be somebody who prefers one sense over another.
- **Plan!** – Use a weekly planner and a to-do list to keep track of tasks, especially if you have taken on extra roles in the family. Being more organised could help you feel more grounded and more in control.

Managing other people’s expectations

You might think (or people might be telling you) that you should ‘be positive’. It can help to be optimistic, but you don’t have to feel happy and hopeful all the time. The pressure to be positive might make it hard to talk about what scares you.

Reminder that it’s okay to:

- still get angry and not be the perfect sibling
- not feel brave and think that the whole experience will be worthwhile
- not feel positive all the time.

TAKING CARE OF YOURSELF

Stress and worry can show up in a few ways, this may include sleeping troubles, changes in eating patterns, headaches, trouble concentrating, or withdrawing from family and friends.

When things seem to be too much

Feeling sad, down or upset is completely natural when your family is dealing with cancer. If these feelings stick around and you're feeling this way most of the day, or for a length of time that doesn't feel right, like over 2 weeks, then this could mean that you might have developed or are developing a more specific mental health problem, like depression.

It can be confusing to work out what a normal response to cancer and when it becomes more of a mental health problem, checking in with an adult, GP or even your Canteen worker could be a good place to try to start work out what's what.

Depression

When you're going through something big like cancer, it can be important to look out for some of the warning signs of depression and check in with yourself regularly. Common symptoms include:

Mood

- feeling sad or grumpy nearly every day
- feeling guilty and blaming yourself for things that you might not usually
- feeling hopeless and helpless
- unable to feel good or not enjoying things you used to like
- trouble concentrating, remembering things, and making decisions
- believing that you can't cope and that things are out of control

Behaviour

- not interested in activities that you used to like
- crying a lot
- not wanting to spend time with friends and family

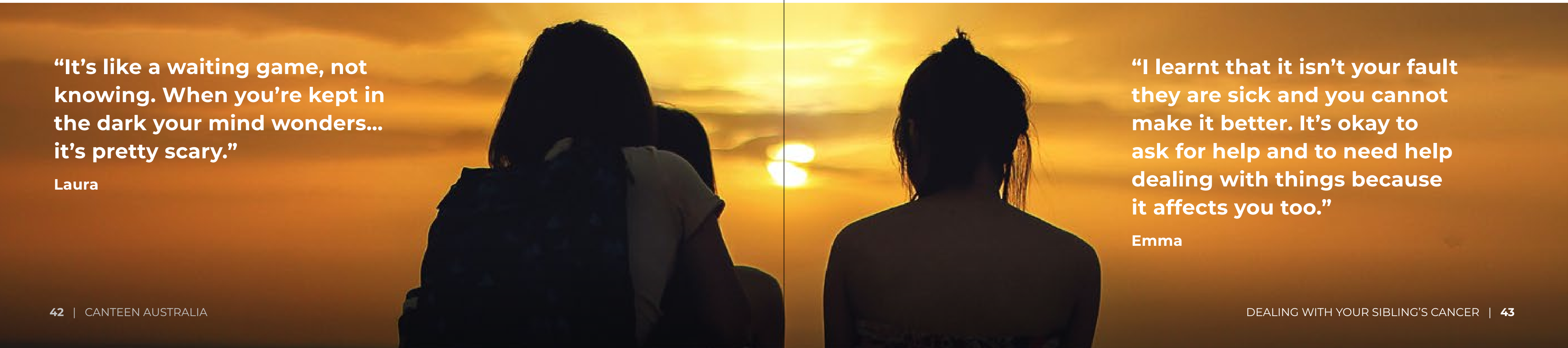
Physical

- not feeling hungry or eating too much
- sudden changes in weight
- change in sleep habits, e.g. waking up during the night or sleeping more than normal
- feeling physically sick, e.g. stomach aches, nausea, or headaches

If you are experiencing depression, it probably won't go away on its own, but getting the right support for it can help and it is very treatable.

A good first step is to talk to your parent and doctor. They could help you arrange to talk to a psychologist, counsellor, or social worker if this is needed. **Canteen's online Community, Canteen Connect**, is available 24/7 for you to get support from other young people who are going through similar situations to you. If you're a client of Canteen your key worker may also be able to support you with counselling, which may be enough to help.

If you have thoughts of suicide or hurting yourself in other ways, call **Kid's Helpline** on **1800 55 1800**, **Lifeline** on **13 11 14** or the **Suicide Call Back Service** on **1300 659 467**. If it is more urgent, you can call **000**, go to your nearest hospital emergency department, or find the nearest mental health crisis service in your area by searching online. For other phone numbers and websites check the 'More information and support' chapter on **page 93**.



> **"It's like a waiting game, not knowing. When you're kept in the dark your mind wonders... it's pretty scary."**
>
> **Laura**

> **"I learnt that it isn't your fault they are sick and you cannot make it better. It's okay to ask for help and to need help dealing with things because it affects you too."**
>
> **Emma**

Self-harm or non-suicidal self-injury

This is when people can hurt themselves on purpose to try to deal with strong physical or emotional pain and distress, it can happen by the person cutting their skin and could also be things like drinking alcohol too much.

If self-harm is something that is happening for you, it can be hard to know how to get help. People can feel lots of different and challenging things about themselves when it's happening, it can be important to get the right help and to not feel judged or blamed.

Online there are several very good resources and websites that suggest ways to help if self-harm is happening for you, e.g., Beyond Blue or headspace, it may also be best to reach out to a family member and your family GP as a good first place to start.

beyondblue.org.au/mental-health/suicide-prevention/feeling-suicidal/self-harm-and-self-injury

headspace.org.au/explore-topics/for-young-people/self-harm/

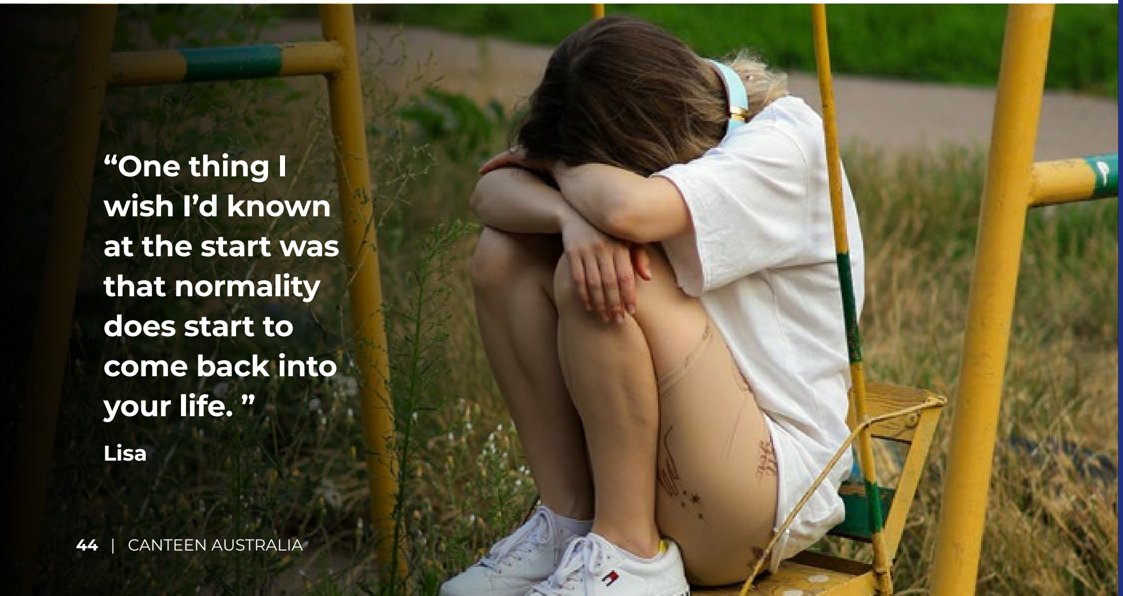
Bullying

Having a sibling with cancer can sometimes make you or them a target for teasing or bullying.

Changes in how they look such as losing hair, changes in weight, losing a body part, using a wheelchair can make your sibling stand out.

Some people also think you can catch cancer – and they think this is a good reason to give you or your sibling a hard time.

You don't have to put up with bullying and it's important to let a teacher or your parents know what is happening. You have enough going on without having to deal with bullies.



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

PRACTICAL STUFF

PRACTICAL STUFF

When your sibling has cancer, you may have to deal with tasks or practical things in the family more so than you did before.

Study and work

School, study, or work don't stop because your family member has cancer, and keeping up with study and work while your sibling is sick could be a challenge for you.

Study

School

Challenges you may face with school could include:

- finding it hard to concentrate or stay motivated during class or study
- feeling more tired than usual
- having less time to do homework or study
- not wanting to be around other people as much as you used to or having days where you're wanting to be quieter or alone.

While you might not want to be treated differently, it can help to let your teachers know what's happening at home. You're in control of how much you tell them. There could be options for your studies to be supported through 'Special Consideration' that allows for things to be put in place to help with your learning.

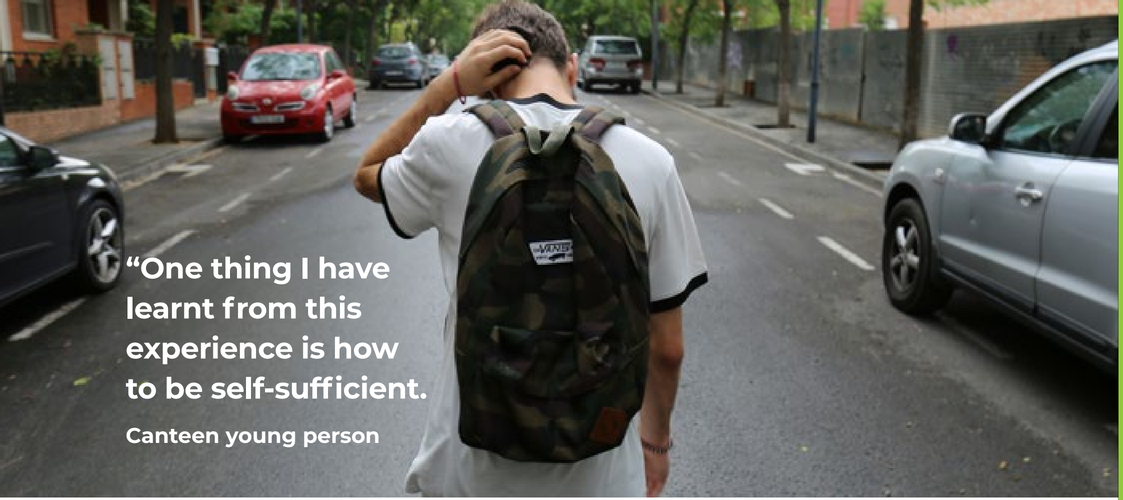
Bullying

Having a sibling with cancer can sometimes make you or them a target for teasing or bullying. This may be something you see or hear about if you go to the same school, it may also be something you experience from others.

Changes in how they look such as losing hair, changes in weight, losing a body part, using a wheelchair can make your sibling stand out.

Some people also think you can catch cancer – and they think this is a good reason to give you or your sibling a hard time.

You don't have to put up with bullying and it's important to let a teacher or your parents know what is happening. You have enough going on without having to deal with bullies.



> **"One thing I have learnt from this experience is how to be self-sufficient.**
>
> **Canteen young person**

Tertiary study

If you're at university or TAFE, you might want to let your lecturers, tutors or department heads know what is happening in the family, they may be able to work out ways to support your learning.

Most universities and TAFE campuses have student services that provide counselling and support. These services could be other support options to help you get through the tough times.

Work

What you tell your boss or work mates about your parent's diagnosis is up to you. You don't have to tell them at all.

Check with your supervisor, manager, or human resources manager about your rights for leave, they may also be able to support you in the workplace in other ways.

For more information about your rights at work, visit the Fair Work Ombudsman website at **fairwork.gov.au**.

Help with cooking

If your parents are not at home, you may have to prepare meals for yourself or the rest of the family.

The following tips will help make cooking a little less stressful and mealtimes a little less boring.

- Find some simple recipes that don't have too many ingredients or too many steps.
- Stock up pasta, bottles of pasta sauces, pizza bases, and other healthy pre-prepared meals.
- Buy some frozen meals to have as emergencies.
- Plan your meals for the week to make sure you have all the ingredients you need.
- Set aside one 'cooking' day a week and make big batches of food to freeze and then reheat when needed.

MEDICAL STUFF

GETTING THE RIGHT INFORMATION

Not knowing what's going on can be stressful. Finding out about cancer is a good way to understand what is happening and could happen in the future. Information may help clear up some of the confusion, reduce the fear of the diagnosis and help you feel more involved.

Your family members will each deal with the diagnosis in their own way. Some people may want to know every little detail all at once, others want information a bit at a time. You can ask more questions as time goes on. Whatever you choose is okay.

You're probably used to getting information from friends, the internet and social media. But because everyone's cancer experience is different, the information may not be relevant or right. Asking your parent, doctors, nurses or the social worker questions will mean you have accurate information and help clear up misunderstandings. If they use medical words you don't understand, ask them to explain.

Here are some questions to consider:

About the cancer

- What type of cancer does my sibling have?
- Where is the cancer?
- Will my sibling get better?
- Is there a chance that I might get cancer too?

About the treatment.

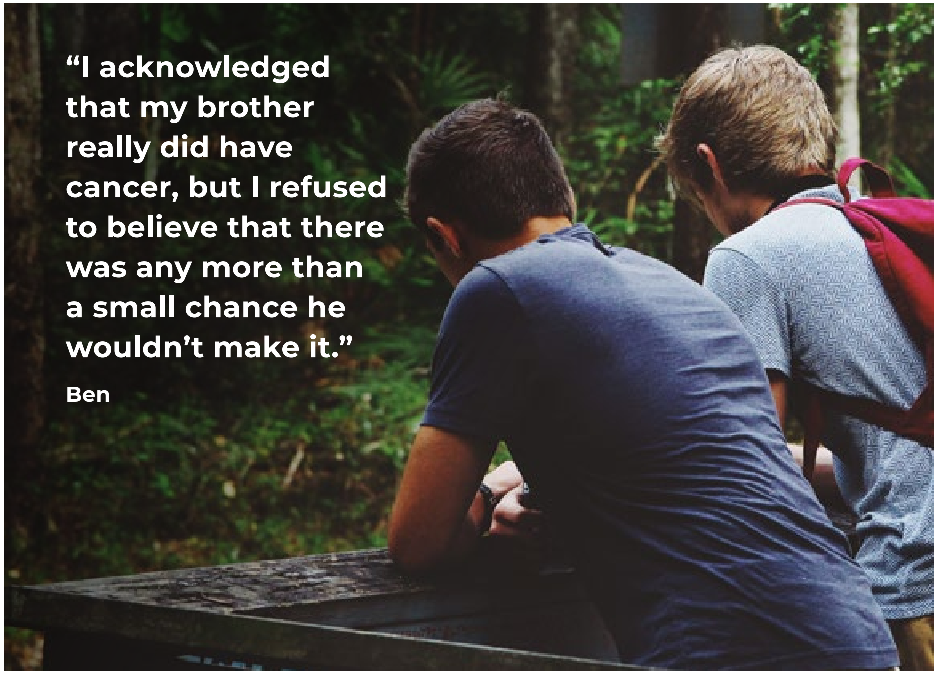
- What treatment will my sibling have?
- Are there other options?
- Where will my sibling have treatment, and can I go with them?
- What are the side effects of the treatment?
- Is the cancer painful?
- Will the treatment be painful?
- How often do they have treatment and how long does it take?
- Will the treatment change the way they look, feel or behave?
- How will we know if the treatment is working?

About advanced cancer

- What happens next if the treatment doesn't work?
- Have the doctors done everything they can do?
- What's a realistic expectation of how long they will live?

"At the start I really wish I knew... what cancer was and what it can do.

Canteen young person



"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 you want to know more

If you want to know more about cancer and how it's treated, as well as the prognosis, you can ask them for more information. And you don't have to ask everything all at once – you can keep asking questions. Knowing what to expect may help you cope better with the situation.

Will my sibling get better?

The toughest question you and your family may have is will your sibling get better and when. Some people want to know this information, others prefer not to know. The outcome or prognosis is the doctor's opinion of how likely it is the cancer will spread and the chances of your sibling getting better. This is a difficult question to answer. No doctor can give an exact prognosis – it's an educated guess based on what usually happens to someone in a similar situation to your sibling.

In the worst-case scenario, your sibling may find out the cancer can't be cured or is no longer treatable. You can read more about this tough situation in the 'If the treatment doesn't work' chapter from **page 63**.

Hearing the prognosis may be difficult. It's a good idea to have support at this time – you could try talking to a family member or friend or using the 'Chat to a counsellor' function in the Canteen Connect app may also be somewhere to start.

Information overload

When you're stressed, upset or scared, it can be hard to understand and remember new information, especially in the beginning.

These tips may help:

- make a list of your questions before appointments
- write the answers down
- ask people to repeat things if you don't get it
- ask people to explain what they mean using simple words or a model or drawing a picture
- ask where you can get more information.

Dr Google

The internet is a great source of information, but we know that not all information online is true. Here are some tips for finding reliable information on the internet.

Always check the source of the information – Information online can be misleading or out of date. For cancer organisations with accurate and up-to-date information, see the 'More information and support' chapter on **page 93**.

Don't believe it all – When your parent has cancer it's natural to look for other treatments they can try. Keep in mind that personal posts on forums, blogs or social media only relate to one person's experience.

Search the right stuff – There are over 100 different types of cancer. The likely outcomes are different for every cancer and different for every person and will vary depending on the stage and where it is in the body.

Search websites you trust – There are many reliable cancer organisations that have accurate and up-to-date information. A list of these reliable sources is on **page 93** in the 'More information and support' chapter. Canteen can also help you to access the right information. Visit **canteen.org.au**.

You could use the information you find to start a conversation with your sibling. Your sibling might not feel like searching the internet so this could be a way to offer them support.

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

Canteen young person

LIFE AFTER TREATMENT

When your sibling finishes treatment, you might think that life will go back to normal. But normal may not look exactly the way it did before. They will probably feel relieved the treatment is over but also could feel worried that cancer may come back. This chapter explains what happens when your sibling finishes treatment, tips on getting back to 'normal' (or creating a new normal) and dealing with loss and change.

After treatment your sibling enters a phase called 'survivorship'. But going from 'patient' to 'survivor' isn't always easy for people. Surviving cancer is more complicated than just having treatment. Your sibling might still be dealing with side effects from treatment such as tiredness and feeling down. And they may need time to adjust to the changes cancer has made to how they look and feel.

Changes after treatment

Tired – sometimes called ‘fatigue’, it’s not just normal tired that sleep can fix. This type of fatigue can last for months, and in some cases, years

Pain – ongoing from surgery, radiation therapy and chemo

Mouth sores and teeth problems – the gums, insides of the cheeks, tongue and throat may have sores, especially if they’ve had radiation therapy to the head and neck area

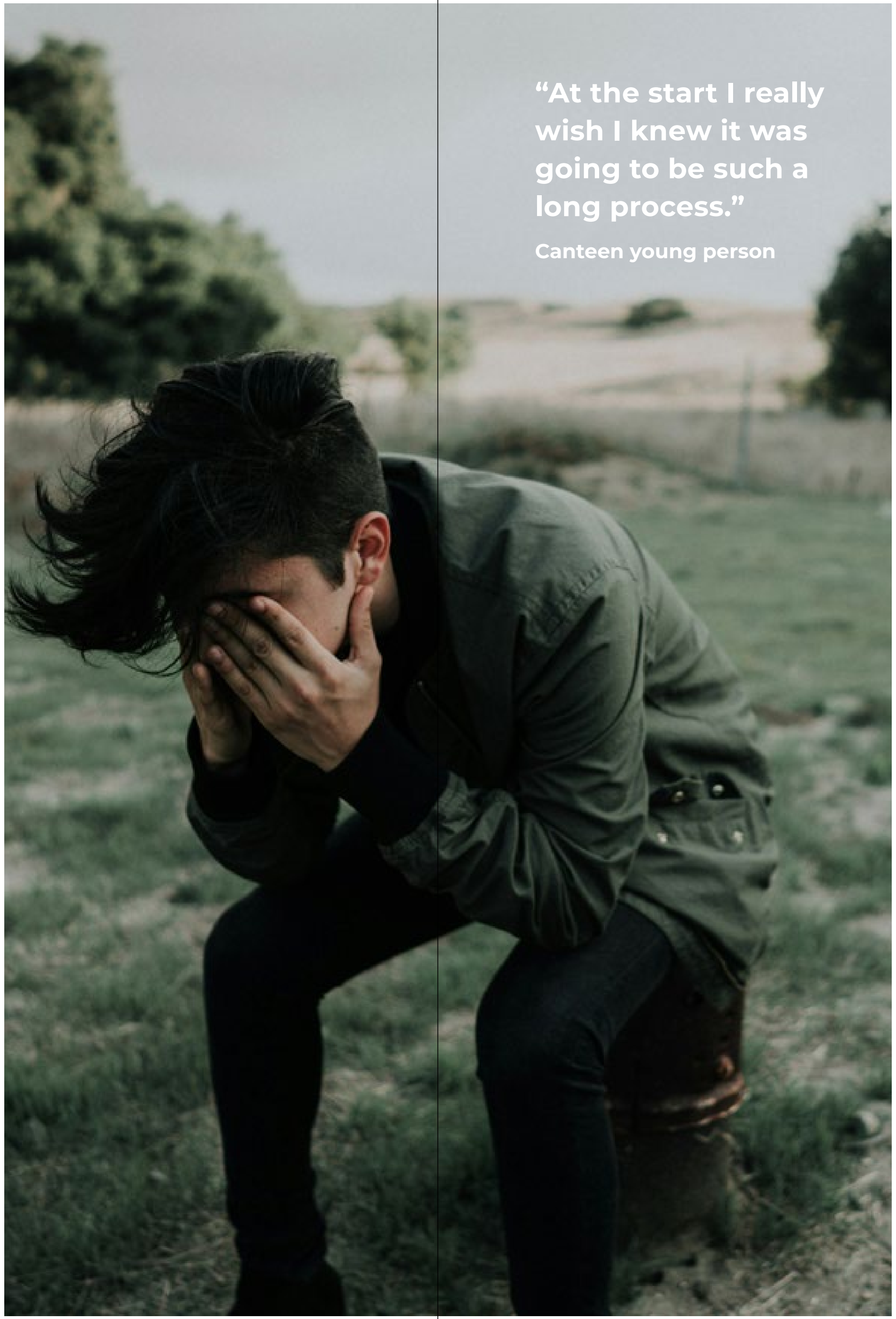
Changes in weight – treatment can change what they can eat

Growth failure – they may not grow as tall as they would have or they may go through puberty later than others

Hair loss – this is usually temporary but hair may not grow back the same

Amputation – may need to use a wheelchair or wear an artificial arm or leg

Brain fog or ‘chemo brain’ – foggy thinking, problems concentrating and paying attention are often called chemo brain. Chemo can affect how the brain works. It usually gets better with time but for some people is ongoing



> **“At the start I really wish I knew it was going to be such a long process.”**
>
> **Canteen young person**

Getting back to normal after your sibling’s cancer

Your family may expect that life will return to how it was before your sibling was diagnosed with cancer, but some things may be different.

Your sibling has just dealt with a life-threatening disease. At least some of their life and how things were before cancer has changed. This is often called the ‘new normal’. Everyone will need time to adjust.

You might feel a lot of different emotions:

- relieved that your sibling is okay
- confused that your sibling looks fine but still feels tired or isn’t ‘back to normal’
- frustrated that life hasn’t gone back completely to the way it was
- sad that your sibling is not the same person they were before they got sick
- angry that your sibling is still getting special treatment
- happy cancer isn’t the focus of the family
- worried that the cancer will come back
- pressure to learn something from the experience.

You might find it helpful to chat with or read stories by other young people whose sibling is a cancer survivor. Join Canteen’s online community, Canteen Connect (**canteenconnect.org**), or find out about our peer support programs and groups.

Dealing with pressure from others to ‘move on’

Your friends, partner, teachers, or employers might think everything should be ‘back to normal’ now that your sibling has finished treatment. But this doesn’t mean that cancer is no longer part of your life and things don’t still feel different or difficult. It’s natural to worry about the cancer coming back.

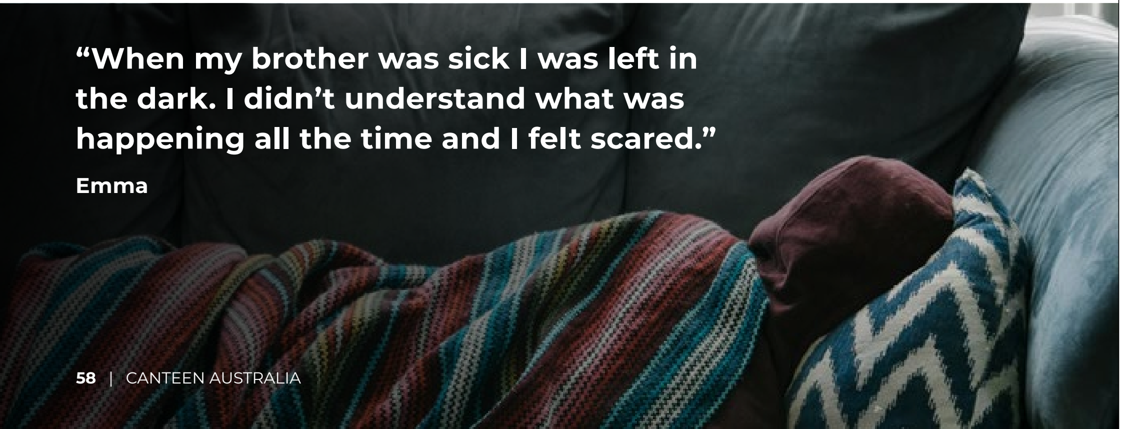
Tell them you need space and time to adjust. But if you feel like you’re not coping (like if you can’t stop worrying about the cancer coming back or someone else in your family getting cancer), talk to a Canteen counsellor (by phone, online or in person).

Understanding grief and loss

Grief is the term we use to describe how we respond to a loss. You might think grief is just about when someone dies, but you may also experience grief when your sibling is living with cancer. You can experience grief and a sense of loss when you’re told about the diagnosis, and other times during and after treatment.

Other reasons for your grief include:

- not feeling as though you’re able to have fun like everyone else your age
- not taking part in one-off experiences (e.g. the year 12 formal, playing in the rugby final)
- missing out on going to uni, TAFE or work for a while
- missing out on a planned holiday or not being able to plan holidays because of treatment
- not celebrating special occasions– religious holidays, birthdays and anniversaries – in the same way
- you don’t feel connected to your friends because you couldn’t go out as much or you’re no longer interested in the same things
- changes in your parent’s attention or affection
- missing your ‘old’ sibling – if they’ve changed because of what they’ve been through
- you miss the routines you used to have



“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

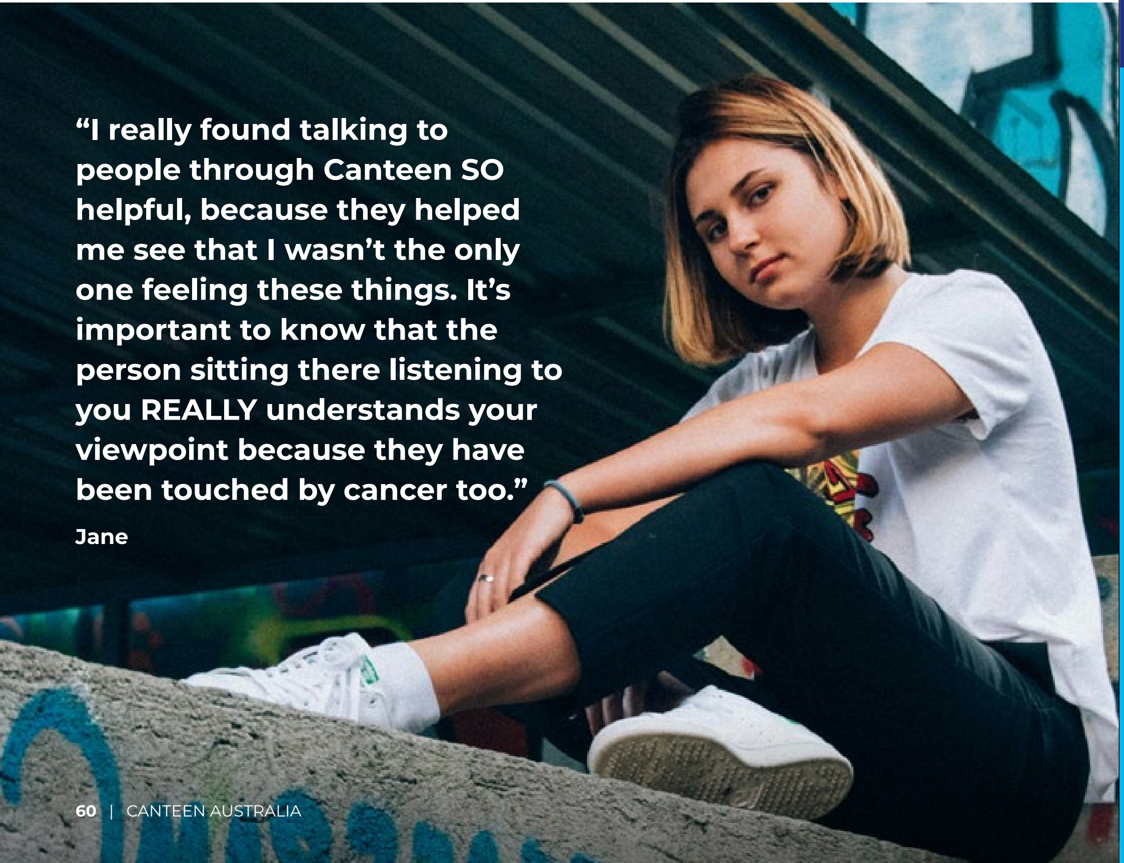
“Even if you are feeling alone, there is always someone there. You just have to find that special person that you feel comfortable sharing with.”

Ashley

Things that can help

It's important to find ways to take care of yourself and to develop healthy habits throughout the grief process.

- Try to go easy on alcohol and other drugs. While you might feel like they help you cope with stress and intense emotions, they can be unhelpful for your body and mind in the long run.
- Seek comfort from cultural, spiritual or religious traditions. Even if you're not into traditional religion, you might find you are developing an interest in other beliefs and types of spirituality. This can be a way to find meaning in what is a tough situation.
- Find ways to live around the grief and not get 'stuck'. See 'More information and support' on **page 93** for support services that can help you.
- Get in touch with Canteen. We offer counselling and an online community for you to connect with young people in the same boat as you (**canteen.org.au**). You can also contact Kids Helpline (**kidshelpline.com.au**, 1800 55 1800) or Lifeline (**lifeline.org.au**, 13 11 14).



> **"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**

HEAVY STUFF

IF TREATMENT DOESN'T WORK

In this chapter you'll find information about a very difficult situation – a sibling who has advanced cancer. Sometimes, cancer may come back (recur) or spread. Or the cancer may have been diagnosed at an advanced stage. Feel free to skip this chapter if the cancer was diagnosed at an earlier stage and treatment has helped control it.

We know that a diagnosis of advanced cancer is hard for your sibling, but we know that it's hard for you too. Cancer affects the whole family.

Sadly, cancer cannot always be cured. Sometimes treatment doesn't work and they don't get better. At this point, the focus changes to helping your sibling be as comfortable as possible.

Don't feel like you have to read this whole chapter. There might be certain things you're not ready to think about yet. That's okay. You can read the parts you are comfortable with now then put it away to read at another time.

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

Andrew

Finding out

Taking it in

Learning that your sibling is not going to get better can be devastating. You might be shocked and find it hard to accept – you may be thinking, 'No, you're wrong. I don't believe you!' or 'You've made a mistake'.

Even if your sibling has been feeling sick, having more tests or spending a lot of time in hospital, you may have thought they would get better. You may find it hard to accept that there are no treatments left to try.

Ask for more information

If you want to understand more about what's happening with your sibling, you might need to ask. The questions on **page 52** may help you think about what you want to ask your parents. You can also search the Internet for reliable information (see **page 54** for more details). If you need tips on taking in new information, see **page 54**.

People are living longer with advanced cancer

More and more people are living with advanced cancer for longer periods of time – this can be for many months or years. And there are treatments that can help your sibling feel better.

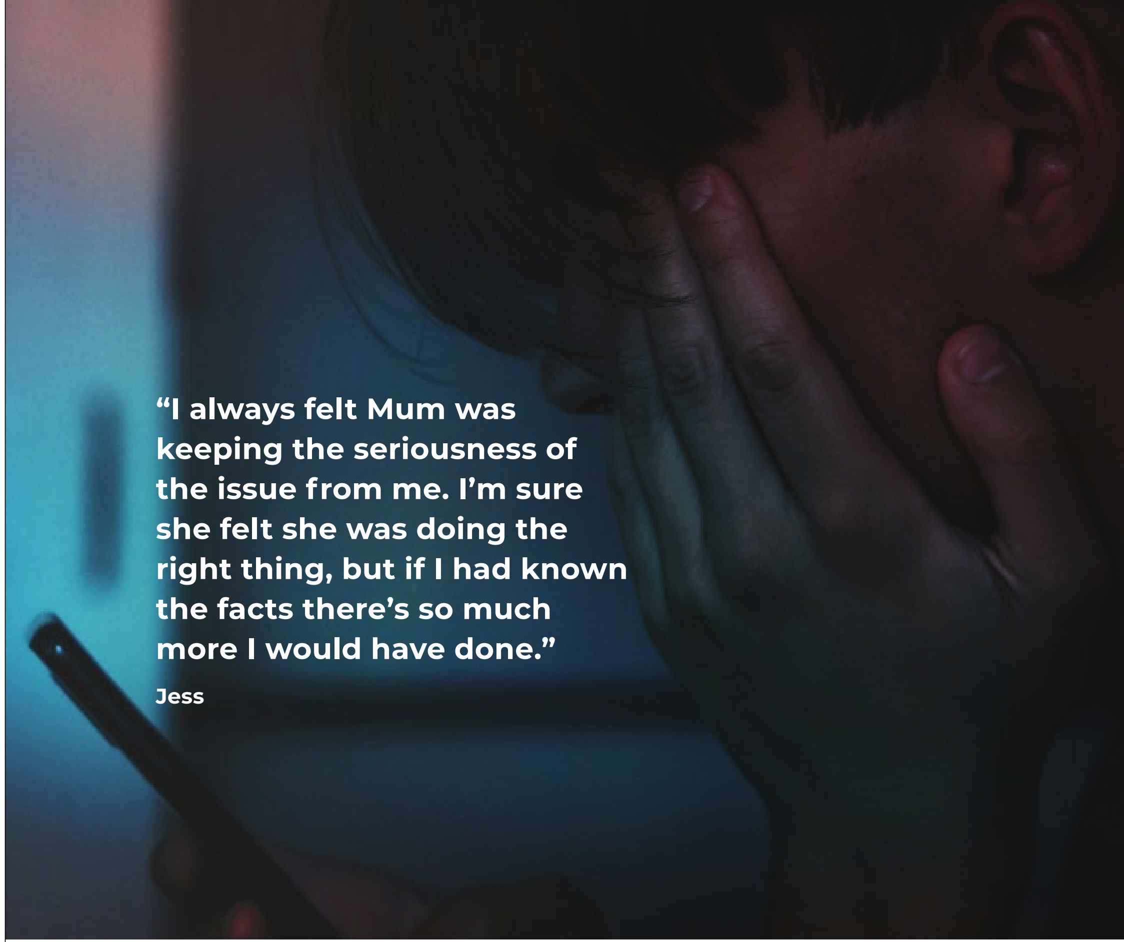
Denial can be okay

You might feel that you don't really want to know everything about your sibling's illness. Denial can give you time to adjust to something really distressing until you feel more able to cope.

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

"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



"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 known the facts there's so much more I would have done."

Jess

Managing uncertainty

Living with advanced cancer is a time of uncertainty. You may not be sure what's going on or how long your sibling might be around. Or frustrated that the doctors have no clear answers.

In the loop

Parents can sometimes try to protect their children from bad news because they don't want you to worry. They may hide the diagnosis or not share all the details.

If you suspect that something is wrong or you hear your parents talking in whispers, you may fill in the gaps with your own guesses, which may be worse than what's really going on. This can be stressful and make you feel worried or left out.

You might be feeling frustrated that, as the sibling, you might be the last one to find out what's going on. Many young people say that knowing what changes to expect in their sibling's health helps them feel more able to cope.

“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.”

Jess

You can get support

Even if your friends or partner don’t really get what you’re going through, there are people who do. Social workers and counsellors are trained to listen, and can help build your coping skills and link you with support. You can talk to them in person, online and on the phone.

Canteen provides a free and confidential counselling service (check out **canteen.org.au/counselling**). You can also ask your doctor to recommend a counsellor or psychologist.

You can also connect with other young people who understand what you’re going through at Canteen Connect (**canteenconnect.org**).

Who says they will not get better?

When treatment doesn’t control or shrink the cancer, a doctor may say there’s nothing more they can do. This means your sibling will not get better and they will die from the disease at some point.

It’s not possible for a doctor to say exactly how long a person will live. They may give you an estimate, but your sibling may live longer, or unfortunately, for less time than they predict.

How you may feel?

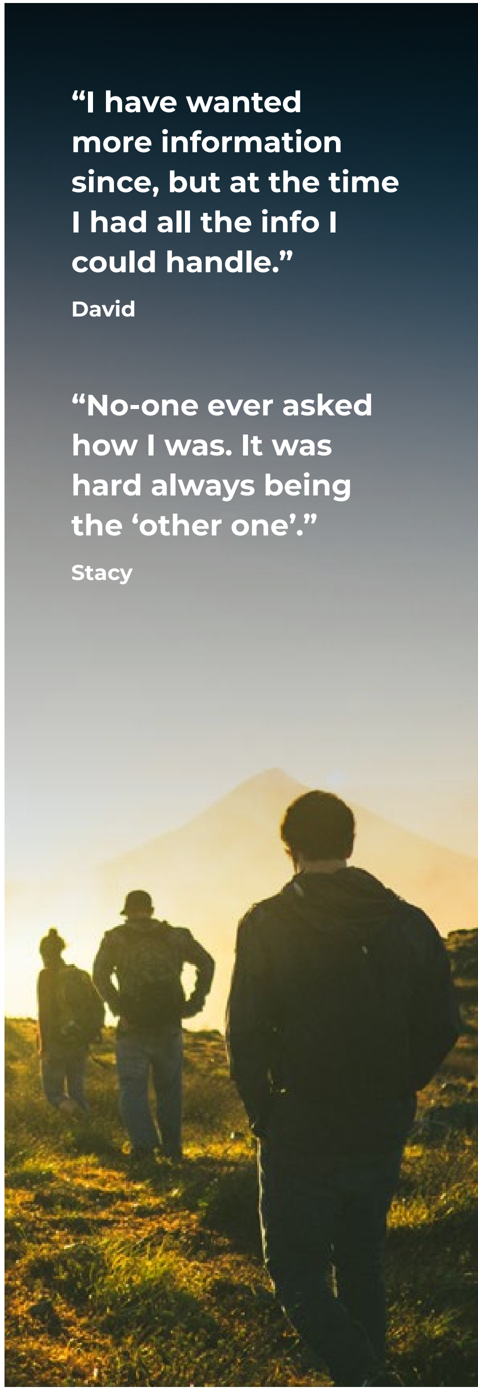
Being told that your sibling might not recover will be one of the hardest things you will ever have to hear. Nothing can fully prepare you for this emotional rollercoaster.

You may experience some of the similar feelings you had when your sibling was diagnosed with cancer – see **page 30**. When you’re living with the stress of advanced cancer, it’s important to find ways to share how you’re feeling – see **page 23**. Sometimes your emotions can be strong and confusing. Read ‘When things seem to be too much’ on **page 42** for signs of depression.

How your sibling might feel?

Your sibling will probably find being told that they’re not going to recover from cancer devastating and hard to cope with. They’ll have lots of strong emotions that can change from day to day or even throughout the day – see **page 33** for more details.

Just like you, your sibling probably never expected that their life wouldn’t be as long as they’d hoped. They may worry about how their death will affect you and the rest of the family. The best way to understand what your sibling is going through is to hang out together. You don’t have to talk. Just being together will let them know that they don’t have to face this alone. Your support may make them feel less scared and angry.



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

David

“No-one ever asked how I was. It was hard always being the ‘other one’.”

Stacy

How your parents might feel?

Being told that your child is not going to recover from cancer is probably the toughest thing your parents will ever hear. Aside from feeling extremely upset, they'll have lots of strong emotions that can change from day to day or even throughout the day – see **page 26** for more details.

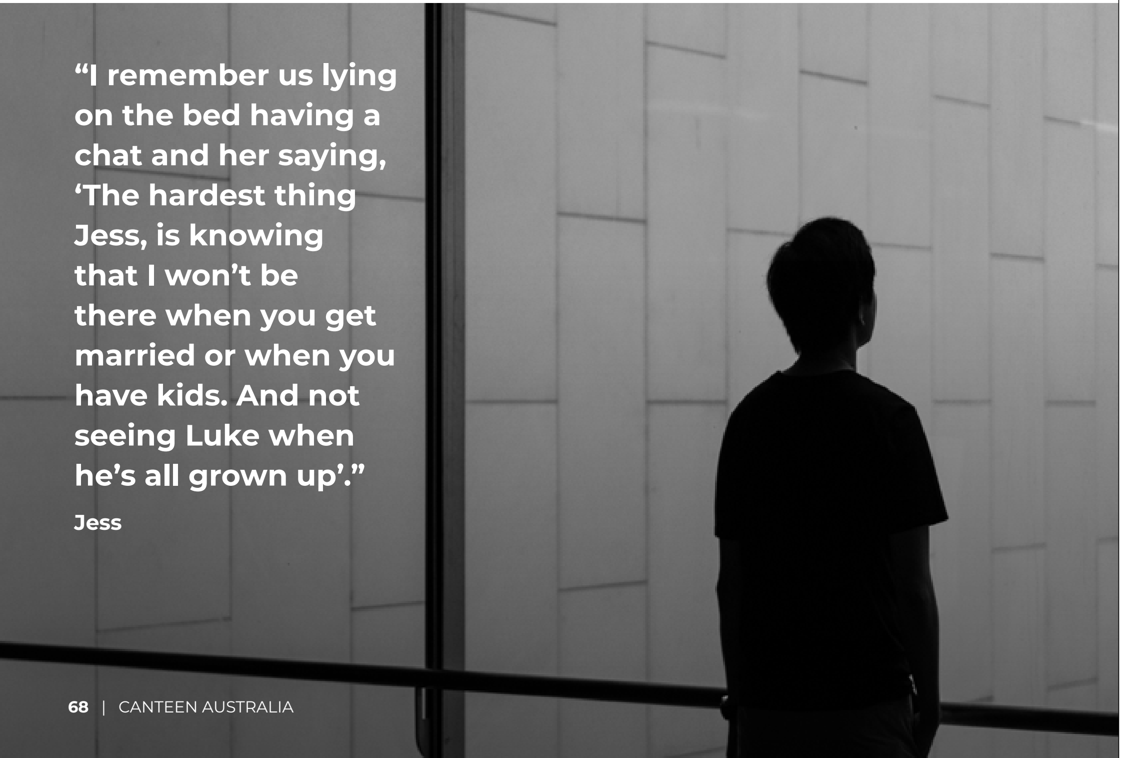
Talking about advanced cancer

Many people say it helps to talk about the diagnosis but don't know how. Your parents and sibling may avoid talking about what advanced cancer means because they don't want to frighten you, or you may be worried about upsetting your sibling.

This will be a challenging time and it will help to talk about how you're feeling. You could talk to your parent, another family member or friend, or you could consider professional help from a counsellor.

How can you help?

Treat them the same – Your sibling is still the same person and it's okay to laugh and argue with them sometimes. And every conversation doesn't have to be about cancer. Talking about study, work or your friends can help them to feel included in what's going on. You don't have to pretend to be happy all the time.



> **"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**

> **"Only you know what you can handle. You've got to look after you too."**
>
> **Anna**

Talk about dying – Most people find it hard to talk about death and dying, and even avoid the words by saying 'passed away' or 'gone away'. If you're okay talking about dying, it may help your sibling feel less alone.

It can help to talk about the practical aspects of dying – Where your sibling would prefer to die, who they would like to be around them when it happens, and what they want their funeral to be like.

Asking these questions doesn't mean that you want your sibling to die or that you have given up hope. You and your family can also talk to the palliative care team about how they can support the family.

Follow their lead – If your sibling doesn't want to talk about dying, you need to respect their wishes. Or your parents might not want you to because they think it will be too much for your sibling or talking about death will make death happen sooner. It may even be disrespectful in your culture to talk about dying.

As the cancer progresses, your sibling might be tired, trying to put on a brave face, or overwhelmed by sadness. The cancer or medicines may have changed how they think or behave. Your sibling might cope by withdrawing from family activities, or becoming argumentative or demanding. Try not to take their behaviour personally.

If your sibling wants to talk, listen. You don't have to pretend it's not happening by saying things like, 'No, you're not. Don't talk like that'. It's okay to be upset and afraid together. You could say something like, 'I know this is hard. But it would help me to talk about what's happening'.

Offer practical support – Let your parents and sibling know if you would like to help care for your sibling. For example, you could help your sibling stay in touch with their friends by updating their social media or sending out group texts.

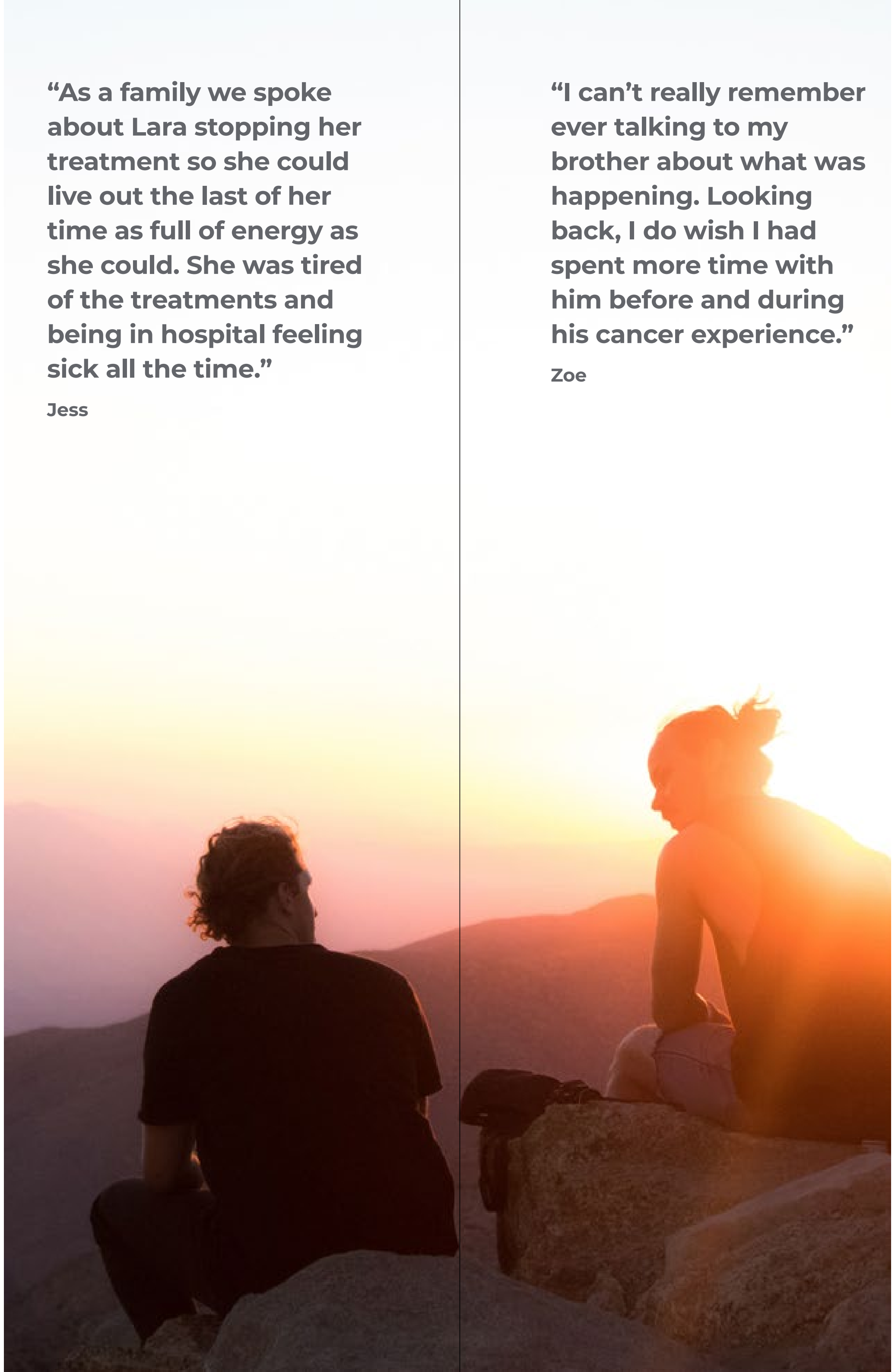
Spend time together – Most young people say that even though it's difficult to see their sibling unwell, they find comfort in spending time together. Think of activities you can do together that don't take much energy, like watching a movie, playing a video game or listening to music. Expect that some days your sibling will be too tired or sick to talk. They may seem irritated or distant. This may make you feel hurt, disappointed or worried.

Having palliative care

When it no longer seems likely that your sibling will get better, the focus of treatment shifts from trying to treat the disease to helping them live as comfortably as possible. This type of care is called palliative care or supportive care.

If your sibling is referred to palliative care, it's natural to have questions. One of the most common questions is, does this mean my sibling is about to die?

Palliative care can help people whose illness has not responded to treatment and it's likely it cannot be cured. Palliative care does not aim to make someone's life shorter or longer. It aims to make them comfortable. This could be for weeks, months or years.



> **"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**

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

How palliative care works

What support does palliative care provide?

Palliative care will help to maintain the quality of life of your sibling by dealing with their physical, emotional, cultural, social and spiritual needs. Palliative care also supports the family.

Each palliative care team tailors its services to the unique needs of a family. This may include:

- nursing and medical care – to control symptoms and side effects of cancer, like pain and nausea
- counselling and social workers
- hire of equipment, e.g. special beds, chairs
- therapists skilled in music or colour therapy, massage or aromatherapy
- physiotherapy and occupational therapy
- advice on what to eat
- spiritual support and pastoral care from different cultural and religious backgrounds
- volunteers to help your family care for your sibling

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

Starting palliative care as early as possible can make things easier for your sibling and your family. A lot of people avoid having palliative care for as long as they can because they're afraid that it means they're going to die soon.

Your sibling's health care team will probably suggest when it's time to consider palliative care. If your sibling is over 18, they can even refer themselves by contacting a local service. And they can stop and start palliative care as their needs change.

How can we access palliative care?

Depending on what your sibling needs, they may receive palliative care from their own GP or health care team, or they may be referred to a specialist palliative care team. Services are available in most areas of Australia.

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 also not like voluntary assisted dying, which is when a person with an incurable illness uses medicines specially prescribed by a doctor to end their life. Voluntary means it is the choice of the person to end their life. Laws have been passed in all states in Australia.

Who can I ask if I have questions?

The palliative care team can answer your questions and help you too.

Saying goodbye

It can be hard to know how to say goodbye. This is a sad and difficult thing to do but a chance to tell them what you'd like them to know.

You might feel awkward having deep and meaningful conversations, when your sibling might still be around for months or years. Or you might worry that they'll think you have lost hope if you talk about life without them.

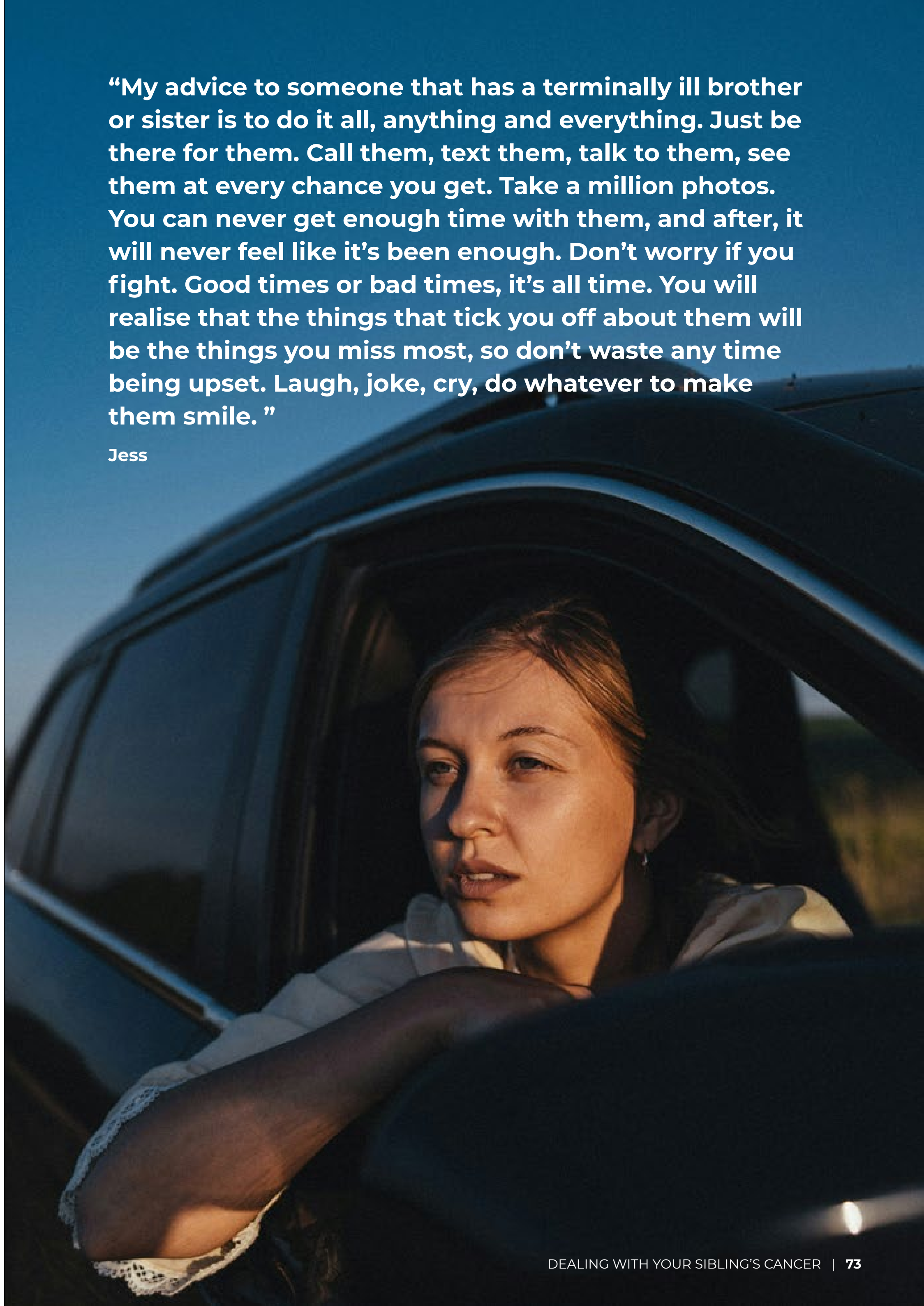
But your sibling might like to know that you love them and that you'll miss them.

Here are some suggestions to get you started:

- Thank you for...
- I'm sorry that...
- I forgive you for...
- What I'll miss most is...
- I'm proud of you for...
- I love you because...
- A favourite memory I have is...
- You make me laugh when...
- I'll miss you because...

Whatever way you say goodbye to your sibling, it's a good idea to do it while they're still as well as possible.

> **"My advice to someone 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**



When it all seems too hard

It's hard to think about everything you have ever wanted to share with your sibling before they die. It's okay if you forget something. The truth is, they know how much you love them and how much you will always love them.

When you experience grief before a loss occurs, it's called 'anticipatory grief' or pre-loss grief. When your sibling is dying, they and you might experience grief for what is about to come. While they are still a part of your life, you grieve a future without them. It's a weird in-between state. Anticipatory grief doesn't make grief after the death any easier or shorter, and the death can still feel like a shock.

Memories and stories

Often when a person is dying, they like to reflect on their past and what they've achieved so that they can see that their life has been important.

You could ask them about their life and share memories. If they don't have the energy to reminisce, you might be able to collect stories from other family members or friends.

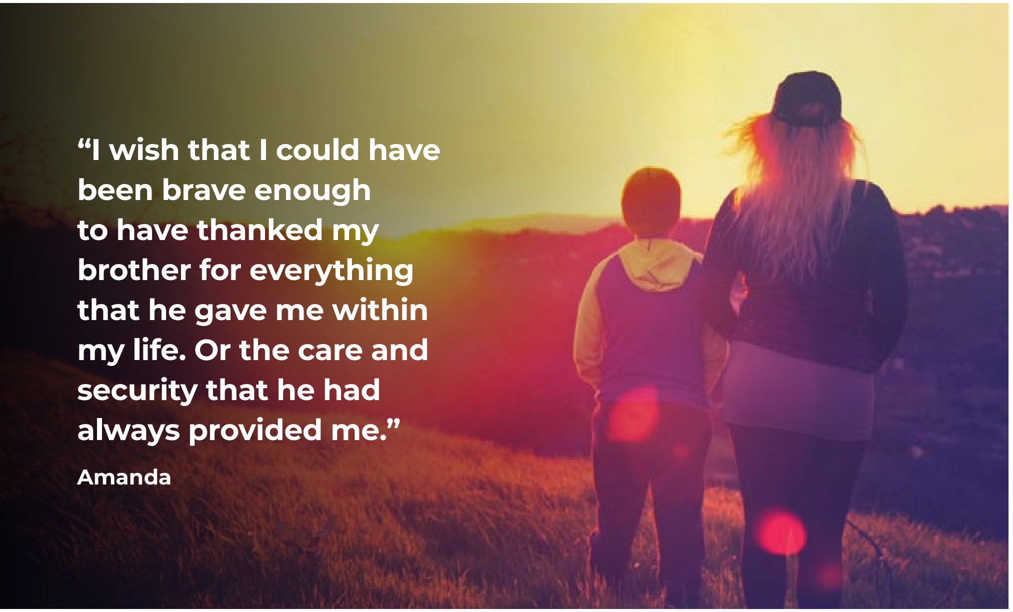
Collecting memories and stories might make you both laugh and cry, but that's okay. Knowing that you had the chance to share this special time with your sibling will be something you'll be grateful for later on.

It's natural to find imagining the future without your sibling upsetting. It will be hard to think of the occasions and events they will miss – finishing school or study, your wedding, having kids.

At moments like this in the future, you may wonder what your sibling would think or say about the situation. You will not be able to predict all of the conversations you might ever want to have with them, but you might want to hear about their thoughts and dreams for you and the future.

Questions to ask your sibling:

- 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?



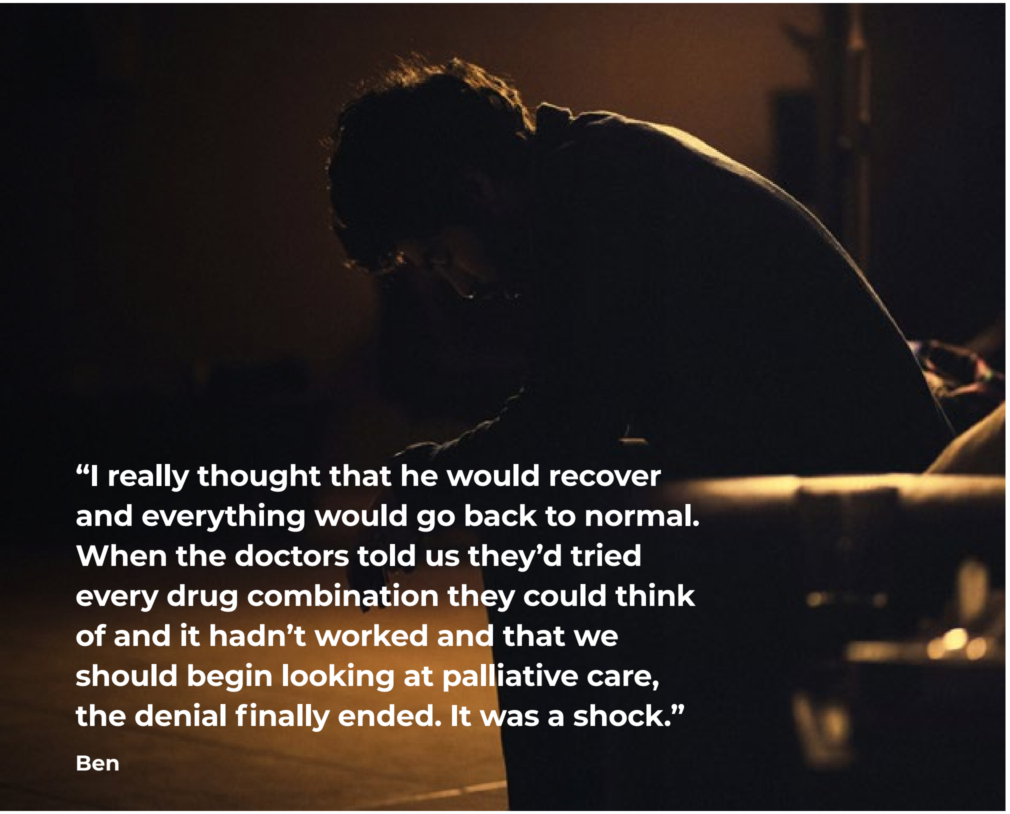
"I wish that I could have been brave enough to have thanked my brother for everything that he gave me within my life. Or the care and security that he had always provided me."

Amanda

Collecting memories

With time, memories of your sibling will become precious. You may want to put together things that will remind you of them in the future. This is a good way to spend time together.

- Create a photo album, slide show or scrapbook. You could write a note next to each one about what your sibling remembers about that photo.
- Make a playlist of your sibling's favourite songs.
- Put together a box of special things, e.g. photos, concert tickets, cards, clothes or jewellery, that remind you of them. This is often called a memory box.
- Make a physical record. Draw around their hand, record how tall they are, cut a lock of hair.
- Take photos. If your sibling doesn't want you to take photos of them because they look sick, you could take photos of their room, where they like to hang out, etc.
- Record a video or voice message of stories and shared memories.



> **"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**

Making plans about end of life

We all know that eventually we're going to die, but nobody wants to think about that before they really have to.

Your family might avoid talking about dying with your sibling. This might be from fear that if your sibling accepts their death, they will give up hope and die sooner. Or perhaps your family has never been comfortable talking openly with each other. This doesn't necessarily change when someone is dying.

Making decisions about the type of care a person would like to have in the future is called advance care planning. Having these conversations is hard but planning ahead for the death will help ensure that your sibling's wishes are met.

- **Advance care directive** – This describes what kind of treatments are or are not wanted, and whether they want to go on life support. Depending on where you live, this could be called Advance Health Directive, Health Direction or an Advance Personal Plan. See **advancecareplanning.org.au** for more information.
- **Substitute decision-maker** – This nominates a person your sibling trusts to make legal, financial and medical decisions if they lose capacity. If your sibling is under 18, this will be your parent.
- **Ideas for their funeral** – Whether they would like their body to be buried or cremated, type of flowers, colour to wear or music.
- **Hold a 'living funeral' or 'party'** – If your sibling is well enough, organise an event to celebrate their life.
- **Will** – This is a legal document that states what a person wants to happen to their money and property (estate) after they die. Usually to make a Will a person must be over 18.
- **Organ or tissue donation** – This may not be possible depending on the type of cancer.

Choosing where to die

A major decision your family will have to make is where your sibling will be at the end. It may be important to your sibling to have some control over where they will die. The decision will depend on what your family feels comfortable with, what support they need, where you live, and what services are available. Care may be possible at home, in a hospital, in a palliative care unit, which is sometimes called a hospice.

Changing the place of care

It's okay for your sibling to change their mind about where they'd like to have care. They may do this because their needs change or the family no longer feels confident or capable caring for them at home.

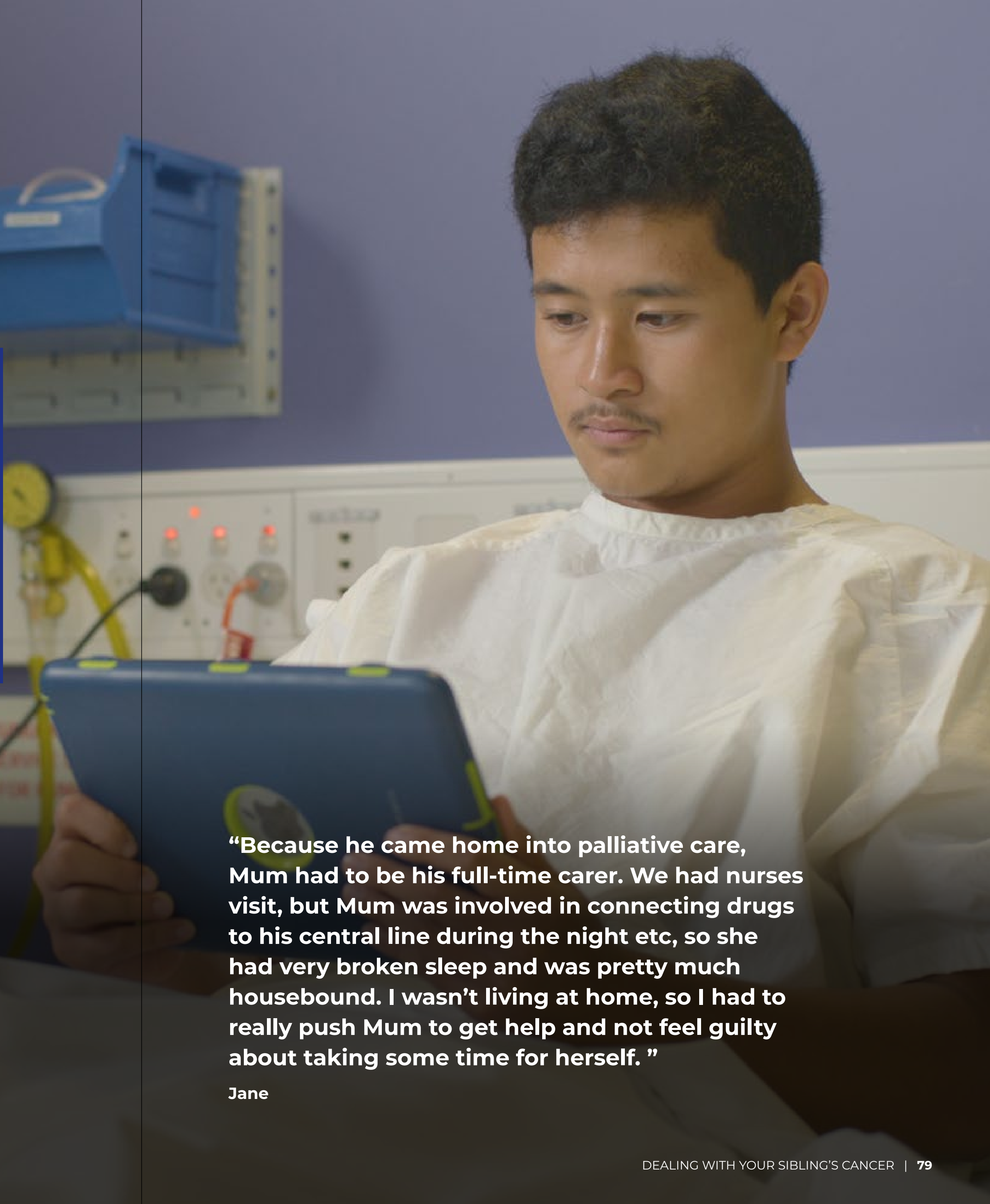
Your sibling may go to hospital or a palliative care unit for a short time for symptom control. Your family may decide that it's better if they stay there or come home. Sometimes things change and your sibling doesn't die where they would like or the death happens more quickly than expected.

Care at home

Many people say they would prefer to die at home. They may want to be in a place they know, and surrounded by their family, friends and pets.

Having your sibling at home in their final stages can be a special experience. You may appreciate having the time to spend with them. The palliative care team can provide support to make your sibling comfortable and to help your family care for them at home.

Caring for your sibling at home can be physically and emotionally tough. You may want to let your family know what care you feel comfortable providing. If you don't want to help with their physical care, there are many ways to help improve their quality of life and offer support – you could play music, read to them, light a scented candle.



> **"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 housebound. I wasn't living at home, so I had to really push Mum to get help and not feel guilty about taking some time for herself. "**
>
> **Jane**

There may be changes in the way your sibling looks, feels and behaves when they are approaching the end of life. You may find it distressing to see them become weaker and have less energy.

During this time, it's important to take care of yourself. Try to have regular breaks, get as much sleep as you can and eat healthy meals and snacks. This will mean you have more energy to spend time with your sibling.

Your family may decide that it's not always possible for your sibling to die at home, for lots of different reasons.

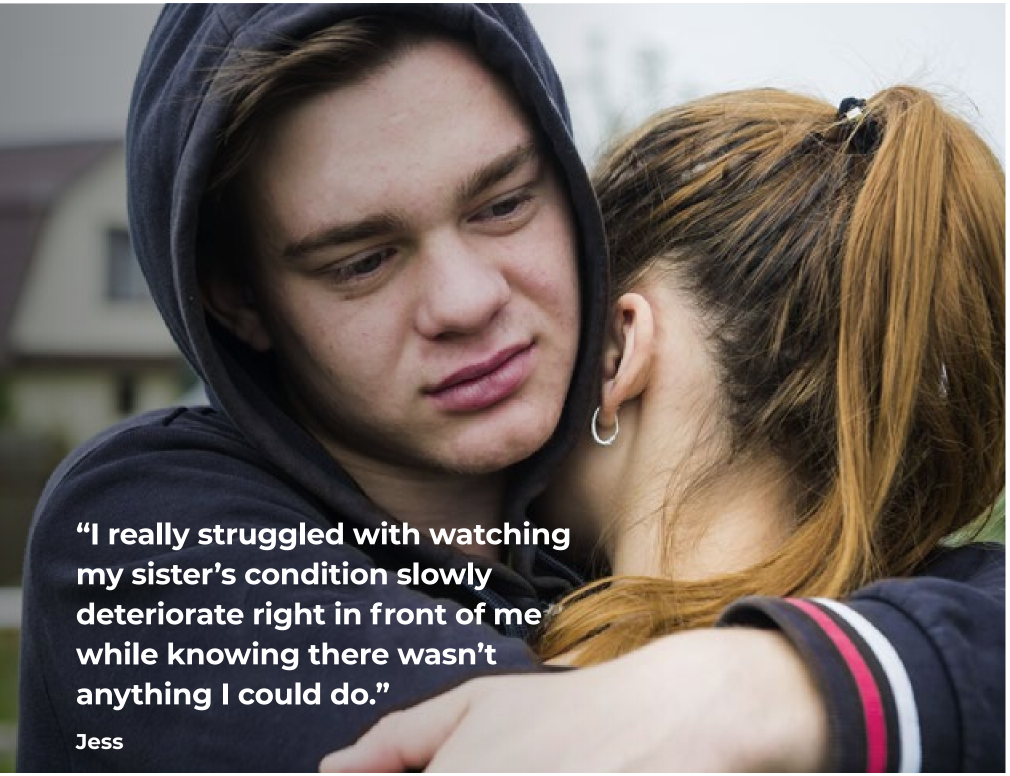
Care in a hospital

Your family may feel more comfortable if your sibling is cared for in a hospital. Here health professionals can look after them and relieve pain and other symptoms as necessary.

Care in a palliative care unit

A palliative care unit (hospice) is a specific ward in a hospital or special facility. It provides care for people with an illness that is unlikely to be cured.

Many palliative care units are often smaller and quieter than hospitals.



"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

You may be able to stay overnight with your sibling – but try to spend some time outdoors if that's what you need to do. If your sibling goes into hospital or a hospice, you might worry that they might not come home again. But often someone goes to hospital or a hospice for a short time to have their symptoms managed and then can go home again. You can visit your sibling as much as you would like. Your sibling might be able to go into a palliative care unit for a little while to give your family a rest from looking after them.

The last few weeks

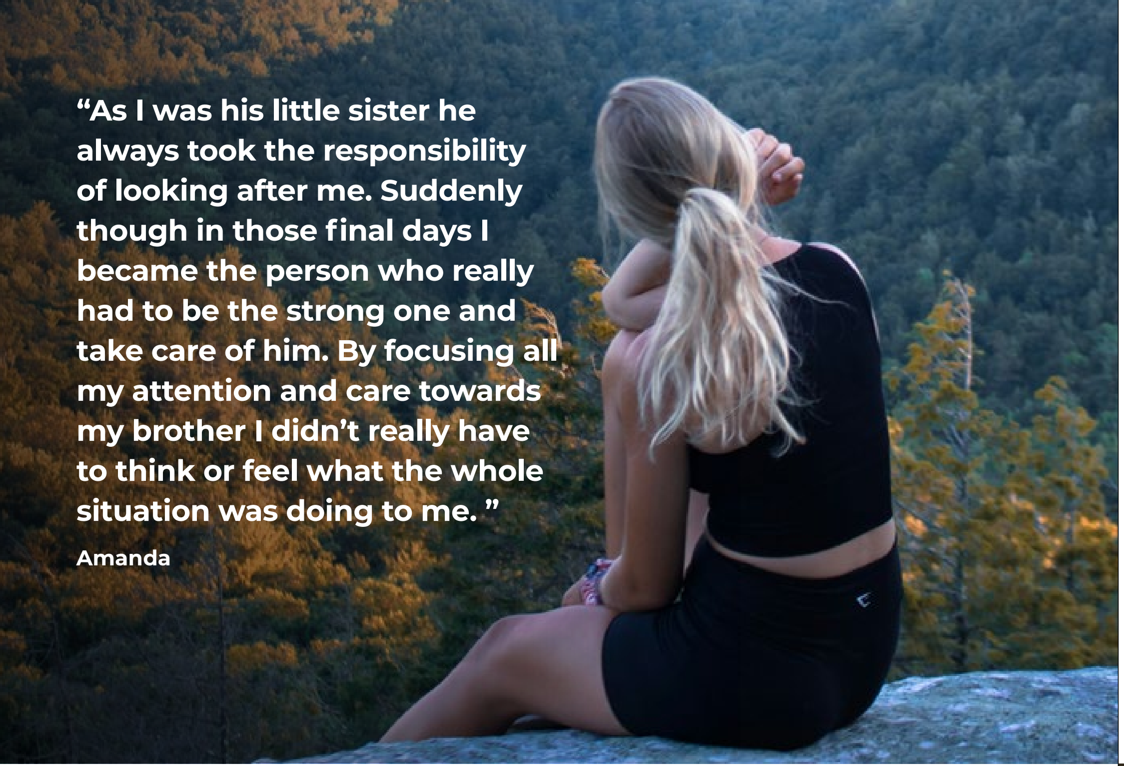
You might worry about what will happen during the dying process. It can be scary to see your sibling sick and drowsy. The distress of knowing that your sibling is going to die cannot be taken away, but knowing what to expect can help you feel less scared. If you feel like you need a bit more space, this is okay.

The doctors and nurses will do everything they can to make sure your sibling is comfortable and not in pain. The time before death is usually peaceful. The body slowly closes down as it starts to 'let go' of life.

No-one can say exactly when someone will die but there are some signs that death is near. Changes happen over a few weeks or days. You may find these changes distressing, but they're a natural part of gradually withdrawing from the world.

Signs you might see include:

- **Sleeping more** – They spend more time asleep and are less alert. It's best to let them sleep and talk to them when they seem most alert.



> **“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**

- **Not talking very much** – They might become withdrawn, talk less and lose interest in things and people around them. Sometimes it might seem like they don’t recognise you.
- **Changes in mood and behaviour** – At times they might be angry or irritable. You may not have done anything wrong and just being there and listening can be supportive.
- **Eating and drinking less** – As your sibling gets weaker, they may have trouble swallowing or digesting food. Small sips of water or ice to suck can help dry lips and mouth.
- **Changes in temperature** – Sometimes they may feel cool, other times hot and clammy. This is because their blood circulation is slowing down.
- **Incontinence** – This is when they lose control over their bladder and bowel. The palliative care team can help you manage incontinence.
- **Changes in breathing** – As saliva and phlegm begin to collect in the back of the throat, breathing becomes noisier. This can create a gurgling or rattling sound. They may have one fast breath then no breath for a few moments. You may find the breathing changes distressing, but your sibling probably isn’t uncomfortable or in pain. Raising the head of the bed with pillows can help.

It is said that people can still hear and feel touch when sedated or unconscious. So even if your sibling doesn’t respond to your voice, they can probably hear you. Talking or reading to them, or holding their hand can be a comfort.

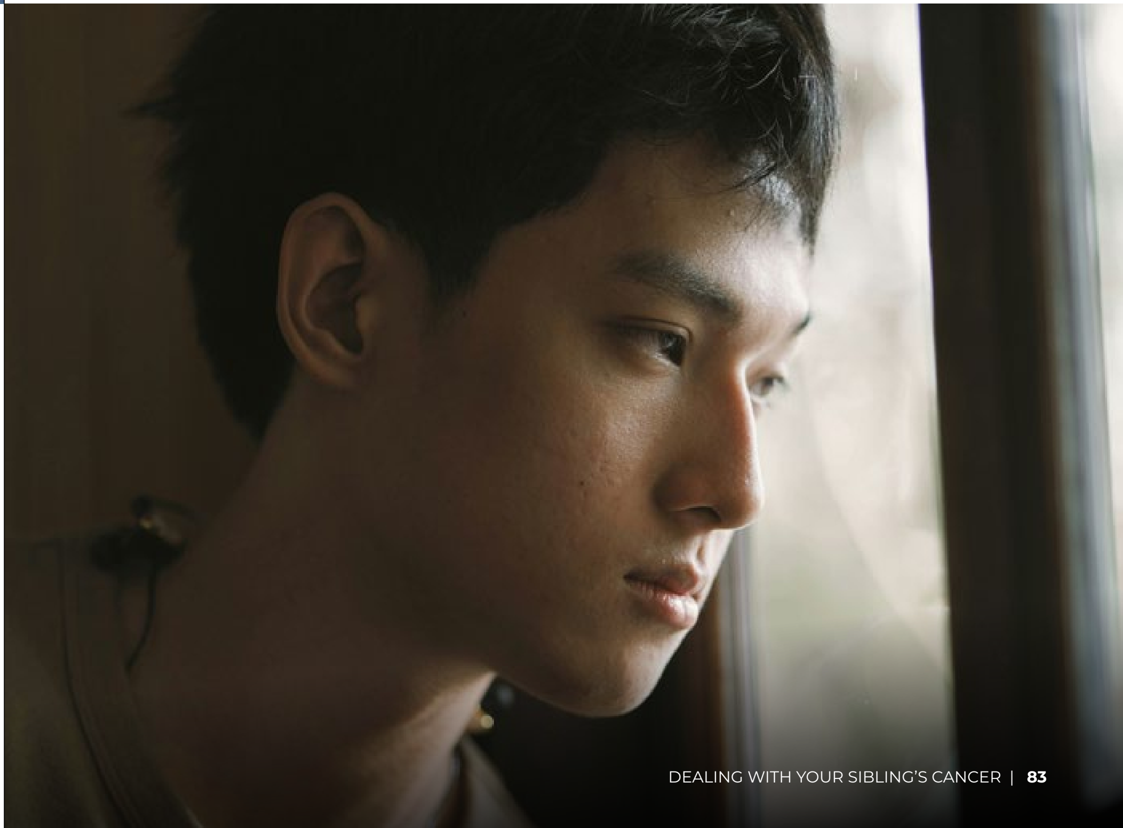
If you notice any changes in your sibling that you’re unsure about, ask the medical and nursing staff for more information. They can also help manage any symptoms.

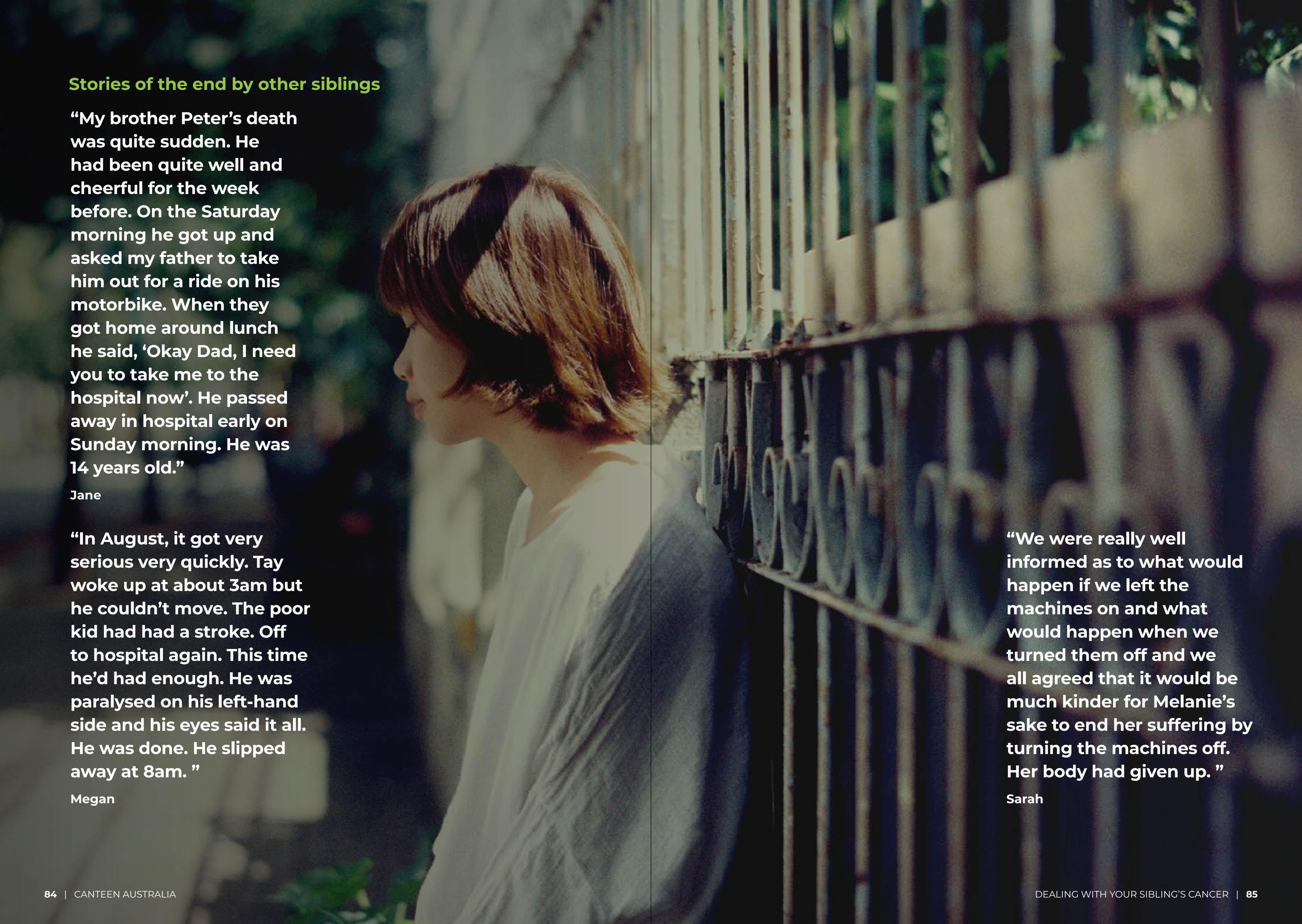
At this time, it may feel like life stops. It’s common to want it all to be over. This doesn’t mean that you don’t care. It’s a sign that you want your sibling to be at peace.

Do I need to be there when they die?

This is a very personal decision. It’s a good idea to talk to your family about how you feel. Many people want to be with the dying person as a way to show love. This is called keeping a vigil. Your sibling may be sedated or unconscious at this time.

You may worry that if you go to school, uni/ TAFE or work you’ll miss the moment of death. If you want to be there at the end, ask your family to let you know what is happening. Some people don’t want to be there at the final moments, and that’s okay. You can say goodbye to your sibling in other ways.





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, ‘Okay Dad, I need you to take me to the hospital now’. He passed away in hospital early on Sunday morning. He was 14 years old.”

Jane

“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. ”

Megan

“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

When your sibling dies

Knowing what might happen can help you feel more prepared when your sibling dies.

Signs that the person has died include:

- breathing stops
- pulse stops
- they don't respond to anything
- skin feels cold and looks pale
- eyes stop moving and may stay open
- pupils of the eyes stay large, even in bright light
- might lose control of the bowels or bladder as the muscles relax.

What do we have to do?

After your sibling dies, you don't have to do anything straight away. You and your family may want some time on your own to say goodbye.

Some families wish to sit quietly together and hold their hand, sleep next to their child or sibling, wash and brush their hair, or cut a lock of hair. Some people feel comfortable touching and holding their sibling, others don't. This is a personal decision and it's okay to do what feels right for you.

If your sibling dies at home

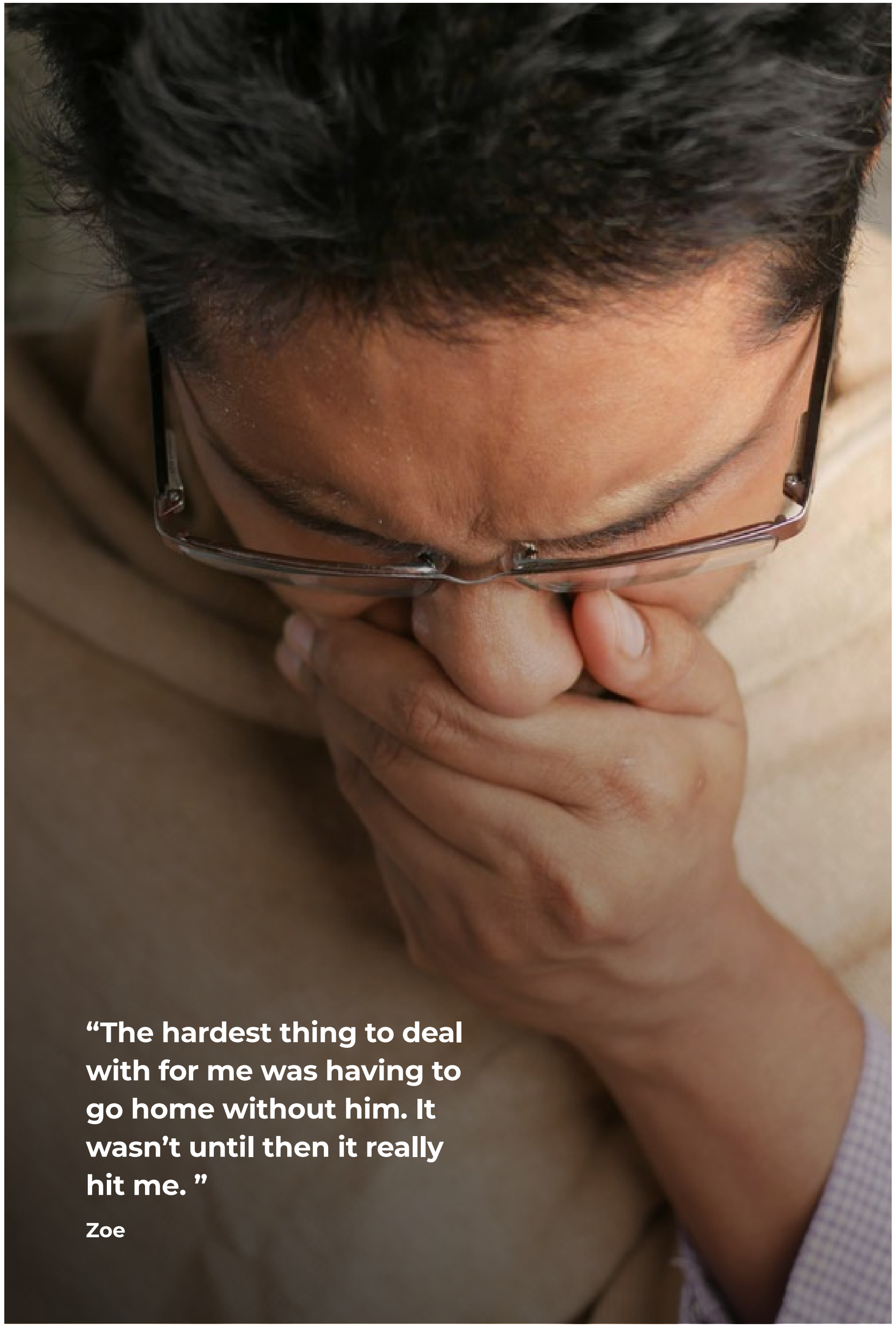
Your sibling's palliative care team will tell you what you need to do and who to call.

The doctor will need to come and check your sibling and sign a death certificate. But there's no rush to do this. If your sibling dies during the night, it's okay to wait until morning before you call the doctor and funeral director. They will talk you through the next steps.

If your sibling dies in a hospital or palliative care unit

The doctor will give your family a death certificate to give to the funeral director. Your family may want to arrange to have your sibling at home for a short time before the funeral. The funeral director might collect your sibling's body from the hospital or palliative care unit.

It can be hard to leave the hospital or palliative care unit without your sibling. The staff will support you and let your family know what you need to do next.



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

Funeral or memorial service

Some people say that a funeral or memorial service is for the living. It can give the family and friends of the person who died a chance to come together to support each other, share memories, laugh and cry, and say goodbye.

A funeral or memorial service is a very personal occasion. What it looks like might depend on your family's cultural and religious traditions. Your sibling may also have given you some ideas about what they would like before they died. There is no 'right' way.

Your family will probably start planning the funeral or memorial service within a couple of days after your sibling dies. But there's no rush, you don't need to think about the funeral or memorial service straight away. Tell your family if you want to be involved.

Most families use a funeral director to help organise the details of the day such as:

- When and 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?
- What sort of casket or coffin? Who will carry it? Can you decorate it?
- Will the family spend time with your sibling before the funeral (this is called a viewing)?
- Who will be invited?
- Who will speak? You can read letters from your sibling, poems or bits from the books or movies they liked. It's okay to make people laugh with funny stories.
- 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 – like music, flowers, clothes – can you add to show your sibling's personality?
- Will there be a gathering called a 'wake' after the service? This could be anything from a cup of tea and a biscuit to singing and dancing.

Being part of the funeral or memorial service may give you a sense of control. For example, you could do a reading, write a letter or poem, talk about your sibling, choose the music, put together photos or a slideshow, or place a photo or memento in the coffin.

> **"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**

> **"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**

Should I go?

You can decide whether you'd like to go to the funeral or memorial service. Attending your sibling's funeral or memorial service may be one of the hardest things that you will ever have to do. You don't have to put pressure on yourself to act or feel a certain way.

You might feel more comfortable going if you know more about what you will see, hear and do.

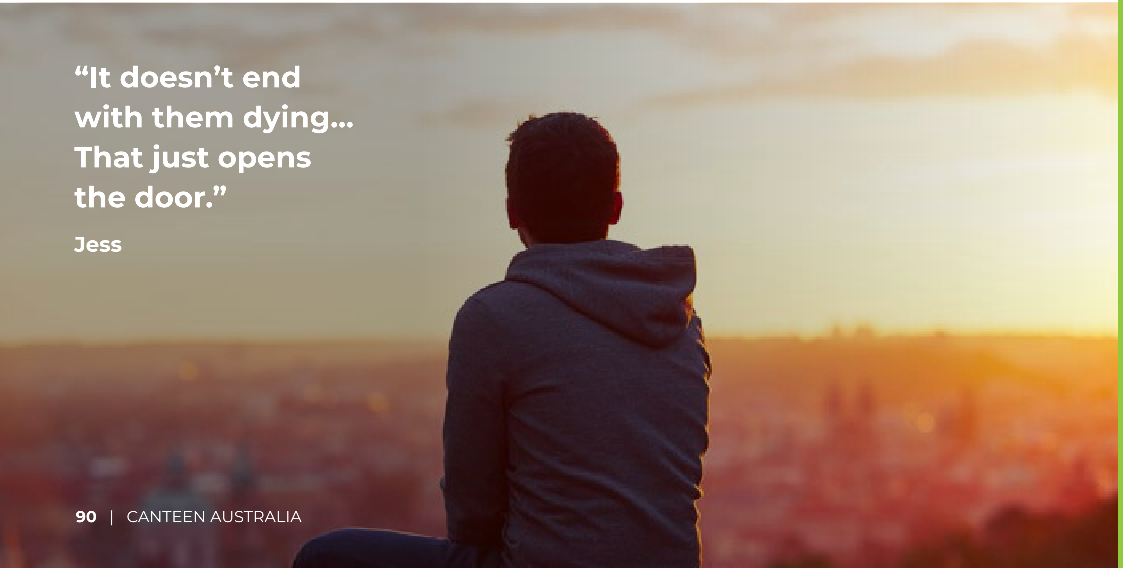
Many young people find going to the funeral helps them. They can share their sadness with their family and friends, hear other people's memories of their sibling and celebrate their sibling's life.

But it's okay if you don't want to go to the funeral. Or you may decide you feel more comfortable going to only part of the funeral like the service but not the burial or cremation. There are other ways you can say goodbye. You could plant a tree, light a candle, tie a message to a balloon and let it go, or visit a special place you used to go to together.

Grief

The mixture of thoughts and feelings you have as you deal with your sibling's death is called 'grief'. The way you show your grief is called 'mourning'. This will be different according to your culture, religion, family traditions, as well as your personality. The death of your sibling is one of most challenging things that will ever happen to you, so don't feel like you have to act a certain way or say particular things. Whatever you're feeling is okay.

Our book *Living with grief after cancer* focuses on how you deal with grief. You can download a copy from **canteen.org.au/resource**.



> **"It doesn't end with them dying... That just opens the door."**
>
> **Jess**

MORE INFORMATION

MORE INFORMATION AND SUPPORT

These organisations and websites can help you deal with a sibling who has cancer. We have included some of the most well-known and reliable sources.

Websites

General

Canteen
1800 226 833
canteen.org.au

Canteen helps you find the emotional strength you need to deal with cancer. We make cancer support stronger through connection – with other young people who 'get it' and with specialist staff who are always in your corner. We're here for the tough stuff and for a break from cancer when you need it.

Canteen Connect
canteenconnect.org

Canteen Connect is an online community where you can connect with other young people impacted by cancer, check out events and chat to a counsellor.

Cancer Council
13 11 20
cancer.org.au

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

Cancer Hub
cancerhub.org.au

Initiative of Camp Quality, Canteen and Redkite to provide a digital one-stop shop to help families with children aged up to 25 access practical and emotional support.

Stupid Cancer
stupidcancer.org

US site to empower people aged 15–39 who are affected by cancer.

Carer services

Carer Gateway
1800 422 737
carergateaway.gov.au

Practical information, support and resources for carers.

Young Carers Network
youngcarersnetwork.com.au

Support for young people up to age 25 who care for a family member or friend with an illness, disability or mental health issue.

Counselling

Beyond Blue
1300 22 4636
beyondblue.org.au/youth

The youth website of Beyond Blue. You can call or chat online with a counsellor or join a forum to connect with people who are going through similar experiences to you. It has links to other support organisations and fact sheets on depression.

headspace
1800 650 890
headspace.org.au

Online and telephone support service for young people who don't feel ready to attend a headspace centre in person.

Kids Helpline
1800 55 1800
kidshelpline.com.au

Free and confidential online counselling service available by phone or webchat as well as other helpful information on dealing with tough things.

Lifeline
13 11 14
lifeline.org.au

Offers 24-hour crisis support by phone, text or webchat.

QLife
1800 184 527
qlife.org.au

Provides peer support and referrals about sexuality, identity, gender, bodies, feelings or relationships through an anonymous online and phone counselling service. Available 3pm-midnight.

Reach Out
au.reachout.com

Online support and information for young people going through tough times. Includes information on depression, drugs and alcohol, relationships, sex and grief.

Suicide Call Back Service
1300 659 467
suicidecallbackservice.org.au

24-hour telephone and online counselling for people affected by suicide.

Funerals

Australian Funeral Directors Association
afda.org.au

Use the 'Find a Funeral Director' search to find a funeral director near where you live.

Funeral Celebrants Association Australia
funeralcelebrants.org.au

Use the 'Find a Celebrant' search to find a funeral celebrant near where you live.

National Funeral Directors Association of Australia
nfda.com.au

List of independent funeral directors and information about planning a funeral.

Legal and financial information

Centrelink
servicesaustralia.gov.au

Offers financial support for people with a long-term illness and their carers.

Youth Law Australia
yla.org.au

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

Fair Work Ombudsman
fairwork.gov.au

Government website with information on National Employment Standards, leave and making complaints.

Palliative care

CareSearch
caresearch.com.au

Australia Government website with resources and information about palliative care and how to find services in your area.

Palliative Care Australia
palliativecare.org.au

Information about palliative care services. Includes links to palliative care organisations in your state and provides directories of palliative care services in your area.

Planning ahead

Advance Care Planning Australia
1800 208 582
advancecareplanning.org.au

Information about planning for future health care, including advance care directives.

Dying to Talk Discussion Starters
palliativecare.au/campaign/discussion-starters

Palliative Care Australia series of books and cards to encourage people to talk about dying.

Talk to someone

Canteen	1800 226 833
Beyond Blue	1300 224 636
Cancer Council	13 11 20
eheadspace	1800 650 890
Kids Helpline	1800 55 1800
Lifeline	13 11 14
Reachout	**au.reachout.com**
Redkite Telephone Support	1800 592 410

ACKNOWLEDGEMENTS

Dealing with your sibling's cancer

First published 2024. Previously published as two separate titles: Dealing with your brother or sister's cancer: Now what? And When your brother or sister's cancer can't be cured: Now what?

Free copies of this book are available by calling Canteen on 1800 226 833 or by visiting **canteen.org.au/resource**.

We acknowledge the contribution of young people with cancer, health professionals and the editorial teams who have reviewed previous editions of these two titles.

This book was developed and funded by Canteen, the Australian organisation for young people living with cancer. Free copies of this book are available at **canteen.org.au/resource**. This book is provided free of charge to young people affected by cancer. If you would like to support the work of Canteen, please visit **canteen.org.au/donate**.

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