

GUIDES
TO THE
FL!PSIDE



**LIVING WITH
CANCER
AND BEYOND**

**YOUTH
CANCER
SERVICE**

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 website 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

Cancer is probably the last thing that anyone would invite into their lives. But now that it's here, having the right kind of help and information can make a big difference in dealing with it.

With everything that's happening, it can be hard to know where you are, let alone what's going to happen or what you might do.

This book provides information that other young people, and health professionals at Canteen, have found useful during and after treatment.

It's mainly aimed at young people who have recently been diagnosed with cancer. It will also be useful for young people who have had cancer for some time or who are cancer survivors.

Your need for information will probably change before, during and after treatment.

Different sections of this book will be relevant for you at different times. We recommend that you just read the bits that are important to you now, then put it away to refer to at another time.

This book is not a substitute for talking to your healthcare team (including doctors, nurses, social workers and others). If you are confused or worried about anything, talk to your healthcare team.

We've had a lot of input from other young people diagnosed with cancer. We thank them for sharing their experiences so generously.

We hope you find information that helps you get your head around the weird and scary world that you've just landed in.

CONTENTS

FINDING OUT

Getting support.....	9
Support organisations	11
Online support.....	11
How Canteen can support you.....	11
Youth Cancer Services	12
Finding out	13
Take a breath.....	13
What is cancer anyway?.....	16
Common questions.....	16
Talking about cancer	19
You've got what?	
Who to tell you have cancer.....	20
What do you have to tell?.....	22
How do you tell people?	22
Sharing online	24
But what if talking is too hard?	25
Telling children about cancer	26

HEART STUFF

Let's talk about feelings	29
Understanding grief and loss	30
Common feelings of grief	31
Finding a way through	33
Religious beliefs and spirituality	34
Where to find support	36
Managing other people's expectations	36
When you're LGBTQ+	37

LIFE STUFF

Taking care of yourself	49
Self-care.....	49
Infections	50
Getting enough sleep	50
Drugs and alcohol	51
Sex and cancer.....	51
Practical stuff.....	52
School and study.....	52
Work	58
Money matters.....	60
If you're from a rural or remote area	62



Legal stuff.....	63
Planning travel	65
Getting the right information.....	68

MEDICAL STUFF

Argh! Information overload!	73
Dr Google	75
Making treatment decisions.....	76
Treatment and support especially for young people	77
An insider's guide to hospitals.....	78
What happens in hospital?	78
If you live in a rural or remote area	80

RELATIONSHIPS

Managing relationships and cancer	85
If you're older	88
Siblings	91
Friends.....	92
Partners.....	97
Starting new relationships	100

BEYOND CANCER

Dealing with changes to your body.....	103
After treatment – late effects.....	106
If cancer returns	108
How will I feel?	109
Treatment decisions	110
When treatment doesn't work.....	111
Getting the right information.....	112
Making plans.....	112
Recording your treatment wishes	113
Beyond cancer.....	114
Redefining your life plans	115
What does it all mean?.....	116
Your identity	116
Uncertainty and worry	117
Relationships after cancer	118

MORE INFORMATION

More information and support	123
Canteen	123
Canteen Connect	123
Youth Cancer Services	123
Getting Cancer Young – YouTube channel ..	123
LGBTQI+ specific.....	124
Acknowledgements	125



FINDING OUT

GETTING SUPPORT

Getting the right sort of support when you're living with cancer is very important. While there may be lots of people looking after the physical side of things, it is just as important to look after the emotional stuff.

The cancer experience may last for a long time and the kind of support you need may change.

It's important to find people who will:

- listen to you
- not judge you
- be there when you need them
- keep things private (if you ask)
- be honest with you
- have a sense of humour

- not tell you that they know how you feel.

Your support people might be:

- Parents/carers
- Siblings
- Other relatives
- Friends
- Your partner
- Psychologists
- Social workers
- Teachers
- GPs
- Religious and community leaders
- Support groups
- Online support



“There was no one my age in the adult oncology unit where I received treatment. As an 18-year-old, I thought I had to be brave because I was young, fit and healthy and that I should be able to handle cancer. But I couldn’t, especially not alone. So please reach out for support and don’t feel pressure to handle everything by yourself.”

Fiona, 22



Support organisations

It’s likely your treating team may tell you about different organisations, like Canteen, that support people facing a similar cancer experience to you. That might include services specific to the type of cancer (e.g. Leukaemia Foundation), or local charities and groups. Different organisations offer different things, like accommodation, financial support, wish-granting and information. Depending on what you need right now, there may be a place to access the support you need, which can make all the difference.

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 needs, regardless of which organisation is providing the service. Visit cancerhub.org.au or call 1800 945 215.

Online support

There are lots of online support groups, blogs and forums for people who have been diagnosed with cancer, such as Canteen Connect (canteenconnect.org).

Joining an online support group is a good way to connect with people. It means you can chat to people but don’t need to meet face to face. Some people prefer to remain anonymous and simply read other people’s stories, which makes them feel like they’re not alone in what they are feeling or experiencing.

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 counsellor, help you get involved in a clinical trial and connect with other young people going through cancer.

Canteen can support you in other ways, including:

- Robots Service: stay connected to your school and friends even if you're stuck in hospital or at home.
- SPACE (Surviving, Prospering and Adjusting to the Cancer Experience) program: connect with other young cancer patients going through active treatment and develop coping skills to manage the impact of cancer on your life.
- Education and Career Service: get expert advice on keeping up with study or work as well as improving your job readiness skills.

- Question lists: use these as a prompt to get answers to the cancer questions that matter to you.

Find out more at canteen.org.au/youngpatients.

Youth Cancer Services

Cancer is tough for everyone to deal with, but especially for young people who have unique and complex medical and support needs.

Youth Cancer Services provide specialist treatment and support for young people with cancer aged 15 to 25 in major hospitals throughout Australia.

To find a service near you, visit youthcancer.com.au



“Before being officially diagnosed, there was some small part of me still in denial that all those tests and scans I was having done would show something bad. Even hearing the words ‘you have cancer’ is a surreal experience for someone so young. I’m grateful that after hearing those words I suddenly had a team of medical professionals who helped me in every possible way, and helped my family and I get through such a difficult time.”

Marnie, 25

FINDING OUT

If you are reading this section, you may have been told you have cancer. How the doctors arrived at that diagnosis may be a bit of a blur, but it probably involved lots of tests and scans and waiting for results.

Suddenly your world has been turned upside down and you're probably wondering, now what? Everyone reacts to a diagnosis in their own way, but it's never easy.

The truth is that, right now, whatever you're feeling is fine. You may be numb, confused, angry, sad, or scared. You may be feeling several or all of these emotions at once. You might feel blindsided or be asking 'why me?'. So much has changed, so fast. It's going to take time. Be kind to yourself – your heart and mind are adjusting to a lot of news.

You might have been told there's a clear plan for treatment and things start to move quickly. Or there may still be a lot to figure out and a lot of unknowns. Whatever the case, there will be lots of new words and terms, new people to meet, perhaps big decisions to make. But for now, go gently wherever you can – lean into the people who care about you, write down questions when you think of them and ask for support.

Take a breath

Been holding your breath since you found out you had cancer? As hard as it might be to focus on anything, here are a few things that might help you get a better handle on the situation.

Most young people survive cancer

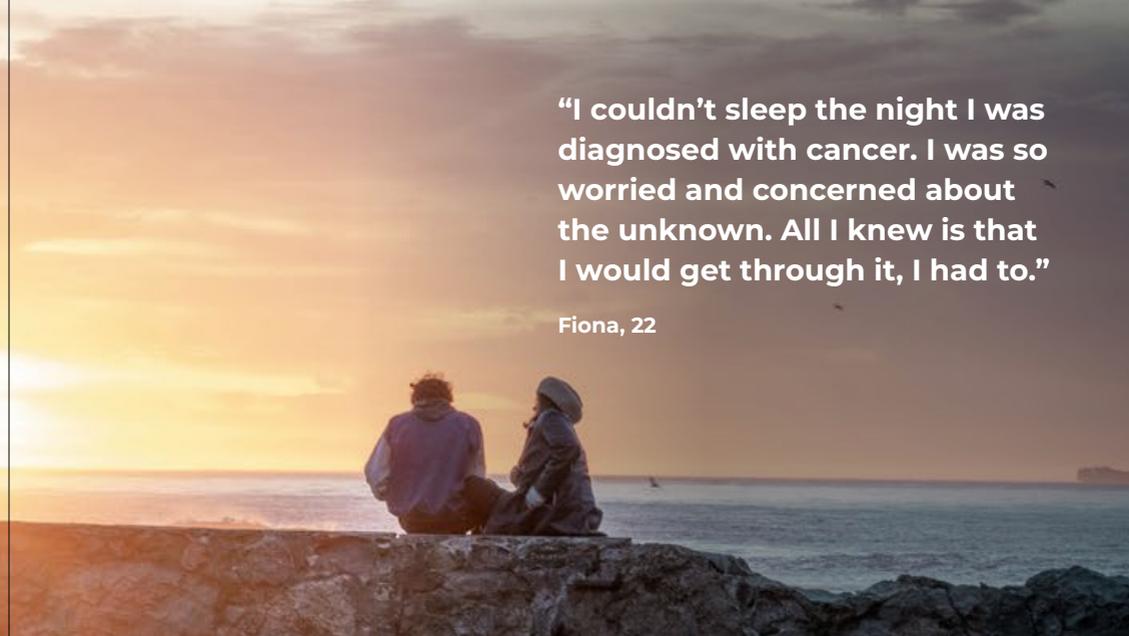
Discoveries of new and improved ways of diagnosing and treating cancer are being made all the time, leading to improved survival rates.

Even though you may be overwhelmed, worried or feeling sick, remembering this may give you some hope during tough times.

You're not alone

Although no one will feel the same way as you, lots of other young people live with cancer. It can help to know that others are experiencing similar things.

While it might feel like your family or friends don't really get what you're going through, they can still offer support and love. If want to feel heard and like you're not alone, Canteen can help you can meet and support other young people who understand how you feel because they are dealing with similar stuff. You can connect online 24/7 or go to Canteen events. Find out more at canteenconnect.org



“I couldn’t sleep the night I was diagnosed with cancer. I was so worried and concerned about the unknown. All I knew is that I would get through it, I had to.”

Fiona, 22

It’s not your fault

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

(Correct) knowledge is power

Things imagined can often feel worse than the reality. It’s common for our mind to think about the worst thing that can happen. Learning about your particular cancer and its treatments from a trustworthy source can take some of the fear out of it.

If you are wondering about anything at all, don’t be afraid to ask. Your healthcare team, including specialists, won’t mind you asking questions. See **page 70** or check out the list of questions to ask at canteen.org.au/questions.

Hang on to hope

Try to hang on to what gives you purpose, but sometimes this can be hard. Remember, this is your experience to manage. Be honest about how tough it might feel sometimes. Surround yourself with people who make you feel good and treat yourself with kindness and compassion. Learning more about the disease and its treatment may help you feel more hopeful.

Let your feelings out

Living with cancer is one of the hardest things you will ever have to do. Every person will react to the news and cope in their own way. Your thoughts and emotions can feel overwhelming, but they will come and go.

Things usually get easier

Cancer can make your life difficult – from side effects and changes to your body, to interrupting study and messing with your relationships and emotions. The way you feel about cancer and its impact on your life can change over time as you adjust to these changes and some new routines. Try to be patient and give yourself all the time you need.

Everyone’s situation is different

It can be helpful to learn about what sorts of things might happen. But there is no substitute for talking to your medical team about what to expect in your case. Everyone’s cancer, treatment, prognosis and side effects will be different. Comparing yourself to others may cause you to feel worse. The way

people react and deal with their feelings is unique too, so let yourself do it in your own way.

You can get answers and support

Even if it feels that your family and friends don’t really get what you’re going through, there are people out there who can help. Social workers and counsellors are really good at listening, linking you with support and helping you build skills to cope. 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 contact your nearest Youth Cancer Service (youthcancer.com.au).

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.

Common questions

How do they know I have cancer?

Cancer is usually noticed because of symptoms, such as extreme exhaustion, headaches or blurry vision. Some signs of cancer can easily be mistaken for other common illnesses (even a cold or flu).

If you were unwell for a long time, your doctor probably suggested doing some extra tests, such as x-rays, magnetic resonance imaging (MRI) scans or blood tests. You might be starting to get familiar with all that poking, prodding and scanning.

Less commonly, a person can have cancer but have no symptoms, and the cancer is discovered during tests, surgery or treatment for another illness.

If cancer has been found, you might have had more tests to find out what type of cancer it is and how far it has developed or spread. After a lot of appointments and waiting for results, the doctors would have given you your diagnosis.

How did I 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.

Some people worry that there is something they did to cause the cancer, but this is unhelpful thinking. There is nothing you did caused the cancer. You might worry that smoking, drinking or taking other drugs contributed to you getting cancer. Although there is a link between these things and some cancers, it is very unlikely to be the case in people your age. Particularly in young people, cancer can just happen.

“My diagnosis came with an underlying neurological condition called neurofibromatosis. As a result, my doctors told me I would be at high risk of developing a cancerous tumour as I grew up. So I would always have tests done to ensure my tiny tumours haven't turned. I knew there would be a 50/50 chance of them developing; Therefore, it wasn't unexpected or unusual.”

Amy, 25

Can they cure it?

Most young people survive cancer. However, the reality is that sometimes cancer cannot be cured. Many factors affect this, including the type of cancer you have, where it is and how advanced it is when diagnosed.

The likely outcome of your particular cancer is called your prognosis, which is different for every person. Talk to your doctor about what they expect in your case. It is important to get the right information and support.

How long does treatment take?

Everyone is different and everyone's cancer is different. Some cancers may take 3 months to treat, while other cancers may take 3 years or more. One cancer treatment may have bad side effects and other treatments may have none.

This may seem really unfair, but it depends on the type of cancer and the type of treatment.

“Deciding if and when I should tell people about my cancer is something I’m still figuring out years after finishing treatment. Most of the time I only bring it up with someone new if it naturally comes into conversation, and I’ve gotten used to every single person having a unique reaction to finding out.”

Marnie, 25

TALKING ABOUT CANCER

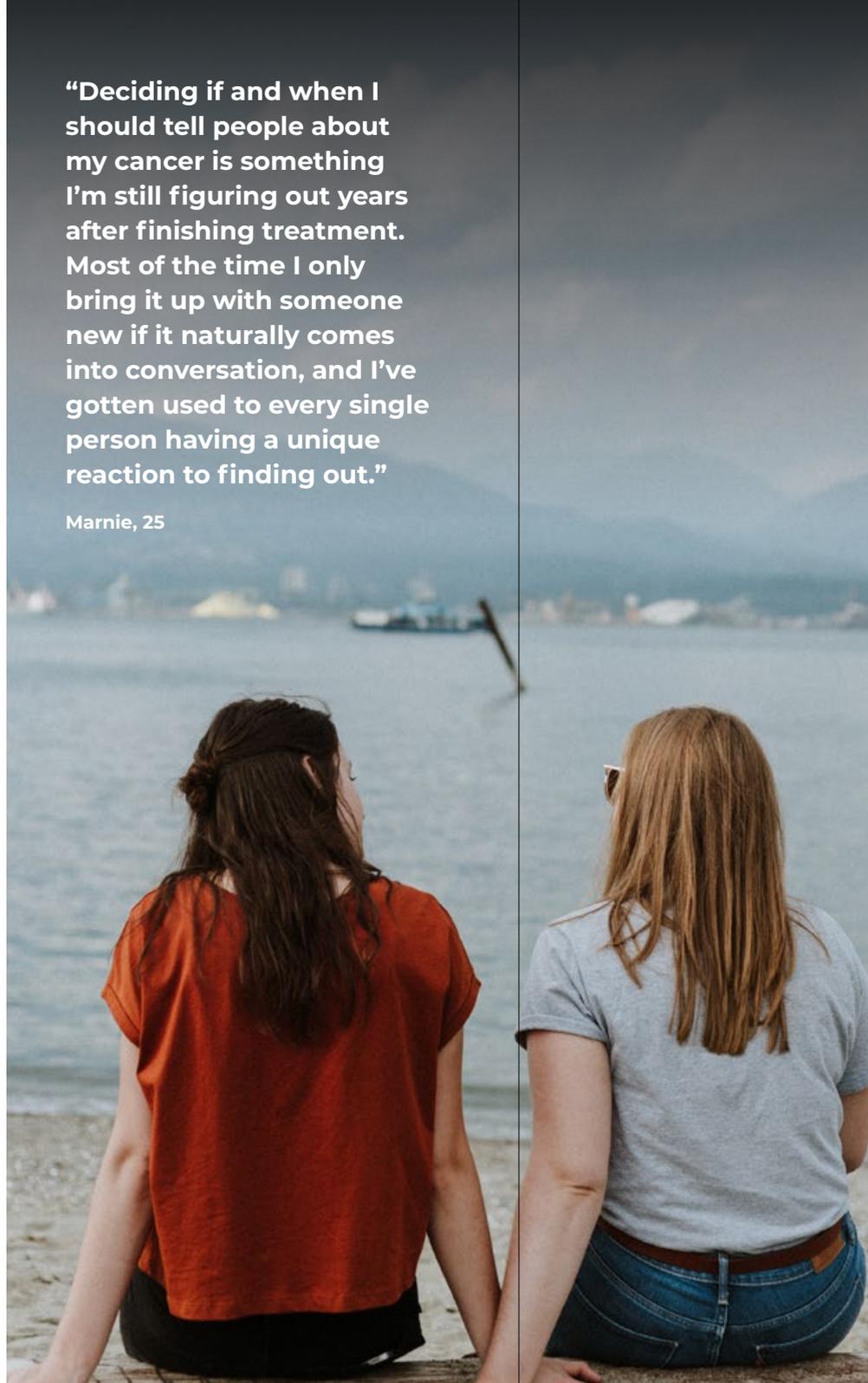
Cancer is a tough topic. You may have stuff that you want to know but you're not sure how to ask or who to ask. You may have many fears and concerns but don't want to worry or upset people.

Lots of websites and videos show families sitting around sharing their innermost thoughts, but the reality is that not all families talk openly and honestly about what is happening or how they feel. How your family communicates about cancer may depend on how you have always communicated and your situation. A cancer diagnosis isn't going to suddenly change that.

You shouldn't go through cancer alone and you may be surprised how much you can manage when you talk about what you're going through. So, the trick is to find the right time and the right way to talk about stuff.

These are some questions to think about before you tell others:

- What do you want people to know?
- What support do you need?
- Who else knows – who can they speak to?
- How would you like them to ask questions after the first conversation – what is the best way to stay in touch?



You've got what? Who to tell you have cancer

Talking about cancer with your closest friends and family can be challenging enough, but how do you tell people in your wider social circle, such as friends at school, uni, TAFE or work?

Deciding who to tell and what to tell them can be difficult. You might be worried about how people will react and afraid that they will treat you differently.

It is your right to decide who to tell about your diagnosis and treatment, including how much you share. There will be different things to consider depending on your situation, such as: what kind of treatment you are having and for how long, who you need to support you (e.g. teachers, bosses and colleagues), and the type of relationships you have with certain people. The treatment process or side effects of the treatment can be noticeable to others and make it tricky not to tell others what is going on.

“After being diagnosed, I told my whole family. I would suggest that it’s best to call, not to text, as they can’t hear your emotions in your voice when you text. Telling people right away isn’t for everyone. Sometimes you need to take your time and take in the information first.”

Amy 25



Reasons to tell:

- To get support from people you trust and who you know will be there for you.
- To feel less alone.
- To make it easier to take time off from study and work for treatment. If you tell your teachers and boss the real reason, they are more likely to support you. Classmates and colleagues you trust can help you keep up or return to study and work.
- If treatment affects your energy and concentration levels, it might be better for people to know there is a reason for this instead of them making one up. That doesn't mean you need to tell them everything.

Reasons not to tell:

- You may feel embarrassed talking about your diagnosis, especially if it affects private parts of your body (such as your breasts or testicles).
- You can't be bothered repeating the same story and answering the same questions over and over.
- You may feel your life is now being dominated by a disease that you didn't ask to have. Maybe work, school, uni or TAFE are one of the only places where you are not feeling like you are defined by cancer.
- People may want to share their own cancer stories with you – good, bad and ugly. Again, you choose if and how you respond to this and that may mean not sharing your own story.

WHAT DO YOU HAVE TO TELL?

If you're a student, there is no legal obligation in Australia for you to tell your school, uni or TAFE about the cancer diagnosis. But if you think treatment and side effects will affect your marks and ability to keep up with course requirements, it is a good idea to let your teachers or student centre know. They may be able to adjust your workload or exams if necessary.

If you are working, telling your boss or the human resource (HR) manager will make it easier to take time off. They may also be able to help in other ways, such as changing your work hours or adjusting your work space.

Canteen's Education and Career Service (canteen.org.au/ecs) can help you work out what to do and keep you connected to study or work during and after treatment.

How do you tell people?

Here are some tips for talking about cancer:

- Practice what you want to say before you start. It might help to write it down or read from a script you've prepared.
- Expect that it will feel hard at first and there may be lots of silent moments. That's okay.
- Accept how people react. If you or other people get upset – keep going or try again later. You don't need to cover everything in one conversation.

- Do something else at the same time – like doing some gardening or cleaning up in the kitchen – talking can be easier when the focus isn't directly on you.
- Take it slowly. This whole thing is strange and scary, and it may take time to work out the best way to talk to others.
- Go online and check out some blogs or forums and see how other people told people and their experiences.
- Give permission to your friends, family or teachers to tell other people if you want them to know but don't want to tell them yourself. Make sure they understand if you want to keep the information private.
- Think about ways to deal with insensitive or silly questions. You could suggest people learn more about your kind of cancer from a website (like the Cancer Council, cancer.org.au).
- If you don't know your teachers, lecturers or bosses very well, you may find it easier to email them. You can use email templates on Canteen Connect (canteenconnect.org) to do this.
- Canteen can help you develop the skills you need to tell people you have cancer. They can also help you negotiate school, uni, TAFE and work during this time.

“You don't have to tell anything to anybody. Sharing your cancer experience always starts with you – don't feel like it, don't have to.”

Ezra, 21



Sharing online

Some people use social media to let their broader network know they have cancer. But before you do, think about the impact of this approach - once the news is 'out there', you can't take it back and it could be shared widely. You may decide you'd prefer to share in closed/private groups.

It's a good idea to talk with those closest to you about how you want your diagnosis shared online - whether any updates and permissions come directly from you, or if a trusted partner or family member can do this for you. See **page 96** for more about using social media to stay in touch with family and friends.

"The most challenging part at the start of my journey was telling my new friends. I never wanted to burden anyone with the news. I did individually call my close friends and then later shared the news on Facebook. It may be scary to tell people about this, but I got so much support when I did."

Finoa, 22



But what if talking is too hard?

Some days you may not want to talk about cancer but still want to express your emotions, just for yourself, or to let your family, friends or partner know how you are feeling.

You can:

- draw pictures, write or play music
- keep a journal - you can choose to keep it private or share it with your family or friends
- write a letter, email or blog

- find songs that say it for you
- send a text message
- leave signs on your bedroom door.

If you or your family really find it hard to talk to each other about cancer, it may help to speak to a counsellor or social worker. They can give you ideas on how to communicate with each other or even be there if you need them. Contact Canteen (canteen.org.au/counselling) for information about free counselling services.

Telling children about cancer

If you have children, telling them that you have cancer can be difficult. The younger the child, the longer it will take them to understand what is happening. Your children will probably be worried about you but also concerned about what will happen to them.

Your children will most likely know something is wrong, especially if your appearance changes, so it's best to be honest. Explaining what's happening will help them feel less confused, anxious or left out.

These tips may help:

- Give children the opportunity to talk about their feelings.
- Share information in bite-sized chunks to help them adjust.
- Reassure them that it is not anyone's fault and they didn't cause the cancer.

- Explain that cancer is not contagious and they can't "catch it".
- Let them know it's okay to ask questions.

If you feel uncertain about how to have this conversation with your children, talk to your treatment team or contact Canteen (canteen.org.au/parents) for support. It might also be a good idea to chat with a counsellor in your treatment team and you can also connect with other parents through the Parenting through Cancer community (parentingthroughcancer.org.au).

Cancer Council NSW has a great resource about how to communicate with your child about your diagnosis and treatment. You can download Talking to Kids About Cancer from cancercouncil.com.au or call 13 11 20 to order a free copy.



HEART STUFF



LET'S TALK ABOUT FEELINGS

Dealing with a cancer diagnosis can bring up all sorts of feelings. Some of these feelings might come as a surprise to you. At times, you may find it difficult to pinpoint what you are feeling and why.

The main thing to remember is that there is no right or wrong way to feel. It is also okay to not know what you're feeling.

Many young people describe having cancer as like being on an emotional rollercoaster. You feel like you are

racing along with no control and have massive ups and downs on the way.

You might not be naturally comfortable sharing your feelings and may hope they will go away if you ignore them. Feelings are not good or bad; they are just feelings. Even if you keep them hidden or try to ignore them, they will still just be there.

When feelings get bottled up, they need to get out somehow and this can lead to emotional meltdowns, angry outbursts, and unsafe behaviour. As hard as it may be, finding ways to express what you are feeling is important in helping you to deal with the stress of living with cancer.

Understanding grief and loss

Grief is a natural reaction to a loss. You might think grief is just about when someone dies but people who live with cancer may grieve for lots of things. You may have felt this sense of loss when you were told you had cancer, but it can also happen at other times during and after treatment. It can feel like everything has changed and that life will never be the same again.

Other reasons for your grief include:

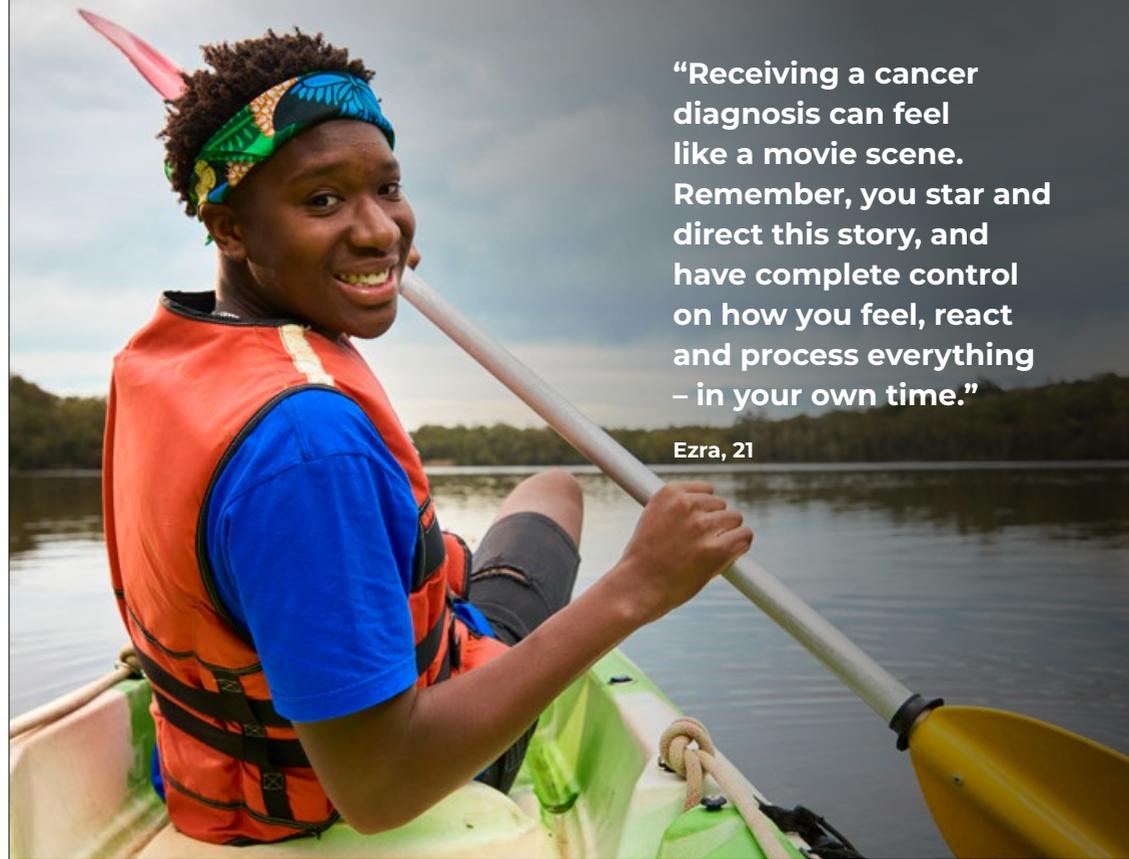
- feeling like your body doesn't work the way it used to
- you look different
- you miss the life you used to have or that plans have changed
- you don't feel as connected to your friends
- relationships with family might have changed
- miss school, uni or TAFE for a while or quit your job to focus on your health
- missing out on having fun like everyone else your age.

When you're grieving, it is normal to experience many different thoughts and feelings. Your response may be unexpected and you may be surprised by your response.

Grieving in different ways

Every person grieves differently. You and your family and friends may react to your diagnosis in similar or different ways. For example, some people might take on a 'management role' and become practical in their thinking and choose not to talk about their feelings very often. Others might cry and openly talk about how they feel.

It can be helpful to think about your response and how this might be different to your family and friends. You might notice ways that you – and possibly others – can cope in a more helpful way. It is important to be practical at times and it is also important to allow ourselves to feel our emotions. Finding a balance between the two can be hard to achieve, but it could help you to get through this difficult time.



“Receiving a cancer diagnosis can feel like a movie scene. Remember, you star and direct this story, and have complete control on how you feel, react and process everything – in your own time.”

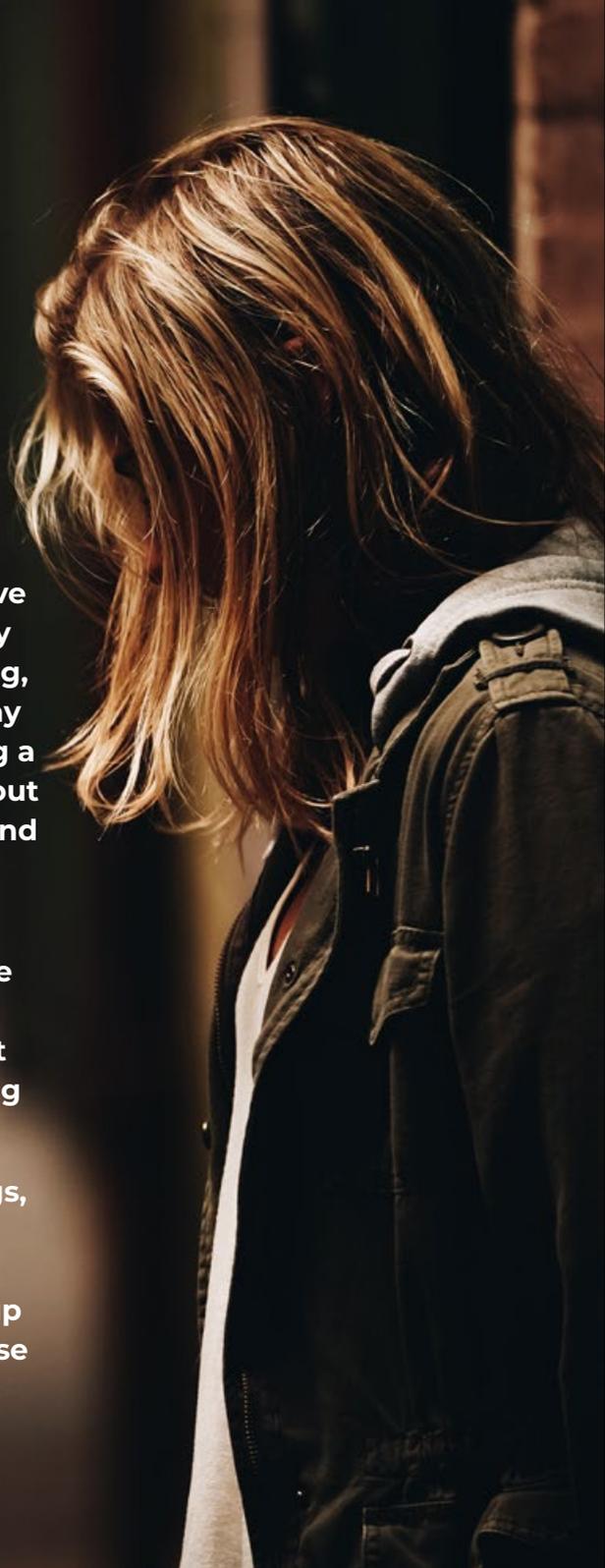
Ezra, 21

Common feelings of grief

Remember, there is no right or wrong way to grieve, and there is no set timeframe of how long it lasts. Many young people have described how they can sometimes feel many emotions all at once or feel just plain numb. These feelings may include some or all of the following:

- shock and disbelief
- pain
- fear and uncertainty
- stress
- regret
- abandonment
- anger
- sadness
- frustration
- hope
- clarity
- guilt
- embarrassment
- jealousy or longing for your old life
- loneliness
- feeling like you have no purpose.





“Through my cancer experience, my emotions were all over the place. I have many journals of my journey that record how I was feeling, whether I had a fantastic day or a not so good day. Having a journal helped me write about how people didn’t understand what I was going through.

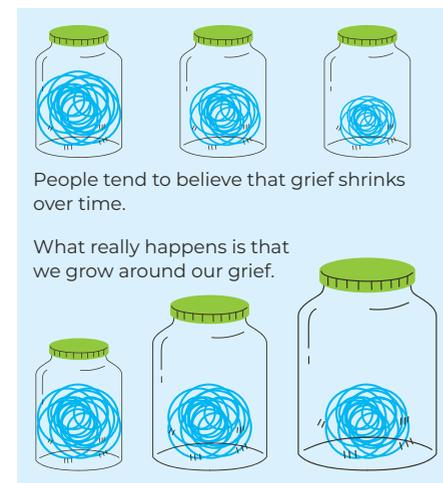
There were days where I hit impressive goals. Then there were days where I used foul language because I couldn’t go out or had trouble finding my words.

I learnt to accept my feelings, cry, write them down and realise that your life is your life; you can’t always keep up with your friends. You choose your path.”

Amy, 25

For some young people, life does not make sense to them anymore and they struggle to find purpose and direction. Others may feel like they have no energy and they stop doing things they once enjoyed.

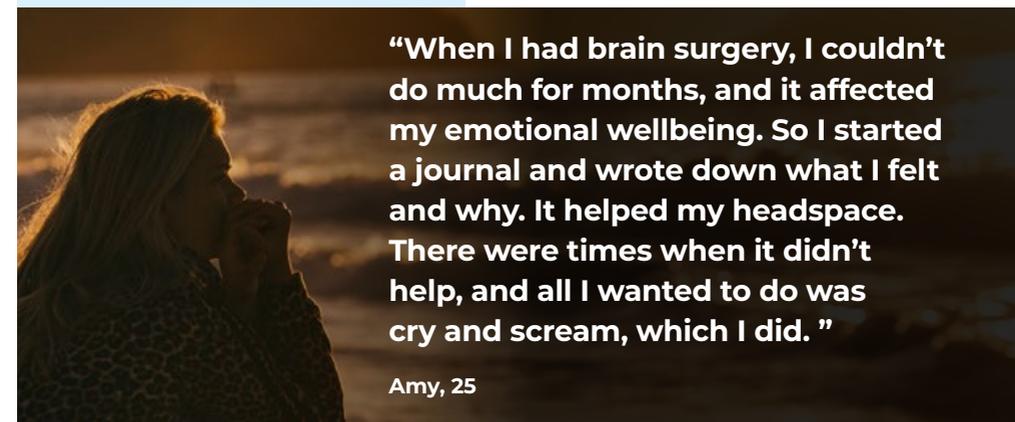
Loss is not a single event. It can cause grief to come and go in waves, so there will be good days and bad days. Grief doesn’t necessarily lessen over time. It can remain present and big and instead you grow around it – like in the image below. It’s hard to imagine now, but it won’t always feel this difficult.



Finding a way through

It’s important to find ways to take care of yourself and to develop healthy habits throughout the grief process. Sometimes when young people are going through tough times, they may deliberately hurt themselves or turn to alcohol or other drugs to try to get relief from the pain. Even though this might seem helpful at the time, this short-term ‘fix’ may cause more issues down the track, including having a negative impact on your health and relationships.

There are ways to live with the grief so that you can continue to move forward in your life and not get ‘stuck’. Look for positive ways to get through the challenging feelings and situations you may experience. Finding strategies that work for you can help with the overwhelming feelings and grief you may feel at different points in your journey.



“When I had brain surgery, I couldn’t do much for months, and it affected my emotional wellbeing. So I started a journal and wrote down what I felt and why. It helped my headspace. There were times when it didn’t help, and all I wanted to do was cry and scream, which I did.”

Amy, 25

Ways to cope with grief

- Write a journal or blog – share it with the world or keep it to yourself.
- Have a routine – a weekly planner and to-do list can help things seem a bit more manageable. Be careful not to take on too much.
- Exercise – a walk, swim, yoga or bike ride a few times a week can reduce stress and help you to feel better (talk to your treatment team first).
- Try something new – ever wanted to learn to play guitar or paint? Learning something new might help to distract you from the worries of cancer and give you a sense of achievement.
- Meditate – you might be amazed at how good this feels. (Try downloading a meditation app to help get started)
- Hang out with positive and caring people.

- Keep doing your usual things – connect with your family and friends, listen to your favourite music and try to do as many of the things you used to do as possible.
- Rest and get plenty of sleep – when you're really tired, emotions and stress can be even harder to deal with.
- Join a support group – get in touch with people who understand what you're going through and can share tips, support and info. You might want to check out Canteen Connect (canteenconnect.org).

Religious beliefs and spirituality

A cancer diagnosis can make you start to think about your spiritual beliefs.

Spirituality is a broad term for how you make meaning in the world

– through nature, people around you, culture, tradition and religious beliefs. Going through something like cancer will likely change how you feel about life, death and everything in between. That's generally because you're seeing things from a new perspective.

It's okay to not have the answers, to change your mind about things, and to explore how you feel about life. In fact, it's an important part of being a young person. You can talk about these things with people you trust or look up to; through art, music, reading and self-expression; or just being in places that mean something to you.

If religion is a big part of your life, it can provide you with comfort and support as you deal with having cancer. But, the experience may also make you question your religious

beliefs. It is common for young people to do this anyway.

If you no longer want to join in the customs and rituals of your family's religion, it might contribute to some conflicts at home.

If you weren't particularly interested in religion before, you might be drawn towards some sort of formal religion.

Religion can help people make sense of what you are going through.

Even if you are not into traditional religion, you might find that you develop an interest in other beliefs and types of spirituality. It can be a way to get some answers or find meaning in what is otherwise an unfair and tough situation.



Where to find support

Even though grief is normal, it can be a difficult and isolating experience. You might struggle to cope with how you're feeling, and it may affect how you cope at school, work and in your relationships. It's important to reach out to someone you trust who can listen and support you through it.

Canteen offers counselling and individual support 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).

Although it's normal to have many reactions to your diagnosis, if you notice changes in your life that are getting difficult to manage and are affecting your daily activities, studies, work, relationships or self-esteem, it is a good idea to get extra support. Talk to your GP or treatment team.

Managing other people's expectations

Young people say that their cancer experience has taught them so

much about themselves and life, has made them appreciate the little things and helped them to find a strength they didn't know they had.

But staying positive and trying to remain composed and 'chilled' all the time can be a difficult expectation to live up to. You may feel pressure to 'keep it together'. Some people in your life may have even told you to keep it together too.

Having cancer may be one of the biggest and scariest things that you ever face, and it's natural to be worried and upset and to show it.

So, this is a reminder that it's okay to:

- still get angry with the people you love and not be the perfect child, sibling, friend or partner
- not feel brave all the time or think that the whole experience will be good for you
- not feel positive all the time
- not feel 'lucky' that the cancer has been cured
- not feel like you've been through a life-altering transformation
- not feel special.



When you're LGBTQI+

Lesbian, gay, bisexual, transgender, queer (LGBTQI+) and other young people with diverse sexualities and genders have unique health needs and concerns when diagnosed with cancer.

If you're a member of the LGBTQI+ communities, you might have experienced bullying and discrimination in the past for being different. This is even more likely if you're trans or gender diverse. Facing bullying and discrimination can be stressful and upsetting, and may make it harder for you to ask for help in healthcare settings. You have the right to receive care in a culturally safe and inclusive health setting.

Your rights at the doctor

Everyone has certain rights when receiving health care in Australia. These rights are set out in the Australian Charter of Healthcare Rights. They apply to the care

you receive in public and private hospitals and by your GP. Your 7 rights include: access, safety, respect, partnership, information, privacy and giving feedback.

This means, that if you're receiving care that is culturally safe and inclusive, you should feel:

- that you can access services that meet your unique needs
- have your body, sexual orientation and gender identity affirmed and respected
- you can include people that you want in your health care and decision-making
- your partner/s and chosen family are recognised and respected
- have your personal and health information kept private
- be able to give feedback or make a complaint.

For more information, visit safetyandquality.gov.au/your-rights.

"It's tough enough going through the cancer experience. I don't think any expectation applies to our reality – other than living out our blessings."

Ezra, 21



When a service isn't culturally safe or inclusive

If you're unhappy about the way a health professional or service has treated you, you can make a complaint. It is a good idea to speak directly to the health professional first if that feels okay for you to do so. You can do this yourself, or you can ask a family member or carer to represent you. You can also speak to another health professional in their organisation, if you prefer.

You can also go directly to your state or territory health complaints organisation if you do not feel safe or comfortable complaining to the provider. Complaints will be managed differently depending on the type of concern and where you live. Contact the Australian Human Rights Commission on 1300 656

419 or humanrights.gov.au, or the discrimination agency in your state or territory to lodge a complaint.

But if you choose not to complain, it's also okay to ask to change doctors. You may be asked for the reason why you want to change doctors, or there may not be another doctor available. It can help to speak to the health service manager or the social worker about what your worries are (even if you don't want to formally make a complaint) and any avenues for the health service to support you.

Common concerns you may have

Exploring your identity – It's common for young people to question and explore their identity, including their sexual orientation and gender identity. Having to

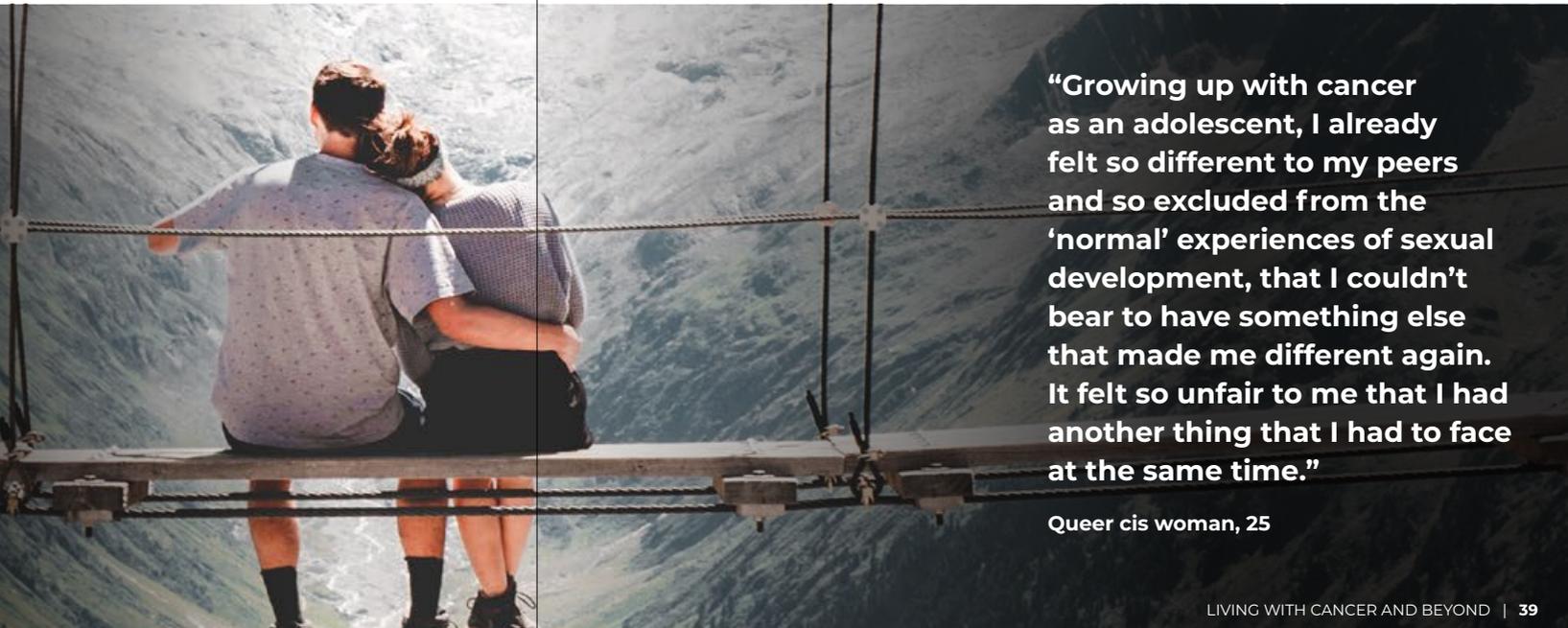
also deal with cancer can feel overwhelming. You might feel like you've always known that you are part of the LGBTQ+ community, or recently started to question or explore your identity. In either case, having treatment can make figuring out your sexual orientation and/or gender identity more complicated.

Cancer can make you re-examine your identity. Some treatment side effects, such as hair loss and loss of a body part, can be upsetting because they change the things that make you, you. Or the changes may help affirm your identity. Whatever you're feeling, it's okay. Adjusting to the diagnosis is a process that you can take at your own pace.

Feeling isolated – If you already feel different from your friends because of your sexual orientation and/or gender identity, cancer can make

you feel even more isolated. And while cancer support groups are a way of connecting with people who understand what you're going through on your cancer care journey, you might worry about feeling isolated or excluded when trying to discuss issues around relationships, sexuality, gender and fertility.

There are other organisations you can connect with that understand your LGBTQIA+ experience. Canteen offers counselling in person, via phone or online, and can also support through email or direct messaging. Minus18 (minus18.org.au) provides support for LGBTQIA+ young people across Australia. You can also chat with a volunteer LGBTIQ+ counsellor at QLife on 1800 184 527, or via webchat at qlife.org.au.



“I came out as gay when I was nearly 15, so just before I was diagnosed. I was still sort of very uncomfortable with myself, and still trying to figure everything out. And then I was diagnosed with cancer, and that sort of took precedence. Going, ‘Okay, I actually have to acutely survive this now. Not even think about that!’”

Carter, gay cis man, 20

“Growing up with cancer as an adolescent, I already felt so different to my peers and so excluded from the ‘normal’ experiences of sexual development, that I couldn’t bear to have something else that made me different again. It felt so unfair to me that I had another thing that I had to face at the same time.”

Queer cis woman, 25

Worrying about coming out – Going through cancer treatment means seeing a lot of different health professionals. And some you'll see for a long time. You might need to decide whether to 'come out' and disclose your sexual orientation and/or gender identity over and over again, and this can feel stressful and exhausting.

You might wonder if your sexual orientation and/or gender identity are relevant to your care, worry about how health professionals will react, whether it will affect your care, or whether they will keep any information you tell them private, especially if you're not out with your own parent, carer or family. Your sexual orientation and/or gender identity are an important

part of who you are, and knowing more about you helps health care professional explain how treatments and side effects may affect you. Sharing your sexual orientation and gender identity is also a good way for your health care team to consider issues they may not have thought were relevant. For example, how your cancer treatment may affect your gender expression, or who do you want to help make decisions. See **page 70** for other questions.

For most young people, coming out is a gradual process. You can choose to just tell the health care professionals you see all the time or feel comfortable with. If you experience negative reactions or feel distressed, you can seek support (**page 36**).

"I don't like how it was assumed that I was straight. The conversation never opened up about my sexuality which really pisses me off."

Bisexual cis woman, 23

"I'm completely out because I choose to be. I will only not disclose it if I don't feel comfortable."

Genderqueer/trans man attracted to men/masc nonbinary people, 23



"I also tend to add it [the fact that I am trans] on my intake forms because it helps the practitioner understand what to expect. I never used to do this but after I had an ECG with a nurse who looked at my bare chest horrified and asked me what was wrong, I decided that it hurt too much not to disclose. People seem to be very easily shocked by physical differences."

Genderqueer/trans man attracted to men/masc nonbinary people, 23

Sharing your name and pronouns

– You might find that health professionals assume that you identify with the gender you were assigned at birth (cisgender). This is more likely when hospital and health records show the gender assigned at birth and/or dead name. Having to deal with misgendering can be distressing and can make some people feel invisible. You might want to introduce yourself with your pronouns and preferred name. Wearing a pronoun badge is another way to remind people of your pronouns. If the misgendering continues, you may want to make a complaint, or ask to work with a different health care team.

Introducing your partner/s and family – If you have a partner/partners, encourage them to come to your appointments. This lets your

doctors know who's important to you. If you feel comfortable, you might like to introduce your partner with their name and relationship to you, such as, "This is Angie. She's my girlfriend". If your family includes members of your biological family or family of origin, and others who you think of as your chosen family, ask them to come to your appointments for support.

Keeping your identity private – If you disclose your sexual orientation and/or gender identity to your doctor, they should keep this information private. If the doctor discloses your sexual orientation and/or gender identity to others without your consent, this can be hurtful and upsetting. If you can, let your doctor know that their action has created a difficult situation for you. You have the right to feel safe and respected.

Avoid teaching others about your needs

– Even though it can feel that there is growing acceptance of LGBTQI+ people, you may feel that you have to teach others about your sexual orientation and/or gender identity. And if you're trans or non-binary, you might find people don't understand what this means. Having to constantly explain yourself can be draining. And if you're still learning yourself, don't feel you have to take on the work of educating others. You could point health professionals to websites such as minus18.org.au or transhub.org.au for more information.

Where to find support

Getting support may be helpful for dealing with feeling of distress. You may wish to reach out to friends and family members. There are also organisations that provide information and support:

- **QLife** – an anonymous and free LGBTIQ+ peer support and referral for people in Australia wanting to talk about sexuality, identity, gender, bodies, feelings or relationships. Call 1800 184 527 (3pm to midnight daily) or visit qlife.org.au to chat online.
- **TransHub** – an online information source for trans and gender diverse people, their loved ones, allies and health providers.
- **DocDir website** – This website lists doctors who are welcoming and safe for LGBTQI+ communities, and know about health needs and concerns. Visit docdir.org.au.
- **Genders, Bodies and Relationships passport** – You can use this booklet to tell your healthcare team about your gender, body and relationships. Visit lgbtiqhealth.org.au/passport.

“I'm aware that I look quite different to what they might expect a typical man's chest to look like. It's just that curiosity should be satiated with professional training and development. I'm very happy to answer people in good faith but it does take an emotional toll on me.”

Genderqueer/trans man attracted to men/masc nonbinary people, 23

Signs that services are LGBTQI+ friendly

Receiving care from services that are safe and inclusive can make you feel accepted. It may also mean that you'll receive care that is affirming of your sexual orientation and/or gender identity.



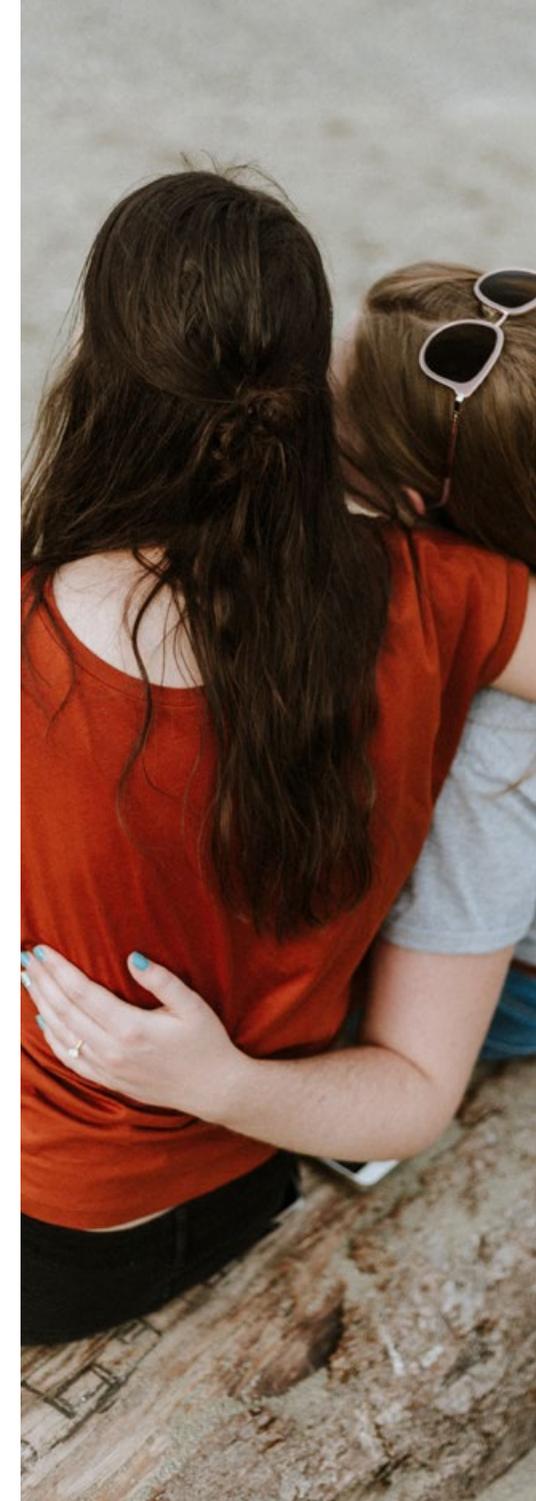
Look for signs of welcome – These can include rainbow or pride stickers and flags, images of LGBTQI+ people in posters, and staff wearing rainbow lanyards.



Check forms – Do they include room to record your pronouns, preferred name, non-binary gender options, and sexual orientation?



Ask about training and policies – You can ask if health professionals and other staff have attended inclusivity training. Learning more about LGBTQI+ issues means people are more likely to have a better understanding of relevant issue. Everyone deserves to be treated with courtesy and respect, regardless of sexual orientation, gender identity, and/or variations of sex characteristics. You might wish to ask about their inclusion and anti-discrimination policies.



Trans and gender-diverse people

There are a range of steps trans and gender diverse people may take to affirm their gender. There is no right or wrong way to affirm your gender. It might include:

- **Social affirmation**, such as choosing your chosen name and pronouns, coming out, wearing new clothing, and cutting or shaving your hair.
- **Medical affirmation**, such as taking some form of hormones, such oestrogen, testosterone, or progesterone, or having affirmative surgeries, such as chest surgery, genital surgery, facial surgeries, or more.
- **Legal affirmation**, such as updating your name or gender marker at work, school, or on forms of ID.

You don't need to tell your health professionals that you're trans, but knowing this information may help them give you the information that is right for you. If you feel understood by your health professional, you are more likely to trust them. It may also mean you are more likely to complete treatment and have a better experience accessing cancer care.

If you have started any medical interventions to affirm your gender, such as taking hormones or having surgery, you might have questions about how cancer treatment might interrupt or change your plans.

Finding cancer specialists who understand how trans health needs affect cancer care can be challenging, which can be frustrating. Support is available if you are feeling distressed. You can call minus18 or chat with counsellors at QLife on 1800 184 527.

Peter MacCallum Cancer Centre has a great booklet specifically for young people who identify as LGBTQI+ and have cancer called Being OK...Being You. You can download a copy from petermac.org. Cancer Council's booklet LGBTQI+ People and Cancer also includes information about how cancer and treatment may affect LGBTQI+ people. Visit cancercouncil.com.au



“I double-check with practitioners that they have read my report, and make sure that they know that I am transgender. This helps me to ascertain what they think about that and how much they know about it, and it also gives them an opportunity to ask any questions. Being transgender is an important part of my care because it means that my body and health outcomes are different to the general population and therefore my treatment should be viewed with this in mind.”

Genderqueer/man, 23



When you're born with intersex variations

The term intersex refers to people who are born with genetic, hormonal or physical sex characteristics that do not fit neatly with the medical or social norms for male and female bodies. These variations of sex characteristics may be apparent at birth or much later. There are at least 40 known variations and may include complete androgen insensitivity; 46,XY complete gonadal dysgenesis (Swyer syndrome); and 47,XXY (Klinefelter syndrome).

Having an intersex variation is about biological features (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) and not your sexual orientation or gender identity. Intersex people have a diverse range of genders and sexualities.

Knowledge in the community about intersex variations is still developing, and some people will not have heard of intersex variations or differences in sexual development. This can result in misconceptions

and assumptions about what being intersex means and what intersex people need.

You don't need to tell your health professionals that you have an intersex variation, but knowing this may help them give you the information that is right for you. And depending on the type of cancer you are diagnosed with, knowing about your intersex variation may help guide your care and treatment.

Treatment for cancer may bring back memories of any previous medical experiences you've had, and you may find this upsetting. If you haven't felt in control of decisions about your body, let your health professionals know that it's important that you are involved in decisions about your treatment. You may be able to help with building trust with your healthcare team.

If you have a variation of sex characteristics and also identify with the LGBT communities, see the When you're LGBTQI+ chapter for more details. For more information and support, visit Intersex Human Rights Australia at ihra.org.au.

LIFE STUFF

"I don't like how it was assumed that I was straight. The conversation never opened up about my sexuality which really pisses me off."

Bisexual cis woman, 23





TAKING CARE OF YOURSELF

Self-care

Eating well

There will be times during your treatment when you don't feel like eating. But a good diet is important. Food is the fuel your body needs to keep it running – and you need extra fuel during cancer treatment.

Speak to the hospital dietitian for advice on what foods you should eat.

Cancer Council has more information about eating well after a cancer diagnosis. Visit cancercouncil.com.au and search for 'eating well'.

Physical activity

Cancer and cancer treatment can make getting out of bed or off the lounge feel like a massive

achievement. Exercise is probably the last thing you feel like doing! But physical activity is good for your body and your mind.

Exercise can help:

- heal your tissues and organs that have been damaged by treatment
- give you more energy
- you have a better night's sleep
- manage your weight better – especially if you are on steroids
- keep your bones strong – some treatments can reduce your bone density, making them easier to break
- you cope with the stress of cancer and its treatment
- feel better about yourself.

Before starting any exercise program check with your GP or treating healthcare team about any precautions you should take.



Infections

Some cancer treatments, such as chemo, can reduce your immunity and increase your risk of picking up an infection. A simple infection can quickly become serious when your immunity is down.

To lower your chances of getting an infection you should:

- stay away from people who are sick – even if it's just a cold or flu
- ask friends and relatives to tell you if they are sick or have been in contact with someone who is
- wash your hands often and well
- consider wearing a surgical face mask if going out
- make sure your food has been washed and cooked properly
- use sterile procedures when you clean your central lines
- call your doctor straight away if you develop a temperature of 38°C or higher or other symptoms like chills or shivering, sore throat, rash, earache or upset stomach.

Getting enough sleep

Even though you may feel very tired a lot of the time, many people with cancer find it hard to sleep. You may toss and turn due to stress and worry, or feeling uncomfortable. Pain, fevers, coughing, nausea and treatment drugs might also affect your sleep. It often doesn't help if you are in hospital and away from your own bed.

Not getting enough sleep can affect your mood and ability to concentrate and can make the stress of cancer even harder to deal with.

A good night's sleep will make a lot of difference. The number of hours needed depends on your age. Teenagers and young adults may need at least 9 hours because they're growing.

ReachOut has great tips on how to sleep well. Visit au.reachout.com and search for 'sleep issues'.

Drugs and alcohol

Drugs and alcohol don't mix well with cancer. To give your body the best chance to deal with the cancer, it is important to be straight up with your treatment team about what drugs you may be using or have used in the past. This includes illegal drugs (such as cannabis, cocaine or ecstasy), and legal drugs (alcohol, cigarettes and e-cigarettes).

Cancer and its treatment can impact how your body feels – your energy levels might be down and you may struggle to fight off infections. Drugs and alcohol will only make this harder. They can:

- make chemo, radiation therapy or other treatments not work as well
- increase the impact of side effects
- increase your chances of getting things like chest infections and other respiratory (breathing) problems
- result in other infections, especially if you are injecting or sharing needles
- affect your mood and behaviour, making it harder to deal with the physical and emotional challenges of cancer.

If you are using legal and/or illegal drugs, it is important to talk to your treating healthcare team about how to use these as safely and carefully as possible.

Help and support is available to you, so reach out as often as you need. Canteen is always here for you –

you can contact a counsellor online at canteenconnect.org.

Sex and cancer

You might wonder whether cancer will affect your ability to have sex now, or in the future. The good news is that unless your doctor tells you otherwise, it is okay to have sex (if you feel like it) while having treatment, but you need to use STI (sexually transmitted infection) prevention methods and/or contraception during any sexual activity. Check with your doctor if there are any other special precautions you need to take.

Cancer treatment might have you feeling washed out and not having much energy for many months or even longer. You may lose your interest in sex, feel unattractive or worry that you will never be able to be sexually active. The main thing to remember is that how you feel right now is temporary and it's really likely to pass in the future.

Cancer Council has more information about sex and cancer. Visit cancercouncil.com.au and search for 'sexuality'.

If you are still concerned or worried about any symptoms you are experiencing, talk with your treatment team. It can also be helpful to speak with a counsellor if you have distress around sex. Canteen has face to face, phone and online counsellors available to support you through this. Visit canteen.org.au for more information.

PRACTICAL STUFF

School and study

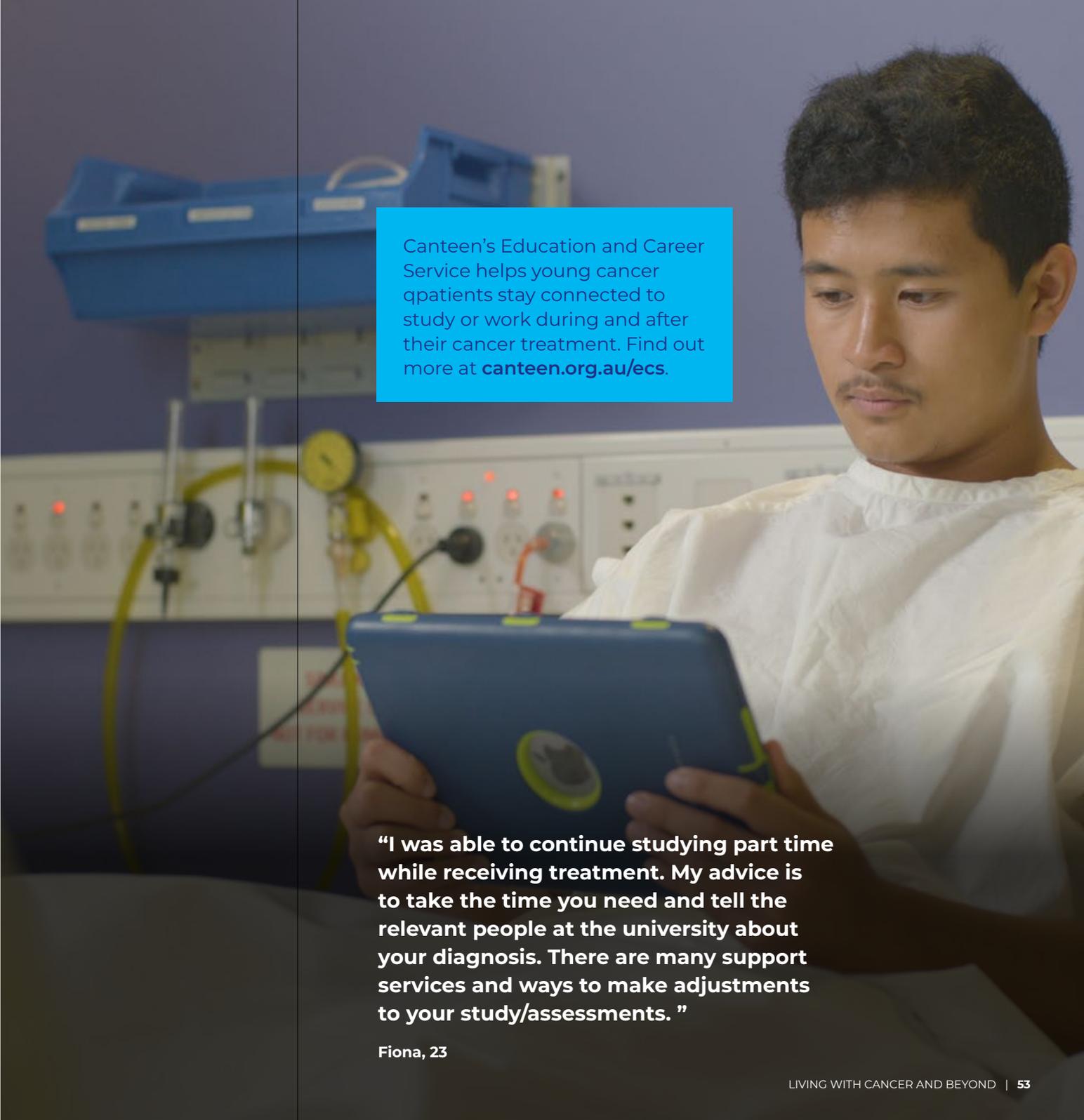
Bet you never imagined that you would miss studying? School, uni or TAFE might be a big part of your life and it can be scary thinking about what will happen to your studies during treatment and recovery.

Many young people who have been through cancer treatment feel it's important to get back to school or study as soon as possible. But if you have been away for a long time, it's normal to feel nervous as well as excited about returning to school or uni.

You may feel self-conscious about the changes in your life and how you look, and unsure how others will deal with them. You may also be worried about catching up on the work, or maybe even having to repeat and being a year behind your friends.

Before you return:

- Ask your parent/s, carers, friends or partner to visit or call the school, uni or TAFE to let them know what to expect and what they can do to help.
- If you're at school, your teachers might be able to tell other teachers and students about what's going so everyone knows and can be as supportive as possible on your first day back.
- Get some work sent to you at home or to the hospital. This might make you feel a bit more prepared before heading back.
- Find out if there is someone from the hospital who can visit your school to teach the teachers and students about cancer.



Canteen's Education and Career Service helps young cancer patients stay connected to study or work during and after their cancer treatment. Find out more at canteen.org.au/ecs.

“I was able to continue studying part time while receiving treatment. My advice is to take the time you need and tell the relevant people at the university about your diagnosis. There are many support services and ways to make adjustments to your study/assessments.”

Fiona, 23

Friends at school, uni or TAFE

Be prepared – people at school, uni or TAFE might act a bit weird around you at first. This is because sometimes people avoid things they don't understand or are uncomfortable with. Talking to people up front about what's going on and letting them know it's okay to ask questions can help.

On the first day, it might help to have a friend meet you at school or uni to walk in with you so that you have support.

Sometimes when people don't know what to say or ask, they can say something that you think is a bit dumb or insensitive. Sometimes people tease because they are confused and don't know how to react. Keeping in mind that people are acting this way because they don't understand can help you cope with this, and can help you resist the urge to say something mean or teasing back. Try to remember that it isn't your fault that someone is teasing you – they are responsible for what they do. If you're feeling uncomfortable about questions or being teased, it is important to tell a parent, carer, teacher, lecturer or student services.

If you are struggling with how you're being treated at school or adjusting with going back to study, it can help to talk to a counsellor or someone who is not involved

in the situation. You can contact Canteen for information about free counselling services (canteen.org.au/counselling).

Keeping up

Even if you have gone back to school, uni or TAFE, you may still miss out on class a lot because you need to go to appointments or have treatment. You may also still get really tired and not feel 100%. This can make it hard to keep up.

You could:

- ask a friend to take notes for you if you miss a class
- get the teacher to email any work or assignments that you have missed, or they could send the work home with a friend or a sibling
- with your teacher, figure out what work is a priority and focus on that – it may be easier than trying to get it all done.

If you live in a rural or remote area and have to travel a lot for treatment, you might be able to continue with your regular schoolwork through distance education and doing courses online. There may also be hospital school services available in your hospital. You can learn directly from a teacher on the ward or sometimes they can visit you where you are staying in town.

Canteen's Education and Career Service (canteen.org.au/ecs) can help.

Marks

You might feel ready to jump right back into school, uni or TAFE and make up for lost time. Going back to study after cancer treatment can be tricky, and some young people find study harder, or their marks aren't as good as they were before the treatment.

This might be because you were away a lot or because some of your treatment has made it harder to concentrate or understand and remember new information (chemo brain!). You might feel like you have to work harder just to keep up. Or maybe your goals have changed.

It can be frustrating, but keeping in mind the long term goals of health and recovery can help. Your teachers, and parents or carers might be able to support you to adjust your education goals for the time being.

Years 11 and 12

If you are doing your final school exams, it can help to speak to your teachers or the school counsellor about 'special consideration'.

Lots of people get special consideration all the time for different reasons. It doesn't have to be a big deal and you don't have to tell everyone about it. It's just recognising that things are really hard right now.

“You deserve no pressure on whether to start, resume or finish study after a cancer experience. It's always there.”

Ezra, 21



Uni and TAFE

Your treatment and the side effects of cancer may impact on your decision to enrol in, or continue with, further study at uni or TAFE. It might also affect your choice of course and method of study.

You might be worried about:

- causing more stress on your body
- not being able to meet the assessment requirements and afraid of failing
- the uncertainty of your health and being unable to predict how you will feel mentally or physically in the future
- fitting in and receiving unwanted attention
- lack of physical access, such as wheelchair access

- not being able to complete particular types of exams, assessments, practical work or go on excursions.

If you are concerned about face-to-face learning, distance learning might be an option for you. This means you could take courses online and study in your own time.

There are also support services at uni and TAFE campuses that will help you to make adjustments and cope.

Access and inclusion

If you're returning to study, there are often systems at school, uni and TAFE to adjust study conditions to make learning accessible.

Types of adjustments might include:

- extra time for exams

- access to lecture notes before class
- providing note-takers, sign language interpreters and readers
- use of equipment and assistive technology
- help with parking and physical access
- special consideration for assessment.

If you're at school, it can be helpful to talk to a welfare teacher, head of year or school counsellor/psychologist. If you're at uni or TAFE, start with student services (or search 'Accessibility' on your institution's website).

If you have a permanent disability (such as physical, intellectual, cognitive, neurological, visual,

hearing or psychosocial), check out the support available through the National Disability Insurance Agency (ndis.gov.au). Ask your healthcare team for advice and support with this process.

Student services

Most campuses also have a student centre that offer a wide range of support services such as:

- counselling
- financial assistance
- tutoring
- career advice
- health services, housing services and childcare
- employment services
- Aboriginal and Torres Strait Islander student support.



Work

Work is an important part of life – and not only for the money. Returning to work can help you to regain your confidence and independence, gets you back into your ‘normal’ routine, which gives you something to focus on besides cancer.

But getting back to work can be hard. Giving yourself some time to prepare can help.

Going back to work

Only you can decide when you are ready to go back to work (and to talk about this decision with your treatment team and your boss).

Before you return, here are some things you may want to consider:

- Know your limits. Don't try to do too much too soon, and take regular breaks. You might need to change the type of tasks you're doing, the length of your shifts, to reduce your hours, or work from home where possible. You might still be dealing with side effects

such as fatigue and changes to your concentration, so be kind to yourself.

- If it's relevant to your work roster, tell your boss about any follow-up appointments, scans and treatments ahead of time (including if you'll need rest days or travel time before or after these).
- Adjust your schedule if possible, so you are doing certain tasks at times you feel the best (e.g. in the mornings if that's when you have the most energy and focus).
- Decide how much and what you want to tell your colleagues about having cancer. You are in control of this. You may only wish to tell your boss and/or direct supervisor, and even then only limited details. It's up to you and what you feel comfortable with. They must keep this information private.

Canteen's Education and Career Service (canteen.org.au/ecs) can help you plan your return to work.



Getting a new job

Looking for a new job can be stressful for anyone. Add cancer and it might seem overwhelming.

Whether you're looking for your first job, have been inspired to make a change or are considering retraining, you have many options and possibilities. Take time to think about what is right for you.

If you are qualified for a job and physically able to do the work, your medical history should not affect your ability to get a job.

These tips may help.

- An employer cannot refuse to hire you because of your medical history.
- You are not legally obliged to tell a future employer that you have had cancer. It is a personal decision to tell or not.

- An employer must keep any medical information confidential.
- An employer is allowed to ask you in an interview about your abilities to perform tasks related to the job.
- You may find it helpful to provide a potential employer with a letter from your doctor that explains your health status and ability to work.
- If you are worried about how to explain gaps in your resumé because of treatment, think about organising it by experience and skills instead of date.
- A career counsellor can give you advice and help with resumé writing and interview skills.

Looking for work will take time. Go easy on yourself. Making time for fun and exercise will help you stay motivated.

“I got back into life as an adult via volunteering. Flash forward to current times, I landed myself a full-time position at a childcare centre.”

Amy, 25

Money matters

Cancer can contribute to money worries for you and your family, but there is support available. You will still be able to get the treatment you need.

How much will treatment cost?

This will depend on where you are treated. Most treatments in public hospitals are covered by Medicare, which is Australia's universal health insurance scheme.

With a Medicare card, you can have free treatment in public hospitals. However, you can't choose your doctor and you might have to wait for treatment.

If you have private health insurance, you may have more control over where and when you will be treated and can choose your own doctor. However, if you are a private patient being treated either in a public or private hospital, there may be fees and charges for things such as hospital accommodation, theatre fees and medicines. These costs may vary depending on the level of your private health insurance.

If you do not have health insurance (or even if you do), you can still be treated in the public health system.

It is important for you to talk to your doctors, the hospital and your health fund to get accurate information.

It may help to know:

- You should still be able to get new health insurance even if you have been diagnosed with cancer. Health funds in Australia are not

allowed to refuse membership or charge higher prices to people because of their health status or claims history. They can impose waiting periods for pre-existing illnesses, but once you have served your waiting periods, you are allowed to claim.

- You can make a formal complaint with the Commonwealth Ombudsman (call 1800 640 695) if you feel that your health fund has treated you unfairly.
- Having cancer history will generally not affect your ability to access financial services in the future such as a credit card, mortgage or personal loan. However, you might have to shop around for new life, travel or income insurance.

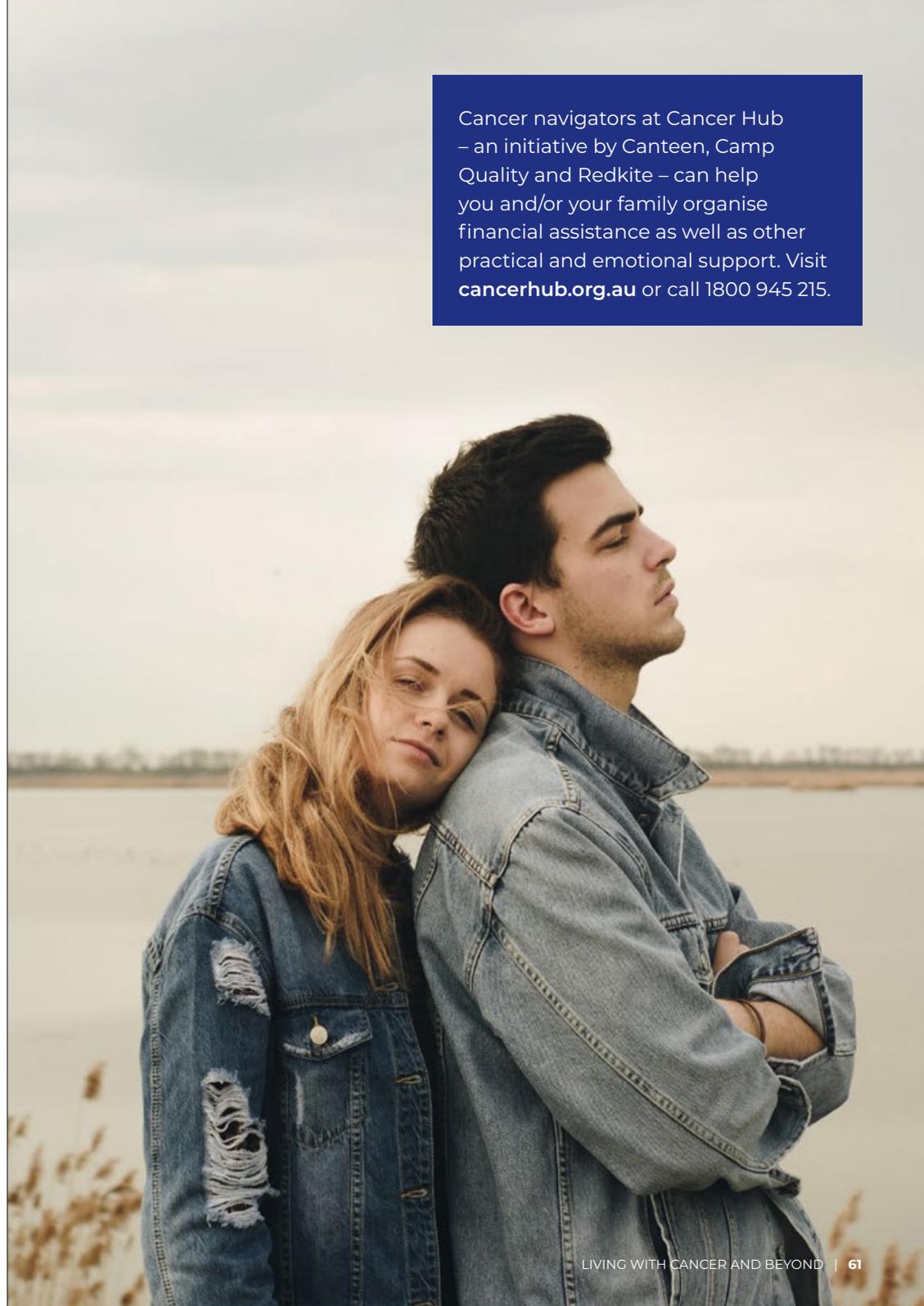
Financial assistance

You and the people caring for you can apply for help paying for all sorts of things. Government agencies and many charities and organisations support people through tough times.

You may get financial help with things like:

- rent
- carers payments
- unemployment support
- study support
- paying for medications
- concession cards
- parking vouchers at the hospital
- accommodation during treatment for you, your parents/ carers or partner
- transport costs to and from the hospital.

Cancer navigators at Cancer Hub – an initiative by Canteen, Camp Quality and Redkite – can help you and/or your family organise financial assistance as well as other practical and emotional support. Visit cancerhub.org.au or call 1800 945 215.



Financial assistance is there for everyone, no matter what their financial situation was like before a cancer diagnosis.

It can be difficult to work out if you qualify for different types of assistance, and know how to fill out the forms. For more information,

talk to the social worker at the hospital or another member of your treatment team.

Most financial assistance from the Australian Government is provided through Centrelink (servicesaustralia.gov.au/centrelink).

If you're from a rural or remote area

If you live in a regional or rural area and have to travel to a capital or major city to have your treatment, you may be able to get help paying for transport and accommodation.

Each Australian state and territory has a program that covers some of the cost of travel and places to stay for people affected by cancer who have to travel long distances for specialist medical services.

The criteria and amounts vary in each state/territory. Ask your treatment team for more information or visit cancerhub.org.au.



Legal stuff

Age of consent

Regardless of your age, you have rights.

From the age of 16, you can be involved in your care. If you clearly understand the nature, risks and likely consequences, the doctor may allow you to make your own treatment decisions without consulting your parents or carers.

If you are under 18, your parent/s or guardian/s are mainly responsible for your care and protection. Even though the doctor will need the consent of your parents or carers on any treatment decisions, the law says that your opinion should be heard in all legal decisions affecting you.

When you turn 18, you are legally recognised as an adult and have the same legal rights as adults. This means you can make your own medical decisions.

Making a Will

A Will is a document that states what you want to happen to your money, possessions and children after you die. You can make your Will when you are 18. Every person over 18 should make a Will – not just people who have cancer. It can help to get legal advice to do this.

If you are under 18, you can only make a Will if you are married or plan to marry. There are strict laws in Australia regarding people under the age of 18 getting married. You could still write down what you want to happen to all your stuff and ask your parents, carers, friends or partners to keep it for you.



Disability discrimination

Disability discrimination happens when you are treated unfairly or 'harassed' because of your illness or its side effects. It might include:

- not being offered a job or being fired from your job
- being treated unfairly at work
- not being able to enrol at uni or TAFE
- not being offered the same opportunities or choices as other people in your class or course
- being unable to access public buildings such as libraries, hospitals and government offices
- not being able to rent a house or room.

It is against the law for someone to treat you differently or unfairly because you've been diagnosed with cancer.

If you think you are being treated unfairly because of your diagnosis, it is important that you bring it up:

- At school – talk to your year advisor, school counsellor or principal

- At uni and TAFE – talk to the disability liaison officer or student services officer
- At work – talk to your manager or HR. If they refuse to take the matter further, you can lodge a complaint with the Australian Human Rights Commission (humanrights.gov.au). It is free to make a complaint and you do not need a lawyer.

Getting legal advice

If you need to know more about the law or your rights, many organisations can help with a wide range of legal concerns.

If you're feeling overwhelmed or stressed about legal issues, it is a good idea to talk with someone about how you're feeling. This might be a family member, a friend or a professional. It is important to only accept legal advice from a lawyer or legal service. If you need help with a legal issue and you cannot afford a private lawyer, you can contact Legal Aid in your state or territory to ask how they might be able to support.

For more information, visit canteen.org.au, visit cancerhub.org.au or call Canteen on 1800 835 932.

Planning travel

You may have dreams of travelling. The good news is that for most people this is still possible, but it may involve more planning and may limit some of the things you can do and the places you can visit. Talk to your treating healthcare team about travelling.

Vaccinations

Depending on the type of cancer and treatments you've had, you might not be able to get the vaccinations you need to travel to some parts of the world. Check with your treatment team.

Travelling with medicines

If you are still taking medicines when you travel, it is important to make sure you have enough

supplies to last the whole trip. You should also take extras.

Some countries limit the number of particular medicines that you can take into the country. Your travel agent can check this out or you can contact the Australian Embassy.

For certain medicines, like morphine, you may need a letter from your doctor. This will also be helpful if you're taking syringes, needles or portable medicine pumps with you. Carry any medical letters in your hand luggage so you have easy access to them at customs and security checkpoints.

Medical records

It is also a good idea to take printed and digital copies of medical files, in case you need to access treatment while you are away. A trusted family member can hold a copy of these documents so they can email them to you if needed.



Flying

There are some situations where you may not be able to fly because oxygen levels and air pressures change in the cabin of the plane at certain altitudes.

You may have to wait or find a place to go by car or train, if you are breathless, anaemic, have had recent surgery, or have a brain tumour and there is a chance of swelling in the brain. Ask your treatment team whether it is safe for you to fly.

Travel insurance

Getting travel insurance when you've had cancer can be more difficult because of the cancer history increasing the risks to the insurance company. They assume that you are more likely to:

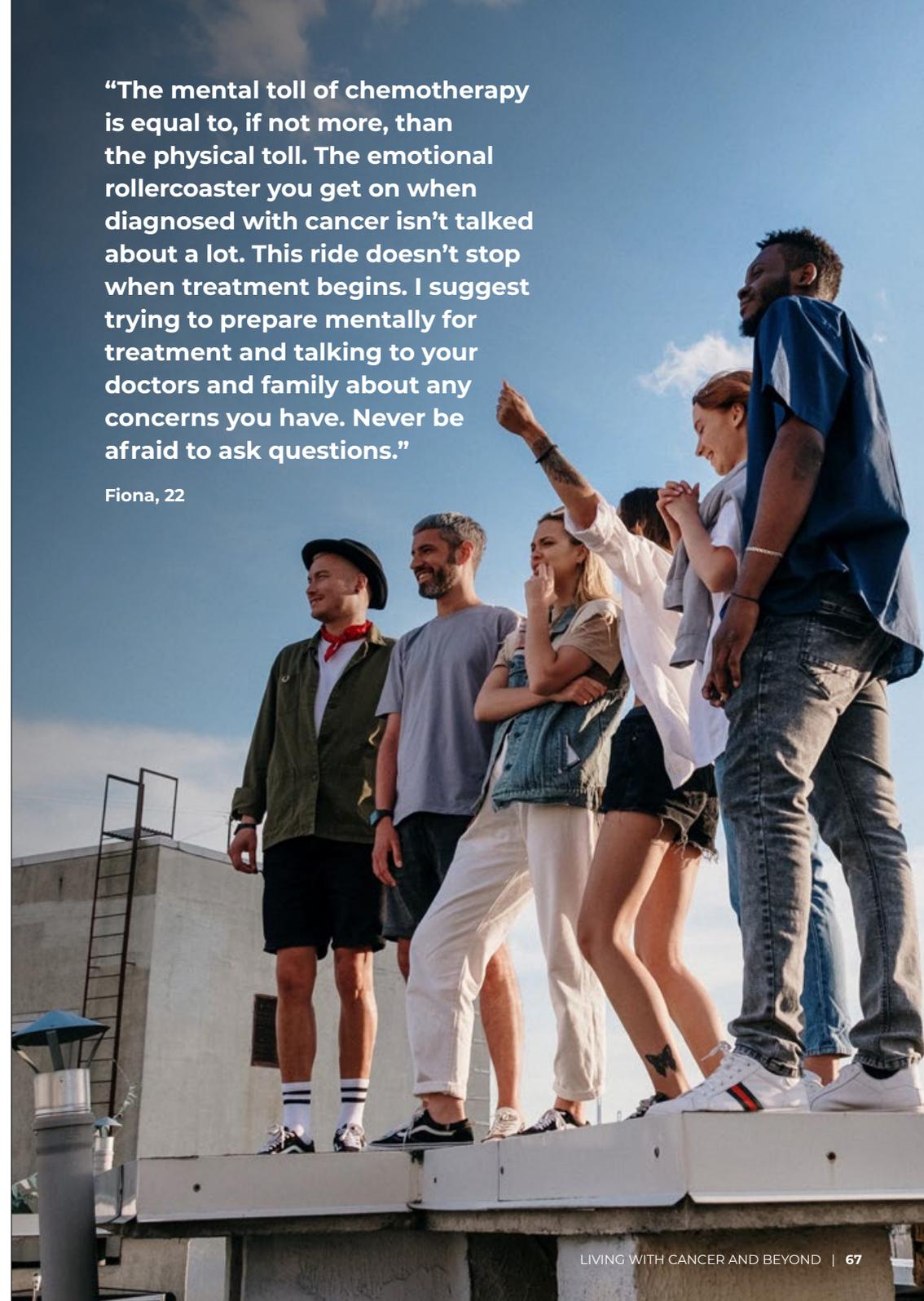
- get sick and need treatment while you're away
- need to come home for treatment
- cancel your trip because you fall ill before going.

This doesn't mean you can't get insurance, but it might just mean you have to shop around. How much it will cost and who will insure you will depend on things like if you are currently having treatment, what cancer you have and how old you are. Make sure you check out the fine print about what is covered.

Cancer Council NSW has a factsheet about insurance for people with cancer. Visit cancercouncil.com.au and search for 'new insurance policies'.

“The mental toll of chemotherapy is equal to, if not more, than the physical toll. The emotional rollercoaster you get on when diagnosed with cancer isn't talked about a lot. This ride doesn't stop when treatment begins. I suggest trying to prepare mentally for treatment and talking to your doctors and family about any concerns you have. Never be afraid to ask questions.”

Fiona, 22



GETTING THE RIGHT INFORMATION

Not knowing what's going on can be stressful. Ask your medical team as many questions as you like about anything you are curious or worried about.

You have a right to know what is happening to you and your body. Having the correct information is an important way to help you deal with the cancer. It might also help to give you a sense of control when everything else seems out of control.

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

Some people like to know every little detail, while others only want to know things in a more general way. Whatever you choose is okay.

If you don't feel comfortable asking some questions in front of your parent, partner or support person, you can speak with your medical team privately. Young people over 16 may be allowed to participate in decisions about their treatment.

Obviously, making decisions about treatment are serious and you need to think about them very carefully. Having the right information will help you to make decisions that are right for you.



Questions to ask

You may have many questions you want to ask your medical team during and after treatment for cancer. The questions below are a good start, and you can check-out canteen.org.au/questions for suggestions on topics from diagnosis to treatment and fertility and relationships.

- What kind of cancer do I have?
- Has the cancer spread to other parts of my body?
- How common is this type of cancer?
- What tests do I need, and what will they involve?
- Where will I have tests? Are the tests performed here?
- How will this cancer and treatment affect me and my life?
- What are the pros and cons of each treatment option?
- Can my parent/s/carer/partner stay in hospital with me?
- What problems should I look out for and who do I contact if they occur?
- How much will treatment cost? Are there guidelines on how to treat the cancer?

LGBTQI+ specific questions

- Do you have an LGBTQI+ inclusivity policy for patients and staff?
- Is the hospital/treatment centre LGBTQI+ friendly? Have staff had inclusivity training?
- Do you have experience dealing with LGBTQI+ people with cancer?
- How will you keep my personal information confidential?
- Can you amend my records with my pronouns and preferred name?
- How will cancer treatment interact with gender affirmation hormones?



MEDICAL STUFF

ARGH! INFORMATION OVERLOAD!

When you are feeling stressed, upset or scared, it can be hard to take in and understand all of the new information you are being told, especially at the beginning.

You will have heaps of appointments with different doctors. They will probably use a lot of medical terms that might at first sound like a foreign language (but you might be surprised by how much you know later on).

Here are some other tips on how to get the right information and ways to remember it.

- Write down your questions before appointments (and also any questions your family or partner might have). See **page 70** for suggestions.

- Write the answers during the appointment or have someone with you who can do this. If there are any restrictions and you can't take anyone with you to the appointment, your support person could be on the phone or on video call. You can ask to record the session.
- Ask people to repeat things if you don't get it the first time (or the second time or the hundredth time); or send a follow-up email with your questions.
- Ask the doctor or the nurse to draw a picture or use an image to show you what they mean.
- Ask if there are any good websites or books you can read afterwards.

Remember, you'll have many opportunities to ask questions – if not today, add it to the list for the next time you see your treatment team.





Dr Google

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

Information found on the internet can be a good way to start a conversation with others, including your medical team. It may prompt new questions and help you get a better understanding.

Here are a few tips for searching the internet.

Always check the source of the information

Lots of information online can be misleading or out of date. Look at

where the information is coming from. Can you find contact information for the people behind the website? What is the purpose of the website – information or advertising?

There are many reliable cancer organisations that have great information that is accurate and up to date, such as Cancer Council (cancer.org.au) and Cancer Australia (canceraustralia.gov.au).

Don't believe it all

If the claims on a website seem too good to be true, they probably are. It's a good idea to check out claims made on the internet with your parent/s or carers, your doctors and nurses or a trusted web source. Most doctors are happy for you to ask their opinion about information you find on the internet.



MAKING TREATMENT DECISIONS

Cancer can make you feel like you have suddenly lost all control over your life. Since your diagnosis, there have probably been lots of people – doctors, nurses, other medical staff, your parent/s or carers, and even the odd stranger – telling you what to do, when to do it and how to do it.

There will be times when it feels like you have to do what your medical team says whether you like it or not. But you can have control over some things, like when or where you get the treatment.

Don't be afraid to ask whether you have any options for when and where you get treated. Maybe you want to be treated closer to home. Maybe you want to delay the next round of chemo until after an exam or maybe you want to be allowed out of hospital for a special occasion like the school formal. Speak up! If you don't ask, you'll never know.

Learning to speak up can be hard, but if it means you get to make decisions that are

important to you, it's really worth a try.

Or perhaps you're happy to let your parent/s or carers make all the decisions about your care and treatment. That's fine too.

Depending on your age you can have a bigger say in what is happening. If you are over 18, you are recognised by the law and the hospitals as an adult and can have control over your treatment decisions.

If you are over 16 and your doctor believes you are mature enough to understand the nature and consequences of treatment decisions, you may be able to make medical decisions without consulting your parent/s.

Some parent/s or carers find it hard to let go. You might feel that they are having too much say when you don't want them to. Your parent/s are probably worried about you and want to do what seems best. Try to be open with them about what you want. See the section on 'Managing relationships', **page 85** – for ways to handle this.



Treatment and support especially for young people

Youth Cancer Services (YCS) provide specialised treatment and support tailored for young people with cancer aged 15-25.

Based in major hospitals in Sydney, Melbourne, Brisbane, Perth and Adelaide, YCS work with more than 25 other hospitals and health services across Australia.

You might be treated at a YCS in a hospital, or the YCS team can work with local doctors to plan and provide the best treatment and support for you, wherever you are.

To find out more about YCS, visit youthcancer.com.au.



Canteen's Robots Service can help you to stay connected to your school and friends even if you're stuck in hospital or at home.
canteen.org.au/robots

AN INSIDER'S GUIDE TO HOSPITALS

As you start treatment for cancer, you will probably spend time in hospital. This may be as a day patient or overnight, known as inpatient. How long you stay, will depend on the type of cancer and treatment.

What happens in hospital?

Checking in

When you are admitted, you will probably meet lots of administrative staff and different health professionals like nursing

staff, oncologists, haematologists, surgeons and social workers.

They may ask you to repeat your story several times. It can help to have someone with you if you're feeling unwell or overwhelmed.

They may ask personal questions. If you're considering coming out to your healthcare team, see **page 37**. You can ask to speak with the doctors or nurses privately if you prefer. If you want to know how your information is stored or shared, ask your healthcare team.

Will I be in bed all day?

This will depend on the type of cancer and treatment you have. How long you stay in hospital can vary widely – from just a day in hospital to many weeks, or anywhere in between.

If you need to stay in hospital, your healthcare team will let you know how mobile you can be. For example, after surgery, you may be encouraged to get up and move around the ward to help you recover. If you're having a chemotherapy infusion in a day unit, you may need to sit for some hours.

Other patients

Most hospitals are not designed for young people and lots of patients in hospital are going to be a lot older or younger than you. This can make hospital stays feel more challenging and isolating.

When you first get admitted, you will meet many other patients and their families in your day unit, ward or treatment centre. Some of the patients may be really sick and in

different stages of their treatment. Some may be doing very well.

It can help to talk to other patients but remember everyone's cancer and treatment is different.

What about visitors?

Each hospital will have different rules about who can visit, for how long and when. Ask your healthcare team about this. The rules may also be different if there are any restrictions.

In some cases, you may need to be in a room by yourself and the hospital might restrict who can visit you and when they can come. Your visitors might also have to wear a mask, gloves and hospital gowns to enter your room.

If you live in a rural or remote area

Cancer can have extra challenges if you live far from the city. If you are used to living in the country, having to travel to a big town or city for treatment might be really stressful.

You may be away from the support and comfort of your family and friends and miss your home, community, lifestyle and the food

you usually eat. Being alone in an unfamiliar place can be hard and you might feel lonely, frightened or uncomfortable.

Cancer navigators at Cancer Hub – an initiative by Canteen, Camp Quality and Redkite – can help you and your family organise travel and a place to stay as well as other practical and emotional support. Visit cancerhub.org.au.

“Living in a rural area can feel isolating enough, but being diagnosed with cancer at a young age on top of that was such a difficult experience. Even when I travelled hours for treatment, I never met anyone even close to my age that I could relate to. As soon as I joined Canteen and started using Canteen Connect I suddenly had all these people that understood what I was going through. Now I have friends from all around Australia and New Zealand and no longer feel so far away from everyone.”

Marine, 25



“Keep your mind busy and do the things you love. Listen to music, play games and watch movies. This is a time of your life where you can focus solely on yourself and your recovery.”

Fiona, 22

Tips for long stays in hospital

- Use headphones and an eye mask to block out sound and light.
- Bring as much media as you can – laptop or tablet, books and magazines. Watch shows and listen to music on streaming services.
- Pack your pillows, photos and other favourite stuff to make the hospital room feel more like your own space.
- Have a bedwarming party. Your friends may not realise you want them to visit you in hospital. Invite them to come and hang out.
- Have Facetime chats, watch shows or movies together or a Zoom party.
- Make a visitor book or poster for visitors to sign and leave messages.
- Take pictures of people who visit.
- If you don't feel like talking to anyone, silence your phone or make a “Do not disturb” sign to let people know you're not up for visitors.
- Get to know the night nurses well. You can chat to them when you can't sleep.
- Take control. Decide when you want visitors. Tell people if you don't like the hospital food.
- Find your release – art and craft, knitting, reading, puzzles, games, crosswords.
- Download and try out a meditation app.
- Make plans about things you will do when you get out of hospital. It helps to have something to look forward to.
- If you don't have enough energy to read, try an audiobook or podcast.
- Find out if there are other young people in hospital and see if you can meet up.
- Get outside the hospital or ward if you are well enough. Some fresh air and sunshine can make a nice change.
- Ask your friends or teachers to bring things from school, TAFE or uni for you to do.

Going home from hospital

If you have been in hospital for a long period, you may be really looking forward to going home. So why can it feel scary when the day actually arrives?

While you are in hospital, there are always people fussing over you, telling you what to do, when to wake up, what to eat and what treatments you will be having.

So when you leave the hospital, you might miss this routine, people who understand your situation and the security of knowing you will be looked after if something goes wrong.

Re-adjusting to everyday life can be tough and people can often need some support in doing this. Keeping a routine at home can help. Lean into your family, friends and community wherever you can. They are the ones who know you best.

Professional support will still be there for you after you leave the hospital, from your healthcare team, your GP and organisations like Canteen.

Canteen Connect (canteenconnect.org) provides counselling and social support that can be really helpful during this period.

“Going back into society is definitely hard when you have been in isolation for a while. For me, I went back out into the community with friends and family helping me, but it was too early. It’s important to know when you’re ready. Take your time in getting back out in society, even if it’s a short trip to your local coffee shop for a takeaway coffee. You don’t always need to keep up with friends. Go at your own pace and enjoy life.”

Amy, 24



RELATIONSHIPS



“Family can be a blessing during treatment – but they must always be there to support, not drain from your journey. Your needs, in this time, come first always.”

Ezra, 21

MANAGING RELATIONSHIPS AND CANCER

Cancer is tough for everyone and you may find relationships change.

What is happening to you will affect family, friends, partners and colleagues in different ways. Their reactions might come from worries for you; from their own

experiences of cancer in their life; perhaps not seeing you as much; and generally dealing with their own stuff.

This could mean changes in some of these relationships. Sometimes you'll grow closer, sometimes apart. Dealing with these changes takes patience, honesty and lots of communication – things that are not always easy to find when you are feeling sick, tired and worried.

Parents, carers and family

There are many different shapes of family – your family may be biologically related to you or people who you intentionally choose to love. You might call these people your chosen family or family of choice. There may be various people who have a parental or caring role in your life right now. Hopefully, these connections can provide a safe space for you through the upheaval of cancer.

As a young person, you're often navigating changes in these parent-child relationships anyway – learning what is possible, changing roles at home, moving out. Add the stresses and challenges of cancer, and these relationships can sometimes be put to the test. Sometimes people can feel closer to their important people and sometimes it can make things feel really hard between you. A diagnosis of cancer for someone in the family can feel really overwhelming for everyone.

Your family is dealing with a heap of stuff, that could include:

- feeling guilty that this is their fault (it's not!)
- shock, fear, anger and disbelief
- worried about you and the rest of the family
- helpless, as they can't fix this for you or make it go away
- overprotective of you and trying to shield you from bad news or tough conversations
- distracted and not focusing on the normal things
- tired, stressed and short-tempered
- trying to hide their feelings and put on a brave face
- worried about money, work, and looking after you and your siblings
- isolated and lonely. Sometimes people don't know what to say or how to support so they stay away. Sometimes people feel that no one else understands what they are going through
- their own personal issues as well. Other life stresses can keep happening and it can be really hard to cope with everything at once.

It's important to know that you don't have to try to 'fix' any of this but being aware can help you find common ground (e.g. maybe you're both worried about not working or have friend who doesn't 'get it').

Support for parents and carers

To help your parent/s or carers understand how you might be feeling and how they can help, check out the Youth Cancer Services' YouTube channel: **Getting Cancer Young youtube.com/@gettingcanceryoung5063** where young people and their parents share their experiences living with cancer.

Canteen provides parent support services including counselling, an online community (**parentingthroughcancer.org.au**) and webinars. Your parents or carers can also get help with money and other practical or emotional support for themselves and their family through Cancer Hub, an initiative by Canteen, Camp Quality and Redkite (**cancerhub.org.au**).

Parents and carers can often access support through social workers (chat with your treatment team) or through their GP.



“Having cancer brought me closer to my parents and family.”

Lena, 24



If you're older

If you've moved into adulthood, you might have already taken on more responsibility and control of your life through significant changes such as moving out of the family home and starting study or work. This growing independence may have shifted your relationship with your parents or carers.

You might feel like you were pretty much capable of looking after yourself and enjoyed that freedom. A cancer diagnosis can change everything.

If your relationship with your parents or family was complicated before, cancer can change the dynamics of the relationship all over again.

You will most likely need (and want) the support of your parents or other family members. Although

appreciating the help, it might not be easy to have parents and other family members involved so much in your daily life again.

On top of this, cancer treatment can be expensive and you might need family members to help out with the financial costs. It can be hard to lose financial independence, particularly when your friends and siblings can still buy their own things.

It's likely your family is very worried and wants to make things easier for you. It is okay to have a mix of different feelings about this. Sometimes chatting with a health professional, like a social worker from your treatment team or a Canteen counsellor, can be a way to see the situation clearly, and to learn ways to navigate these new relationship dynamics.

“Adjusting to life for me was difficult. I was diagnosed in my 20s when I could have been moving out of the home.”

Amy, 25



“I had just turned 18 and was trying to find my independence while living at home. When I was diagnosed, all that independence and control I had over my life disappeared. This was really difficult to deal with at the beginning as I had to rely on my parents. They were always there for me and were the support I really needed at the time.”

Fiona, 22

Over 18? Taking the reins

If you're older, you play a large part in making your own medical decisions. However, sometimes your parents may feel like they have more experience in making big decisions or think that they know what's best for you. They might want to step in on your behalf and this could cause some conflict.

It is important for you to maintain some independence and be included in the decision-making process, especially if you have different opinions about your treatment.

Accessing clear and accurate information and understanding what is happening to you can help you to feel more confident to make choices and regain some control over your life and body.



Helping parents to let go

Telling people what you want and don't want can feel like it's a big use of energy, but it can really help. You may want to let your parents know how they can help you – and when you just want to be left alone. Try to tell them clearly and calmly what you'd like from them. Suggesting practical things can help parents feel like they are doing something to contribute.

Some young people with cancer don't want to tell their parents or carers how scared, depressed or stressed they are because they are worried about upsetting them. It's important to remember keeping your emotions hidden is probably only makes you feel more stressed and alone.

For tips on how to start the conversation see 'How do you tell people?' (**page 20**) or chat with a Canteen counsellor (canteen.org.au/counselling).

Siblings

Best friends or sworn enemies? Probably both – and it can move from one to the other in just a few seconds.

Being diagnosed with cancer won't make this go away.

How you got on with your siblings before the cancer will affect how you get on now, but it's likely your relationships will change. You may stop arguing about the small stuff, but you will probably still argue about some things.

If you have had to move back to the family home, this may have a big impact on your siblings.

You might find that older siblings become protective of you. This can be okay, but it can be annoying to feel like you have another parent.

Being in hospital for a long time can affect your relationships with your siblings. You might feel like you don't have as many things in common anymore – like going to school, hanging out and just doing normal stuff. Even if you fought and annoyed each other, you might be surprised at how much you miss them.

Siblings can be a useful link between you and your friends at school, uni and TAFE and the rest of your world. For some people, they find that the cancer experience actually brings them closer together with their siblings.

Try not to underestimate how your diagnosis will affect your siblings. They may feel a range of emotions, including fear, anger, jealousy, guilt and loneliness. There will naturally be lots of focus on you, and your siblings may feel a bit left out and even resentful. This can show itself in various ways like not wanting to visit you in hospital, saying mean things, ignoring you or behaving badly.

We all react differently to difficult situations and express our fears and pain in different ways. Understanding what is going on for your siblings may help you understand why they behave like they do, and make sense of what can be a super tricky situation.

Support for your siblings

There are ways you can help your sibling understand what you are going through. You can start by talking with them about how you are both feeling. We have a similar book to this called 'Now What...? Dealing with your brother or sister's cancer', which is available at canteen.org.au/resource. Your siblings can also get lots of support from Canteen – find out more at canteen.org.au/siblings.

Friends

Your friends are really important – you probably spend as much time with them (or more) as you do with your family.

Sometimes friends are amazing. They say the right things and are there to lean on when you have cancer. But other times, friendships can start to feel complicated and confusing.

There are all sorts of reasons for this including:

- feeling crappy and irritable while you are being treated
- being in hospital a lot
- not being able to do the same things as you used to
- acting differently because of your diagnosis
- looking different because of treatment.

Sometimes friends can find all of this difficult to deal with.

It might seem like your friends aren't texting you or inviting you out anymore. They might not visit you much. They might make insensitive jokes or say unhelpful things. They might not want to talk about the 'C word' and just pretend that nothing is wrong.

Having your close friends around is probably really important to you. You might feel hurt or disappointed that they are not better at being there for you when you really need their support.

“I had friends who left and friends who stayed. I am very grateful for my friends who stayed and helped me through the ups and downs of my cancer journey.”

Amy, 25



But most people don't have much experience dealing with someone with a serious illness like cancer, and they can act in these ways because they don't know what to say or how to act.

It can help to think about the situation from their perspective. Some things to keep in mind include:

Friends sometimes don't know what to say

Your friends may be scared to say the wrong thing or to ask you a question. So this may mean they just say nothing. If you want to talk, you may have to start the ball rolling. Canteen has a range of resources that can help your friends. Check out canteen.org.au/friends.

Friends won't say things to deliberately upset you

It can be really upsetting when friends say stuff that upsets you, annoys you or makes you angry. It can be hard when you might already be feeling sick and vulnerable not to feel offended. Try to keep in mind that they are really unlikely trying to upset you on purpose; it's just that they don't understand. It's okay to let them know how you feel and what you need from them. You can start with "You know, it bugs me when ..."

You will probably be a bit snappy with your friends sometimes when you're feeling down. It can help to let people know that you're having a tough time and it's impacting how you're showing up with them. Talk to your friends and let them know how much they mean to you.

Friends may ask tough or silly questions

Be prepared for questions that may seem strange – your friends are probably curious about what you're going through. But sometimes you may not want to answer questions about your diagnosis or treatment. It's okay to let your friends know that you don't feel like talking right now.

Your friends have their own lives

They may talk about what's happening at school, uni or work and this may make you feel left out. Unfortunately, the world doesn't stop for everyone else because you have been diagnosed with cancer (although for you it may seem like you have entered a whole different world).

Friends may change

Having positive people in your life is important. Some of your friends may stay with you and become an amazing source of support, able to listen to your complaints, fears and wishes. These are true friends, and you may become very close.

But not all of your friends will be able to understand what you're going through and you may lose touch with some people. If this happens, try not to let it get you down – friendships change all the time.

You may also change as cancer can give you a different outlook on life. You may not relate to your old friends as well.

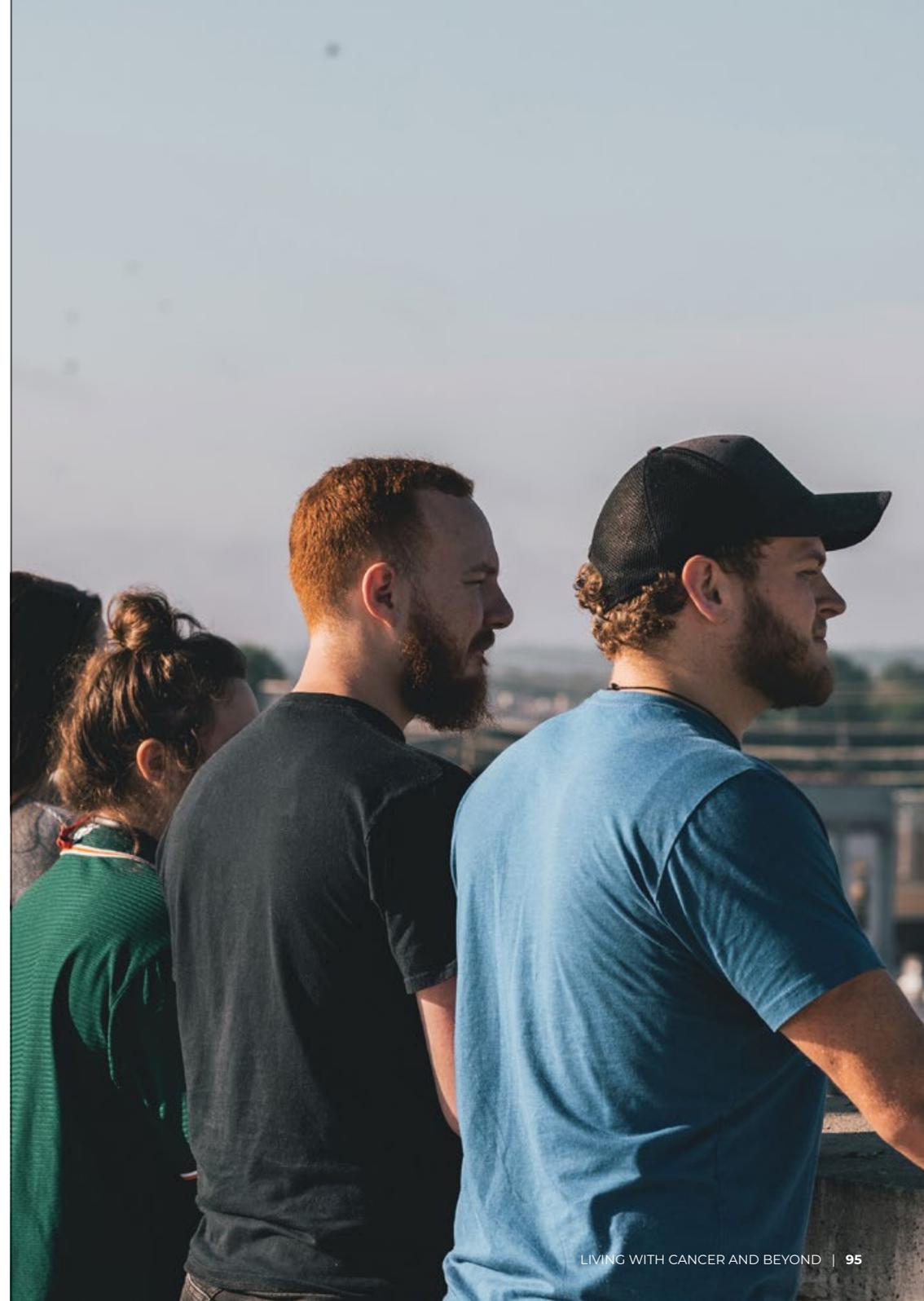
You will find new friends

You may form new friendships. It can be really helpful to connect with other young people living with cancer. They might be easier to talk to about what is happening because they understand. Lots of young people say this is often the best support. Through Canteen, you can connect with other people in similar situations at events or online at Canteen Connect. Find out more at canteen.org.au.

As unfair as it may seem, you may have to take the lead and teach your friends how to handle what is happening to you.

Tips to help you stay in touch with your friends.

- Invite them to visit you in hospital or at home.
- Use social media to stay in touch (see below).
- Ask them to keep calling, texting and messaging you and if you don't feel like talking, you just won't respond straight away.
- Ask them to keep inviting you to things and you'll go when you can.
- Let them know that learning what you're going through can help them understand. Canteen can help them with information and support (canteen.org.au/resource).
- Remind your friends that you are still the same person.
- Tell your friends how they can help – many will be happy to do whatever they can to show they care.





Connecting through social media

When you are having treatment for cancer, it can become incredibly hard to see and stay in touch with your friends. You might also be away from family members and other important people to you if you are in hospital for a while or having treatment.

At other times social media can be a place that doesn't make us feel very good and we need to take a break.

There are so many ways social media can be used in a positive way to help you manage the stresses of cancer. It is a great way to keep in contact with your friends when you might not be able to see them and spend as much time with them as you would like to.

Sometimes we can also get tired of answering the same questions over and over again. You (or a trusted family member or friend) can use social media and group chats to update friends and family about your treatment and other progress.

You can send text or video messages (that you approve) to those you care about. This is a great way to avoid repeating information and to manage who you want to share updates with.

It can be helpful to set the expectation about what info is 'public', and what is just for those closest to you. Using closed or private social media accounts can be a great way to journal your story. You don't need to share it with anyone at the time, but it can be there just for you.

It's also a good idea to think carefully about how your name and image might be used in any personal fundraisers, or updates at your school or work – what you are comfortable with now, and what you are okay with being online and searchable in the future. It can help to talk with your family, the hospital social worker or Canteen about what information feels okay to share if a fundraiser is being organised.

Partners

Your relationship with your partner/s can change during and after cancer treatment. Some couples find that going through cancer makes their relationship stronger and brings them closer together.

But living with cancer puts pressure on everyone. Young people do not expect their partner/s to be diagnosed with cancer. Like you, your partner/s is probably feeling scared, sad, worried, angry, overwhelmed and confused.

They might even seem to struggle more than you do. They will want to make things better for you and might feel helpless and frustrated when they can't make it all go away.

With all the stress of what's happening, you might not be getting on as well as you used to. You may expect that your partner/s

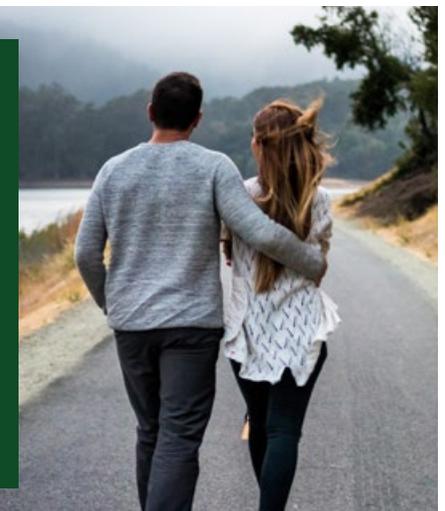
should be able to read your mind and know what you want. You might feel upset or angry if your partner doesn't know the best way to handle things.

Your relationship/s might change in different ways. And sometimes it might not last. Keep in mind that everyone responds to stress in a personal and sometimes unpredictable way.

Things that might happen:

- Your partner/s seems to be withdrawing or avoiding talking about your diagnosis. Some people cope by blocking out situations that are too painful to think about. This can hurt.
- Your partner/s may overwhelm you by trying to protect you and not let you do anything for yourself. This can leave you feeling frustrated or helpless.

It is normal for partners to need some extra support while their loved one is going through cancer. Canteen has a resource for partners (canteen.org.au/resource) and counselling can also help. Your partner can speak to their GP about getting a mental health treatment plan, which will enable them to get support from a private psychologist or through Canteen (free of charge).





- Your partner/s might not feel like they can handle the situation and give you what you need right now, and you find yourself alone.
- Your attitude towards things and your outlook on life changes because of your experience and this affects your relationship/s.
- You and your partner's feelings and attitudes about your diagnosis may not be in sync. One of you might feel hopeful while the other feels more pessimistic. This can make it hard for you to make decisions together about your treatment.
- You worry about how your partner/s will react to scars, changes to your sex life and potentially a loss of fertility, and you become shy or withdrawn.
- You feel guilty for burdening your partner/s with your illness or worry

that they are just staying with you because they feel sorry for you.

- You feel that you just don't have the energy to put into a relationship as well as deal with cancer treatment.

Whatever happens, it's important to remember that it's not your fault that you have cancer. Also, try to keep in mind that your partner/s have a choice to be there with you. If they are offering to look after you – then let them. People often feel better when they have a job to do as it helps them feel like they can be supportive in a tough situation. If you have any doubts about how your partner is feeling about your relationship, talk to them about it. In any relationship, you need to be open and honest. Some couples benefit from seeing a relationship counsellor to support their relationship/s and help with communication.

Sharing is caring

Hiding emotions can create distance between partners. It is normal that you and your partner/s won't always feel the same way. Talk about your differences and respect how they're feeling without criticism or blame.

These tips can help:

- Try to still talk about everyday things. You don't always have to talk about cancer.
- Do something special for each other and plan time to be together.

- Find ways to get your partner/s involved because they may be feeling helpless.
- Laugh and cry together.
- Try to do things you used to enjoy as a couple, such as going to the movies, or have a home picnic if your energy is low. These activities might look different but use these times to remember what brought you together and connected you initially.

“When I was diagnosed, I had waist-length hair, so losing it had a massive impact on how I saw myself. It was also pretty daunting to have strangers ask why I'd shaved my head or even just stare at me in public. At first I wore hats and beanies, and tried on a wig, which wasn't for me, but eventually I found my confidence in wearing bandannas and even learnt to embrace my baldness.”

Marnie, 25





Starting new relationships

Dating and starting new relationships can be hard enough at the best of times. After a cancer diagnosis, it may seem almost impossible.

You may be feeling sick, exhausted and self-conscious about changes in how you look, and going out and hooking up with new people can seem daunting.

But finding an opportunity to socialise and meet new people may boost your self-confidence and help you to feel like things are 'normal'.

You may like to try a new fitness class, book club, art class or join a dating or friendship app. These activities might help you become more comfortable around new people, especially if you have physical signs of cancer such as hair loss, scars or an amputation.

When to tell a new partner/s

It can be difficult to tell people that you've had cancer or that you have had part of your body, like a breast or testicle, removed. Deciding when to tell a new partner about your diagnosis experience is a personal choice.

Here are some tips:

- You may want to wait until you think the relationship could become serious before sharing the information.
- Pick a time to talk to your partner/s when you are both relaxed.
- Try practising what to say beforehand.
- You could tell them about and show them any physical changes before any sexual activity so you can both get used to how that makes you feel. (See Sex and cancer on **page 51**)
- Be honest about your concerns and encourage your new partner/s to be honest about theirs.

BEYOND CANCER

DEALING WITH CHANGES TO YOUR BODY

Some people notice changes to their body during treatment. Some people have said that they haven't quite recognised themselves during treatment.

Everyone experiences confidence and body image issues at some time in their life, particularly as a teenager and young adult. Cancer and its treatment can change how your body looks, feels and works and can make things even harder.

Whether it's changes to weight, loss of hair or scarring, your body may begin to look and feel like it doesn't belong to you. You may be uncomfortable about your appearance and about feeling different.

It is hard not to be affected by these changes. How you look is often tied up with how you feel about yourself. But many people find that with time, your appearance and feelings about your body will change. It may take time to get used to, but it will become easier.

While dealing with unwanted changes to your looks can be really

hard, it may help to remember that underneath all of the changes you are still you!

You might feel:

- Loss of confidence and self-esteem – you might be self-conscious of any physical changes and avoid doing things you used to enjoy like going to the beach, playing sport and wearing certain clothes.
- Shy and withdrawn – you don't feel like hanging out with friends or going out in public.
- Frustrated – that your body doesn't work like it used to.
- Angry – it's not fair that you had to go through this and that you had no control over the changes that have happened to your body.
- Nervous – that you will be laughed at or stared at.
- Embarrassed or ashamed – about the way you look now.
- Grief – over the loss of your 'old' body.
- Scared – that your friends, partner and workmates will treat you differently.
- Worried – about being less attractive and not being able to hook up with someone in the future.

“I didn’t lose my hair, but the surgeons needed to shave some of my hair. My hairdresser, whom I have known since I was a baby, offered to style my hair to help with my confidence with my scar, which I now always like to show off.”

Amy, 25

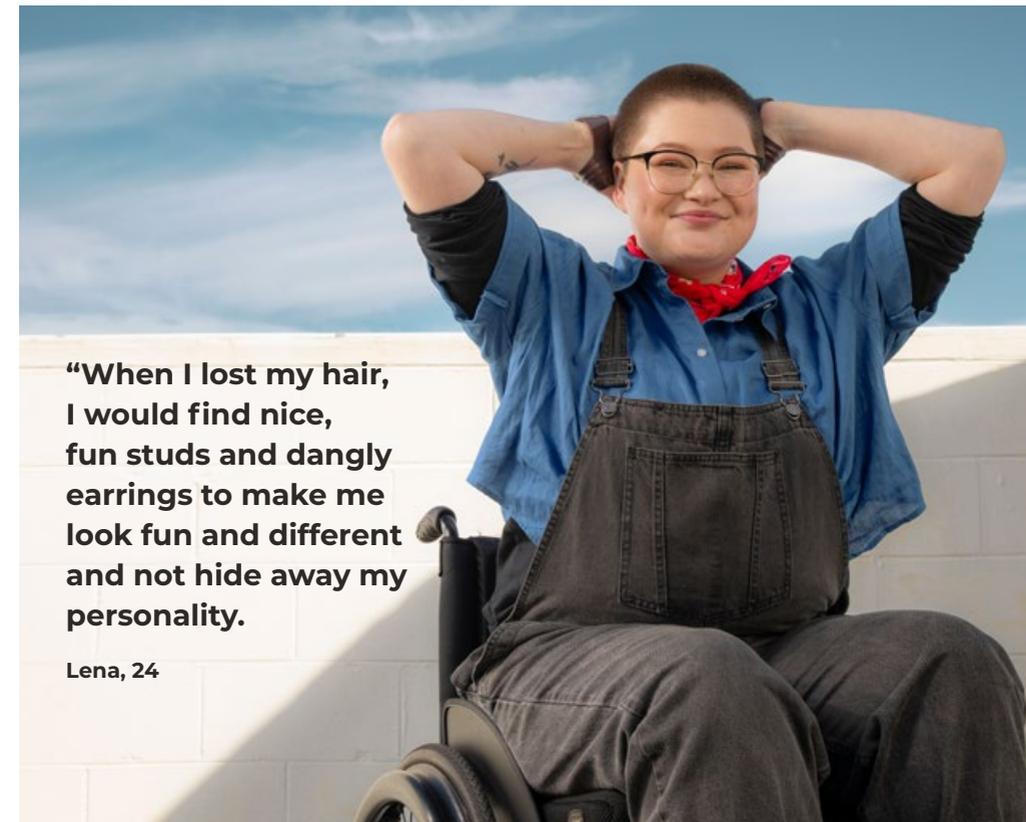


Even changes that you can’t see can affect how you feel about yourself. It doesn’t make you vain or selfish to be worried about your body and how people see you.

Things that may help you cope with changes to your appearance:

- Have a makeover. Experiment with a new look with a wig or hat, some make-up or some clothes ... even if you don’t feel it.
- Talk about it. Sharing how much the change to your appearance is worrying you will help your family and friends understand.

- Try to treat your body with respect. It’s been through a lot already. Eat healthy foods, get enough sleep and try to get as much exercise as your body can handle.
- Hang out with people who make you feel good and accept you for the way you are.
- We know it’s a cliché but try to remember that you are the same person and that your personality, interests and talents are still there. The cancer is not who you are.



“When I lost my hair, I would find nice, fun studs and dangly earrings to make me look fun and different and not hide away my personality.

Lena, 24

After treatment – late effects

'Late effects' are health impacts from cancer treatment that don't occur until years after treatment has finished. They do not mean that cancer has returned.

Not everyone who has cancer treatment will suffer from long-term or late effects. Even people who had the same type of treatment won't always suffer the same side effects.

The potential effects depend on many different factors, including what kind of cancer you had, where it was in the body, how it was treated and how old you were. Late effects can affect any part of the body and include:

- lung, heart, kidney and liver problems
- developing another type of cancer
- cataracts (clouding of the lens in the eye, which can cause difficulty with vision)
- fertility problems
- bowel problems
- thyroid problems
- tooth decay
- changes in bone density (osteoporosis)
- memory and concentration problems.

Managing late effects

Late effects may be hard to cope with, especially after dealing with all the tough stuff that cancer and its treatment has already thrown at you. It might seem like you will never escape from it. These tips might help.

- After finishing treatment, keep a detailed record of your diagnosis, treatments and ongoing plan of care. This will provide doctors you see in the future with a good knowledge of the type of cancer and treatment you received.
- Keep your follow-up appointments. Tell your doctor about any symptoms you have. It is always best to have them checked rather than to worry.
- Ask your healthcare team if you are at risk of developing late effects and what signs to look out for.
- Be healthy. We aren't certain if we can prevent late effects, but it may still help to stay as healthy as you can. This includes protecting yourself in the sun, avoiding smoking and alcohol, and exercising regularly.

Peter MacCallum Cancer Centre has more information about the long-term and late effects of treatment (petermac.org/services/treatment/late-effects).



IF CANCER RETURNS

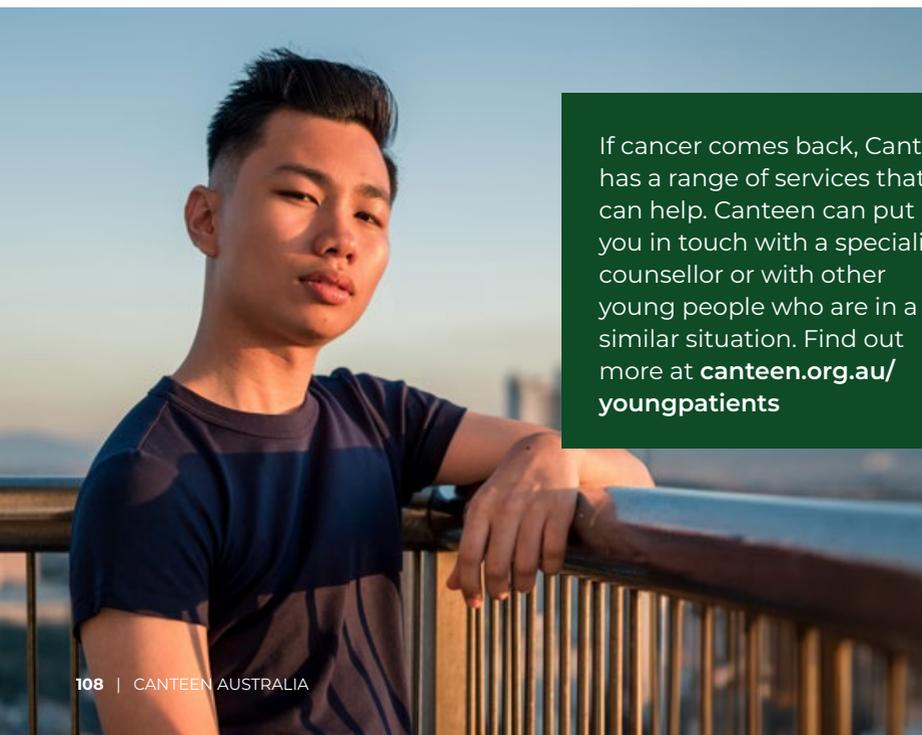
Living with the worry that the cancer will return can be one of the hardest things. Although doctors will give you the very best treatment, there is a chance the cancer will come back. It is important to get as much information as possible and talk over your particular case.

If the cancer comes back, it may be because the first treatment didn't completely destroy all cancer cells. This doesn't mean that the treatment you received was wrong or that you have done anything wrong. It simply means that a small number of cancer cells survived the treatment. This is known as relapse.

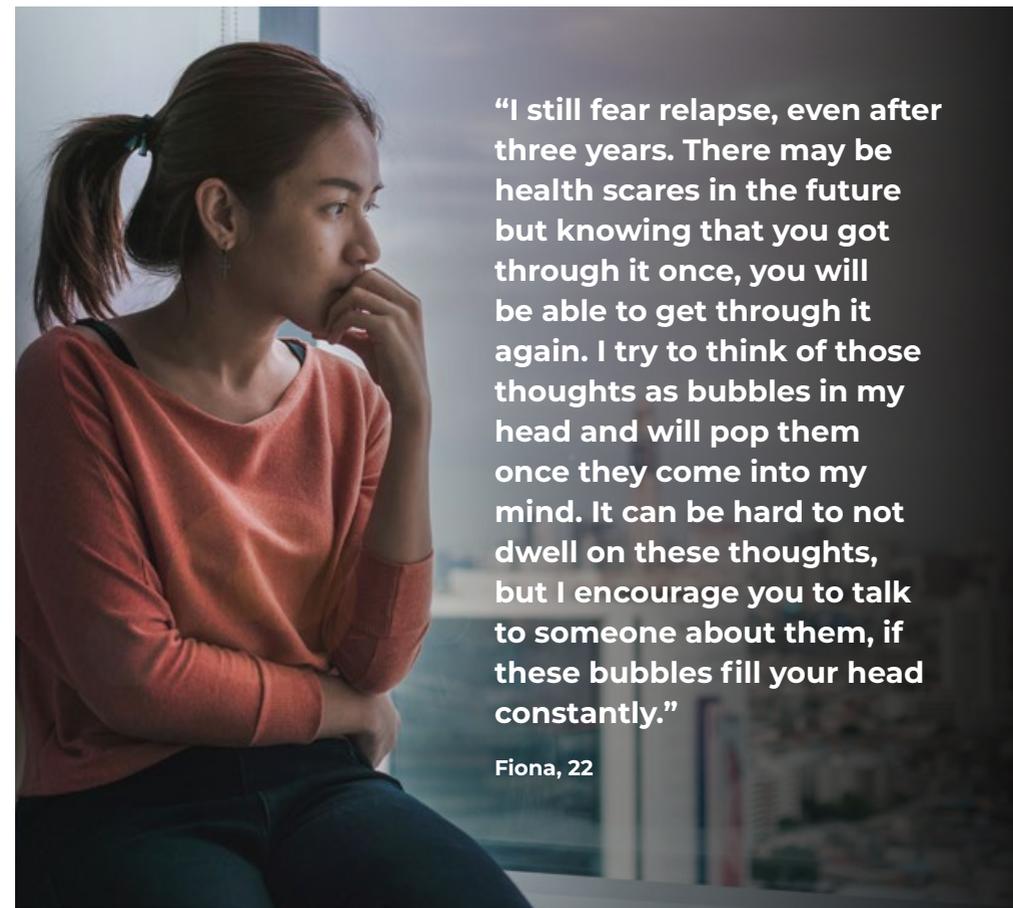
It is possible to develop a new cancer that has nothing to do with your original cancer, but this doesn't happen very often.

When cancer comes back, it can return in the same place or near to the site of the original cancer or it can spread to another part of the body (secondary cancer or metastasis).

Cancer Council has more information about when cancer comes back. Visit cancercouncil.com.au and search for 'advanced cancer'.



If cancer comes back, Canteen has a range of services that can help. Canteen can put you in touch with a specialist counsellor or with other young people who are in a similar situation. Find out more at canteen.org.au/youngpatients



“I still fear relapse, even after three years. There may be health scares in the future but knowing that you got through it once, you will be able to get through it again. I try to think of those thoughts as bubbles in my head and will pop them once they come into my mind. It can be hard to not dwell on these thoughts, but I encourage you to talk to someone about them, if these bubbles fill your head constantly.”

Fiona, 22

How will I feel?

If the cancer does come back, it can feel like the end of the world. The emotions can be intense and overwhelming. It might feel like all the treatment and side effects you have been through have been for nothing. It can be especially challenging if you have been in remission for a long time. (Remission means there are no more signs or symptoms of the cancer that can be detected –

although there might still be some cancer cells in the body).

It is not uncommon to wonder why this is happening to you and to think that it is really unfair when you have been through enough already.

You may have many of the same emotions that you had when you were first diagnosed – they may even be more intense. But you have something now that you didn't have before: experience.

Treatment decisions

Things may have changed since you were first diagnosed. Cancer researchers are constantly developing new treatments and ways to manage any side effects.

What sort of treatment you are offered will depend on what treatment you've already had as well as the type of cancer and where it is.

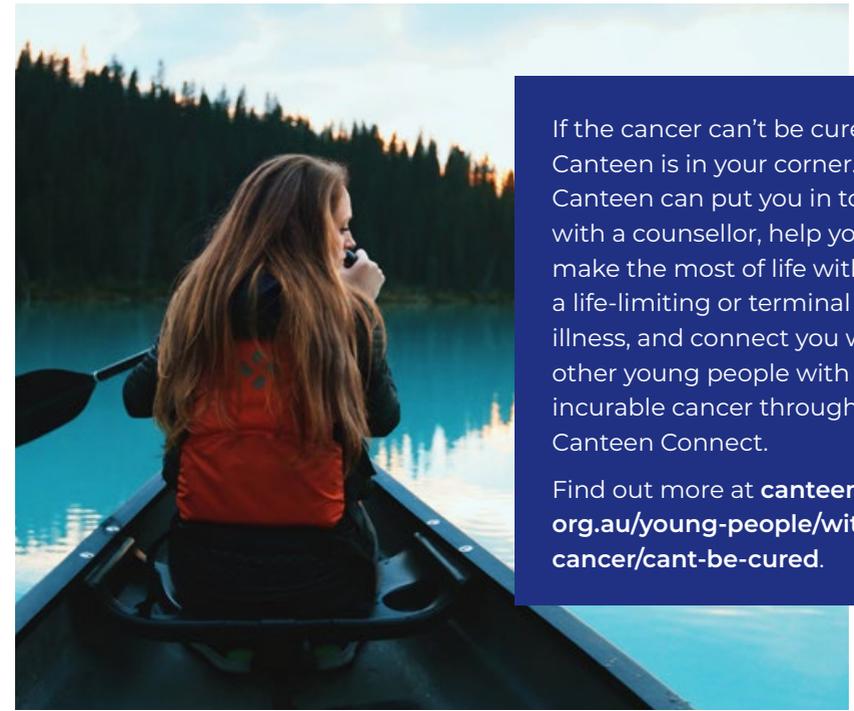
Just like when you were first diagnosed, the doctors and the rest of your medical team will talk you through your options.

Like all the other phases you have been through with cancer, getting the right information and the right support is really important. Ask people to be honest with you about what is happening.

Things to consider when making decisions about what treatment to have include:

- What impact will it have on your quality of life?
- What side effects – both long and short term – will you get?
- What type/s of treatment will you accept?
- Your prognosis – which explains the likely course and outcome of the cancer.

If you are under 16, your parents or carers will have a big influence over your treatment decisions, and may need to make the decisions on your behalf. This may need lots of open communication and negotiation – particularly if you and your parent/s (and/or your partner/s) have different ideas. It is important that you feel okay with treatment decisions.



If the cancer can't be cured, Canteen is in your corner. Canteen can put you in touch with a counsellor, help you make the most of life with a life-limiting or terminal illness, and connect you with other young people with incurable cancer through Canteen Connect.

Find out more at canteen.org.au/young-people/with-cancer/cant-be-cured.

WHEN TREATMENT DOESN'T WORK

Sometimes, treatment doesn't work or stops working.

Being told that the cancer cannot be cured is probably the hardest thing you and your family will ever have to hear.

You have the right to deal with it your way – there is no right or wrong way. It is important to find people you can trust and who will be honest with you. This may be family or friends, but sometimes it may be easier to find someone outside the family.

Sometimes cancer that cannot be cured will be life-limiting, and sometimes it may be referred to as a terminal illness. This means that the cancer is most likely going to be the cause of someone's death.

Making the most of life with a terminal illness often depends a lot on having the symptoms under control. Palliative care can help relieve symptoms and treat any physical, emotional, social or spiritual concerns. If these symptoms are under control, you can get on with doing what you want to do.

Getting the right information

Getting the right information is so important. It can help you make decisions that are right for you and also help you to understand what is going to happen.

Questions you have could include:

- Why did this happen?
- How do you know that there are no more treatments to try?
- Can I get a second opinion?
- How long do I have?
- What will it feel like? Will it hurt?
- Will I be aware of what is happening?

There may be lots of other questions – there is no such thing as a stupid question. Asking may be really hard, but not asking might be harder.

Finding people who will be honest in their answers might be tricky too. You could try your doctor, nurses, social workers or a family member.

In the advanced stages of cancer, there are many (often difficult) decisions that need to be made about treatment, such as:

- what sort of treatment you will be given (if any)
- where you will have treatment
- when to stop treatment
- whether to treat an infection

with antibiotics, or whether there should be resuscitation if breathing stops.

These are all things that need to be discussed with your treatment team and your family and loved ones. It's not easy, but it's important to talk about them and make sure your treatment team and family/partner know what you want. This can prevent more stress for them when decisions need to be made.

Making plans

After you have moved through the initial shock and the other intense emotions of finding out that the cancer cannot be cured, you may start to think about a lot of things that you want to do, say, sort out and get in order.

You may want to pack in as much as you can while you can, or you may want to just enjoy the time you have with the people you love.

The important thing is to find ways to communicate what it is that you want.

If you're able to talk openly about how you feel to your family and close friends, they will probably be relieved and able to respond.

You can choose who you want to talk to – people who will be able to support you. You only need to share as much as you want to share and when you are ready.



Recording your treatment wishes

Advanced care planning gives you the chance to think about, discuss and record your wishes for future medical treatment and care. It helps to ensure that your family and healthcare team will make decisions that respect your treatment preferences if you become unable to communicate your wishes in the future. You can learn more about advance care planning at Advance Care Planning Australia (advancecareplanning.org.au) or talk to Canteen or your treatment team.

Some things to think about:

- Is there something that you have always wanted to do or see?
- Are there things you want to tell people who are close to you?
- Is there someone you would like to see or meet?
- Are there decisions that you want to make while you are still able to?
- Are there certain things you want to be remembered for?
- Would you like to leave any letters or instructions for people, such as for special occasions?
- Do you want to have a funeral, celebration or memorial? If so, what will that look like?
- How would you like to be cared for after you die? Would you prefer to be buried or cremated?
- Have you made a Will?
- Have you made decisions about treatment at the end of life – and made sure your family know your wishes?



BEYOND CANCER

During cancer treatment, you might not have had the time or energy to think about much more than surviving. But when your treatment finally ends, what do you do now?

No matter how much you have been looking forward to returning to life after cancer treatment, it can still be weird, difficult and scary to leave the support of your healthcare team.

As you end active treatment, you enter a phase known as 'survivorship'.

The transition into survivorship can be both exciting and confusing. Figuring out what to do after cancer treatment is one of the hardest things for a cancer survivor. It's important that you give yourself time to adjust. Connecting with other young people in similar situations can be a big help – check out Canteen Connect (canteenconnect.org).

You may be affected by long-term impacts of cancer including:

- health impacts, such as infertility
- low self-esteem about the physical reminders of cancer treatment, such as scars

“However, your ‘new normal’ feels, remember, it is totally ‘normal’. Cancer is a life-changing experience, but it never has to be your whole story.”

Ezra, 21

- health anxiety, including being immunocompromised and that the cancer may come back
- feeling that you need to catch up to your friends in terms of your education, career and romantic relationships
- pressure to feel grateful that ‘you beat cancer’ while feeling that you have missed out on so much.

Redefining your life plans

- You and your family and friends have faced a serious or life-threatening illness and overcome massive challenges.
- When treatment ends, it might be a good time to redefine life rather than reconstruct it. Take some time to ease yourself back in and reflect on whether you want things to look the same as they did before.
- Before you had cancer, you may have been working out what you wanted to do with your life and making plans for the future. During treatment, it might have felt like your life was put on hold. You may have missed a lot of school time or lost momentum in your study, training or career.
- Now that treatment has ended, you may find that you focus on achieving some of your plans

and goals, but others may need a rethink.

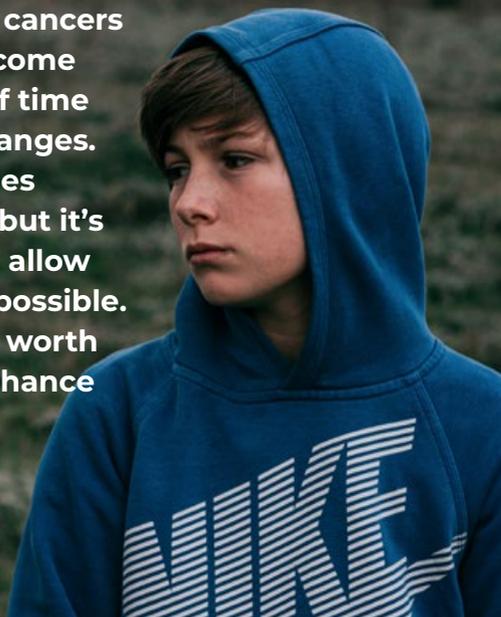
- Cancer may have left you with changes to your body, energy levels or emotional state that will prevent you from pursuing your dream job or fulfilling particular ambitions. This can be disappointing and upsetting and it may take some time to adjust.
- You may have changed your mind about the job or career you want. Sometimes survivors find that their cancer experience inspires them to pursue careers in the health profession or in organisations helping other people who are going through tough times.
- It is also possible that you have no clear idea what you want to do with your life. This is normal too. This is not an easy time of life for many young people and having cancer may not be the only reason for your uncertainty.

Take some time to look into different options, write down a list of short-term and long-term plans. Talk to your family, friends, spiritual leaders, career advisors or social workers. There is no wrong or right way to deal with survivorship – doing what feels right for you is the most important thing.

This can be a difficult time, but Canteen is here to support you through this transition. Check out canteen.org.au/newnormal.

“Having had three different cancers in 18 years, I’ve mentally become stronger and allowed myself time to adjust to the different changes. There will always be struggles related to cancer in my life, but it’s how I handle those that will allow me to live life the best way possible. You realise how much life is worth when you get that second chance after surviving.”

Lena, 24



What does it all mean?

Cancer is life changing, and some young people want to think more about the impact it has had on their lives. They search for the meaning or greater purpose behind their experience. They want to know and understand why it happened to them and what it means that they have survived.

But everybody is different. You may feel:

- That cancer has given you renewed strength and helped you to appreciate the smaller things in life.
- No need to search for deeper meaning in the experience of having cancer. You would rather just accept it and move on – and that is okay too.

- Angry and frustrated that you had cancer and that it was unfair.
- Nothing!

Your identity

As a young person, you are probably just starting to gain a sense of who you are, how you see yourself and how you want others to see you. All of these things together make up your ‘identity’.

Cancer may affect people’s identities in different ways. After your diagnosis and treatment, you may question or change your identity. This might be because:

- Changes in how you look, feel about yourself and have sex have affected your self-esteem and confidence.

- Your role in the family, group of friends or romantic relationships are different.
- You feel more mature and stronger than before and think different things are important now.
- People may treat you differently even if you feel the same on the inside. Many young people find that ‘cancer’ or ‘being sick’ starts to define their identity.
- After cancer, it can take time to figure out a new identity – and you might feel lost and confused for a while.
- You may wish that everyone would stop treating you differently. It can help if you spend as much time as possible doing the things you used to do – going to school or

work, meeting new people, dating and hanging out with people your own age as much as possible.

Uncertainty and worry

It is common to worry that the cancer might come back. Although this feeling is normal, it can still be hard to cope with. For some people, the fear is so strong that it might impact your ability to enjoy life and make long-term plans.

It can be exhausting to act as if you are fine all the time. You may have ‘bad’ days when you feel down, sad and alone. Be kind to yourself and try to accept and work through your feelings rather than ignoring them. Canteen counsellors are here to help – and just listen (canteen.org.au/counselling).



“I try to stay positive and not think of relapse. If you keep thinking of it, you’re not going to live your life. Living my life is better than dwelling on the ‘what ifs’ of my health.”

Amy, 25

Relationships after cancer

Family

Many families expect everything to return to 'normal' when your treatment ends. But be prepared – your family may have changed.

Being patient with your family as they adjust can help. It may be hard for them to give back your independence, or to know how to talk about having cancer.

Spend time working out new routines and what works for the whole family. Continue to find ways to support each other.

Friends

You may feel closer to some friends and like your friendship has strengthened. And there may be friends you feel disconnected from and like you can't relate to them as much anymore. Maybe you feel like you have been forced to grow up faster than them and now feel more mature. Or perhaps you have missed out on a lot of opportunities to hang out with people your age and you feel like your friends have moved on and left you behind.

You may find that you need to rethink and even end some friendships. This may have happened anyway – cancer or no cancer.



As you figure out what is important and interesting to you, give yourself opportunities to meet people who have similar values. You could consider joining a club or a team or connecting with people online.

Over time, you will develop your own unique identity and group of friends. Try to be honest with yourself about what kind of person you want to be and what kind of people you want to be around.

Partners

Dating and exploring your sexual orientation and gender identity is an important part of being a teenager and young adult. Cancer may have affected your confidence, self-esteem and appearance. Some people worry that they are less attractive and will find it difficult to form new relationships. Many wonder whether – and how – they will tell future partners about their cancer, particularly if their fertility has been affected.

If you want to begin a new relationship, consider:

- getting involved in activities where you can meet people and practise your social skills
- connecting with other survivors to talk about their experiences with dating
- talking to your friends, family or counsellor about your emotional and body image concerns.

Pressure from others to 'get over it'

You, your friends, your family or your employer may expect that life should just 'return to normal' now that treatment is over. You may hear statements like, "it's time to move on". While these statements from others are well meaning, it just isn't how it works.

Even when cancer treatment is over, its effects remain. You may be processing what has happened to you and what it means for you and your future. If you feel others are pushing you to move on, explain to them that the cancer experience is not over for you and that you need some space and time to cope with it in your own way.

It's okay not to feel completely happy after you finish treatment. It is often a time when trying to be positive is the most difficult.

If you feel like you aren't coping, it's okay to ask for help. Some things

you may want to try:

- Experiment with new routines and to find out what works for your family or you and your partner or friends.
- Explore new opportunities for personal and professional development.
- Acknowledge the emotions that come with survivorship through things like anniversaries of diagnosis, or the deaths of other cancer patients.
- Focus on the positive ways your life has changed after diagnosis and treatment.
- Join a cancer support group or program to share your experiences and help other young people living with cancer.
- Acknowledge the amount of change, loss and grief you've experienced because of cancer.
- Focus on caring for yourself – eat a healthy diet and get some regular exercise.

MORE INFORMATION



MORE INFORMATION AND SUPPORT

Canteen

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.org.au

Canteen Connect

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. canteenconnect.org

Youth Cancer Services

Specialist treatment and support for young people with cancer aged 15-25 is provided by the Youth Cancer Services based in major hospitals throughout Australia. youthcancer.com.au

Getting Cancer Young – YouTube channel

Youth Cancer Services has created a real-life guide aimed at helping you deal with cancer. These videos were created by people who get it - young cancer patients, their families and friends and specialist health professionals. The channel features young cancer patients and youth cancer healthcare professionals. [youtube.com/@gettingcanceryoung5063](https://www.youtube.com/@gettingcanceryoung5063)



LGBTQI+ specific

QLife

An anonymous and free LGBTQI+ peer support and referral for people in Australia wanting to talk about sexuality, identity, gender, bodies, feelings or relationships. Call 1800 184 527 (3pm to midnight daily) or visit qlife.org.au to chat online.

TransHub

An online information source for trans and gender diverse people, their loved ones, allies and health providers.

transhub.org.au

Intersex Human Rights Australia

Provides support, education and policy information, by and for people with variations of sex characteristics.

irha.org.au

Talk to someone

Canteen 1800 226 833

Cancer Council 13 11 20

headspace 1800 650 890

Kids Helpline 1800 55 1800

Lifeline 13 11 14

Redkite Telephone Support
1300 722 644

Mental Health Line 1800 011 511



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A guide to living with cancer and beyond (for young people aged 12 to 25.)

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The first edition of this book, published in 2011, was written by Pauline Don and Catherine Wood.

Free copies of this book are available at canteen.org.au/resource. This book is provided free of charge to young people with cancer. If you would like to support Canteen's work, please visit canteen.org.au/donate.



GUIDES
TO THE
FLIPSIDE



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Sydney NSW 2000

Free call: 1800 226 833

ABN: 77 052 040 516

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

A circular logo with a green-to-white gradient background. The words 'YOUTH', 'CANCER', and 'SERVICE' are stacked vertically in white, bold, uppercase letters.

YOUTH
CANCER
SERVICE