

Acknowledgement of Country

Canteen acknowledges Aboriginal and Torres Strait Islander peoples as Australia's First Peoples and sovereign Custodians of this land. We pay our respects to Elders past, present and emerging. We are committed to providing inclusive and appropriate support for First Nations young people, their kin and community impacted by cancer. First Nations peoples are respectfully advised this resource may contain images, names or stories of people who have passed away.

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







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Cancer? Are you serious?

You've found out that someone in your friend's family – their mum, dad, brother or sister – has a life-threatening illness. Talk about unexpected.

You might be wondering...now what? What should I do? What am I supposed to say? How can I help?

Being the friend of someone dealing with cancer is not always easy. You may feel confused and helpless and be thrown way out of your comfort zone.

But your friend might need people around them now more than ever.

Since cancer entered their life, your friend has probably experienced a truckload of change and faced a lot of big challenges. They might find all this stuff even harder to deal with if they think they have to go through it alone.

You're not expected to be able to make everything better. It's OK to be lost for words and to find this whole situation a bit weird.

But this book is here to help you understand that a friend dealing with cancer is still your friend – and that they will find it helpful just to have you there through the ups and downs.

So just by showing that you care, you're already awesome!





Your reaction: This affects you too

Whether you know the person who has been diagnosed with cancer really well or not at all, you might be surprised at how much this situation affects you.

You might be shocked, puzzled, totally freaked out, or feel nothing at all.

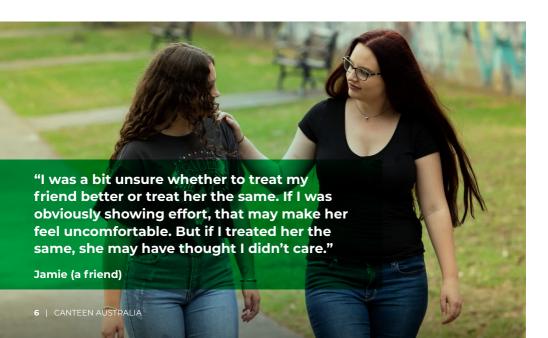
Finding out that your friend's mum, dad, brother or sister has, or has had, cancer can bring up some huge, scary questions about health, life and death that you might not have thought about much before. It may make you worry that someone in your family could get sick too.

You might also feel a bit upset about some changes in your own life. It might seem like your friend has changed and you can't talk to them anymore like you used to. People around you might be acting strange and you might really miss the way things were.

Go easy on yourself for how you handle this situation. You don't have to pretend to understand what your friend is going through or feel bad for not being able to fix it for them.

It's great that you want to be there for your friend. But you are not the only person who can support them and you don't have to be there 100% of the time.

Make sure you take some time out for yourself and get some support too if you need it.







"When I first told my best friend, her hand went straight to her mouth in shock. It made me understand the gravity of the situation: it hadn't really sunk in until I told her." Zoe

So, what is cancer anyway?

You may have heard about cancer but not really thought much about what it actually is. That's OK, most people haven't - the short version is:

Cancer is a disease of cells.

Everything in our bodies are made up of tiny cells. Sometimes cells randomly start to grow and multiply out of control and produce more and more abnormal cells that the body doesn't need. A growing collection of these abnormal cells is called cancer.

In some cases, abnormal cells clump together into a lump called a 'tumour'. In other cases such as leukaemia or lymphoma, abnormal cells travel around the body.

Tumours can be 'benign*' (not cancer) or 'malignant' (cancer). Malignant tumours can invade other areas and stop normal cells from working properly. That's why it's important to treat cancer as soon as possible.

There are more than 100 different types of cancer. They are named after the place in the body where they start.

*All these medical terms are explained in the Glossarv at the back.

Cancer FAQs

What causes cancer?

For most cancers, the cause is unknown.

We know that certain things can increase our chances of getting cancer – like smoking or spending a lot of time in the sun. And a very small number of cancers are thought to run in families.

But a lot of the time, especially in young people, cancer just happens with no explanation.

Can you catch cancer from someone else?

Nope. Cancer is never contagious, so it's fine to be near someone who has cancer.

How do you know if you have cancer?

Cancer is different for everyone.

Depending on where the cancer is in the body, there could be signs like bruising, bleeding, lumps, painful bones or blurred vision.

It's important that a person goes to the doctor as soon as they notice something isn't right to rule out the serious stuff or get treatment quickly if it is something serious.

If a doctor suspects that a person may have cancer, they will send them to a specialist to do some tests to find out. The identification of an illness is called a 'diagnosis'.

Can cancer be cured?

Most cancers can be treated and survival rates are increasing all the time. But the sad reality is that sometimes



cancer can't be cured and the person might die. There are many factors that affect the outcome of cancer and the outcome is different for every person.

Why do people with cancer lose their hair?

Cancer cells reproduce really quickly, so some treatments like chemotherapy and radiotherapy target cells that reproduce quickly in order to kill the cancer. Hair cells also reproduce quickly, so they can take a hit too but hair will usually grow back when treatment ends.

Lots of people who have cancer say that losing their hair is one of the hardest things to deal with.

Note: Some treatments for cancer do not cause hair loss. If someone does not lose their hair, it doesn't mean their treatment isn't working.

Is cancer painful?

People with cancer are not necessarily in pain.

A tumour might hurt if it pushes on other parts of the body. And some of the tests and treatments for cancer can be pretty unpleasant.

But it is often the body's reaction to treatments (called side effects) that makes someone with cancer unwell. rather than the cancer itself.

How long does cancer last?

Cancer is completely different every time. Some cancers might be treated in a few months, but others might take years.

"There were no family meals at the dinner table anymore as everyone was everywhere. There was no real structure to our family life."

Sarah

What is it like to have a mum, dad, brother or sister with cancer?

Some people say that finding out that your parent or sibling has cancer feels like having the rug pulled out from under your feet.

All of a sudden, normal life can become rocky and uncertain, people act weird and it can be hard to find the time for everyday things.

No one expects someone they love to get cancer. It always comes as a shock. Your friend might be confused and frightened and pondering some big guestions that don't have answers, like: "What is going to happen?", "What will the future look like now?" and "Why me?"

Your friend might not even know for sure what is going on in their family. With so much of everyone's attention and time focused on the person who is sick, your friend might feel a bit lost in the whole picture.

Cancer can affect a family's life in almost every way. Some changes will be huge, some of them hardly noticeable and not all of them will necessarily be bad.





Life stuff

Here are some things that might be going on in vour friend's life:

Disruption to the routine

With trips to the hospital, medications to take, visitors stopping by and parents working odd hours, life at home might feel a bit messy and unpredictable now.

Most of us like a bit of routine to feel safe. and calm and it can feel stressful when lots of unexpected things happen.

Extra responsibilities

When someone in the family has cancer, "who does what" around the house may change.

Your friend might have to take on more responsibilities - like cooking, cleaning, washing, babysitting or helping to look after the person who is sick.

Sometimes they might really miss their freedom and feel a bit lealous of friends who don't have to do the same sorts of thinas.

Home alone more

While the thought of having more time at home on your own might sound fun, it may actually feel a bit lonely after a while.

Missing out on doing normal things

Parties, birthdays, sport practice, hanging out with friends, learning to drive, getting a part-time job... your friend may be feeling a bit left behind if they have to keep missing out on what everyone else is doing.

"When my brother was sick I was left in the dark...I felt very shut out and confused."

Emma

School

For some young people with cancer in their life, school is a welcome escape from the stresses of home. But for others, venturing too far away from their unwell parent or sibling can be a major cause of stress.

Your friend might find it hard to keep up at school when their mind is elsewhere or if they don't have time to study. They might even feel that schoolwork is just not as important right now.

If teachers know what's happening, they can usually help take some of the pressure off.

No one's talking about it

People often describe a big obvious issue that no one is talking about as an 'elephant in the room' that people are pretending they don't see. Cancer can be a bit like that.

Families often try to protect each other by not talking about upsetting topics or letting on how freaked or scared they are. The downside is that everyone in the family might feel like they are facing it on their own.

Out of the loop

Children or siblings often miss out on updates about what's going on by adults who don't want them to worry.

But people can actually feel more afraid when they don't know the full truth, because their mind will try to fill in the gaps and the things it comes up with can often be worse than the reality.

Everyone is dealing with things differently

Every person in a family reacts to stress and fear in their own way. Some people cry, some make jokes, some don't show much emotion at all.

Families might fight and argue more when they are under pressure and handling it in different ways. Your friend might feel like they have to hide or hold back their feelings so they don't make other people upset. And they might feel frustrated or sad that no one else truly gets how they feel.



Being treated differently

People can sometimes become overprotective of a young person who is going through hard times. But being smothered with attention or wrapped in cotton wool can be just as upsetting as having people keep their distance.

Your friend is the same person and they will probably like to be treated as they always have.

Relationship with parents

We sometimes forget that parents get just as worried and scared as everyone else. A parent who has a child or partner with cancer might be so focused on the person who is sick that others around them can feel forgotten about. Your friend might be feeling angry or hurt that their parents are not there to support them at the moment in the way they might need. And they might be feeling guilty about feeling angry.

Relationship with siblings

Best friends? Sworn enemies? Bit of both? Sibling relationships can

be a bit love/hate - and that won't automatically change because someone has cancer.

Even if it is your friend's sibling who is sick, they will still argue sometimes if they did before (and possibly even if they didn't!). This is common and OK, but your friend might be feeling bad about some of the things they have said or done since their sibling got cancer.

It might be really hard for your friend if their sibling has cancer and they are feeling forgotten or left out of the family.

Becoming a carer

A carer is someone who helps look after a person who is unwell. Your friend might find it rewarding to be a carer, but it can also be quite stressful, especially if their parent or sibling is weak or moody from treatment. It's really important for carers to get away and take a break from the situation when they can.

Emotional stuff

Your friend might have all kinds of mixed feelings about what is happening in their family.

They might swing from one emotion to another or feel a confusing combo of things at once (it is possible to be happy AND miserable at the same time!)

Some days your friend's feelings might become so intense that they feel completely overwhelmed.

Your friend might feel embarrassed about some of the things they feel and worry their reaction isn't normal, especially if they don't know anyone else who has been through a similar thing.

But the truth is that there is no right or wrong way to feel.

All feelings are normal and understandable. However your friend feels is right for them.

Try to be patient around your friend and forgive them if they get snappy and cranky at times.

If they try to hide their feelings because they are worried about what other people may think, their feelings can build up and become even harder to handle.

At different times, and for different reasons. your friend might feel:

- shocked
- confused
- relieved
- lucky
- numb
- scared
- jealous
- sad
- frustrated
- lonely
- angry
- left out
- auilty
- uncertain
- worried
- proud
- annoyed
- embarrassed
- hopeful
- nothing at all



How can I help?

It can be really hard to understand what your friend is going through and to know what help they might need.

You may wonder if they want special treatment or if you should just try to keep things as normal as possible.

Everyone is different and not everyone will want the same thing. Tell your friend that you want to help and ask them what they need.

Your friend might be feeling really lonely, but they might be afraid to ask for help because they don't want to burden others with their problems.

So if you want to help, be really obvious. Make it clear that you will be there for them – whether they want to scream, cry, talk or just laugh and forget about it for a while.

Here are some suggestions of things that might help:

Stay in touch

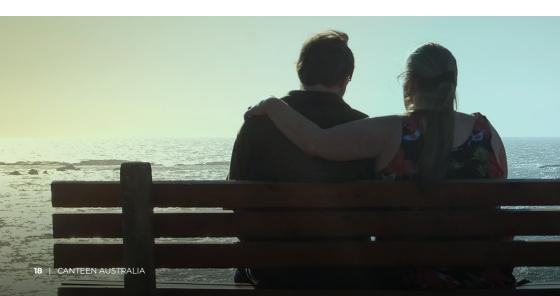
Check in regularly, even if they don't always return your calls or messages. Call just to say, "Hi", forward them funny links, send random texts.

Ask about them

Often people only ask how the patient is, forgetting to check in on the friend they are speaking to.

Keep inviting them places even if they tend to turn you down

Keep them in the loop and make it obvious that you haven't forgotten about them.



Give them an escape

Be a nice distraction. Go to the movies, the gym, play sport, get coffee, anything that will give them a break from the stresses at home.

Be available

Make an agreement that they can just hang out at your place when it gets too much at home, or call at lam for a chat, no questions asked.

Give them something nice to let them know you're thinking of them

A letter, a card, flowers, a magazine, a chocolate bar...

Offer to help in specific ways

Don't wait for your friend to ask for help as they probably won't.

Try to think of practical things you could do - like lifts babysitting, shopping or picking up assignments from school.

Encourage them to talk to a professional

Counsellors, psychologists and social workers are trained to help people understand their feelings and find solutions to their problems. A family doctor, teacher, nurse or chaplain will be able to help you find one. Canteen offers free counselling to people aged 12-25 who have a parent or sibling with cancer. canteen.org.au/counselling

Call a helpline

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



Further down the track

The next few months and years.

Often people get heaps of support at the beginning of a crisis, but later on it can feel like people have forgotten about it or think that they should be 'over it' by now.

Cancer can go on for a really long time and its effects can linger even when treatment has finished.

When treatment ends

When your friend's parent or sibling finally finishes cancer treatment, it's easy to think that everything is over and life will snap back to normal. But 'normal' may not look exactly the way it did before.

Cancer might have changed your friend and their family in some ways like:

- There might be lasting physical or emotional changes to their parent or sibling that will never go away.
- Family roles and relationships might have changed.
- Your friend may have had to rethink their plans or dreams for the future.

- Their outlook on life may be different.
- Their identity and sense of who they are might have changed.
- Your friend could be ongoing uncertainty and fear that the cancer will come back.
- They might continue to feel bad about the way they behaved or things they said when their family member was sick.

Beyond cancer

An experience with cancer can leave a unique impression on a young person and their whole family.

Some people might want to talk about it a million times.
Some people might feel uncomfortable talking about it at all. Other people will want to put it all behind them.

It doesn't usually help to put pressure on someone to be a certain way or to 'move on' after a particular amount of time.

The best you can do is just continue to check in on how they're going and listen to them talk if they bring it up.



Tips for talking

If you're like most people, you're not that great at knowing exactly the right thing to say at the right time. And it can be extra hard to talk to someone who has a family member with cancer.

You might worry that:

"I don't know if I should bring up cancer...or just talk about anything EXCEPT cancer?"

"What if I say the wrong thing and upset them?"

"I don't want to call in case I'm interrupting important family time."

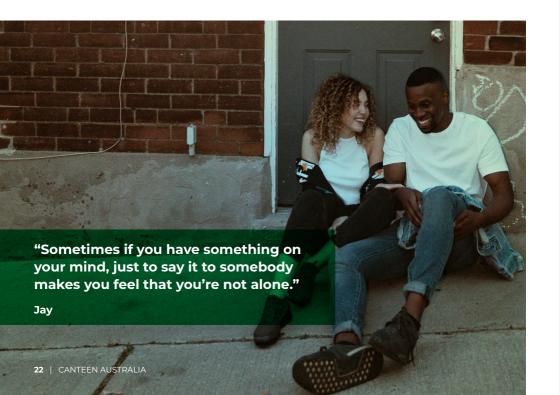
"I want to tell them about this thing

that happened, but my life seems so boring and unimportant compared to theirs now."

Everyone is new at this and these kinds of thoughts are common, but the trick is to not let your fear of saying the wrong thing stop you from saying anything at all.

Talking can help

It can be scary as anything to talk to friends about your personal thoughts and feelings. But most young people with cancer in their life find that it really does help to talk.





What should I say?

Just relax and be yourself. It's better to say, "I don't know what to say" than say something you don't mean, or to avoid the situation completely.

- Just say "How are you going?" every now and again so your friend can talk about how they are feeling if they want to (or not if they don't).
- Don't always wait for your friend to bring it up. They may be worried you're sick of hearing about it.
- · Your friend is not expecting you to have all the answers or to offer advice. Just let them know you care about them.
- · You don't have to be cheerful and positive. It's OK to let them know you find this hard too.
- · Sometimes your friend will just want to talk about normal things and to catch up on the goss.

Remember: Sometimes your friend will want to talk about it and other times they definitely won't.

The best plan is to follow their lead. Try not to be offended if your friend chooses not to talk, or if they open up to someone else. This doesn't mean you have done anything wrong. They might gravitate towards people who have gone through a similar thing.





Tips for listening

If your friend does want to talk:

- · Don't interrupt or change the topic.
- Don't judge or try to change their feelings.
- · Reassure them that whatever they feel is normal and understandable.
- Show you can relate to their feelings by saying things like, "That sounds really hard".
- · Ask questions to show you're interested.
- · Don't fill in the silent spaces, it's OK to just be quiet together.
- · Don't jump in with your own experiences of illness or grief.
- Keep what they say private (unless they ask you directly to tell someone else or you are worried that your friend isn't safe).

What should I not say?

Despite our best intentions, some of the things we say when we are trying to be helpful can be taken in a different way by someone who is stressed and upset.

Best to avoid:

- "I know how you feel." You don't, because you're not them. Only your friend really knows how they feel.
- "Don't worry. They'll be fine." Cancer is unpredictable and if your friend feels sad or negative or afraid, that's OK.
- "Everything happens for a reason." There's no reason why anyone gets cancer. Don't put pressure on your friend to find some greater significance in their experience.
- "You're so brave/You're such an inspiration." Don't put pressure on your friend to appear strong and hide how scared they might really feel.
- "Stay positive. My grandma was given a week to live and she's still here twenty years later" - It doesn't always help to compare different experiences. Cancer is different every single time.
- "It could be worse." Their loved one has a serious illness. It's a big deal and they have a right to feel however they feel.

Sometimes you might make mistakes. But don't dwell on the things you shouldn't have said or could have done better.

The biggest mistake would be to not try to talk at all.





Friendships may change

Some friendships will grow stronger through an experience like this. A lot of people say that a crisis shows you who your true friends are.

But other friendships will drift apart and some might end.

Your friend has gone through a big life-changing experience that will affect them in a lot of ways. They might develop a new perspective on life and think different things are important because of what happened. They may develop new friends and become more distant to thier old ones.

You will also develop new interests and views as you grow up and change and you may get to a point where you realise you don't have that much in common anymore.

It can be really sad when friendships end, but it's not necessarily anyone's fault.

Be forgiving and remember that friends will come and go throughout your life, cancer or no cancer.





Glossary

Benign:

A tumour that is not cancer and is unlikely to spread.

Biopsy:

The removal of a small piece of tissue from the body to look at under a microscope.

Cancer:

A general term for over 100 diseases that have uncontrolled growth and spread of abnormal cells.

Carer:

A family member or friend who looks after someone who has a chronic illness (like cancer) or disability.

Chemotherapy or 'chemo':

The use of special drugs to treat cancer by killing cancer cells or slowing down their growth.

Chronic illness:

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

Counsellor:

A professional who is trained to give emotional and practical support to people who are going through tough times.

Diagnosis:

The identification of a disease.

Malignant:

A tumour that is a cancer.

Metastasis:

A cancer that has spread to another part of the body. Also known as a secondary tumour or cancer.

Oncologist:

A doctor who is a specialist in treating people with cancer.

Palliative care:

Treatment that focuses on relieving side effects or symptoms of a disease, but will not cure it.

Prognosis:

The likely outcome of a person's disease. Cancer has a different outcome in every single case.

Psychologist:

A professional who helps with emotional and mental well being.

Radiation therapy or radiotherapy:

Treatment using X-rays to kill cancer cells, stop them growing or reduce pain.

Relapse:

The return of signs of cancer after a period when it seemed to be gone.

Remission:

When there are no signs or symptoms of active disease.

Side effects:

Problems caused when cancer treatment affects healthy cells in the body.

Social worker:

A professional who provides information as well as emotional and practical support for someone who is going through difficult times.

Surgery:

An operation to remove or repair a part of the body.

Symptoms:

Signs of an illness, such as pain, fever or nausea.

Terminal:

When a disease can't be cured.

Transplant:

The replacement of tissue with tissue from the patient's own body or from another person.

Tumour:

Abnormal growth of cells that clump together and crowd out normal cells.

X-ray:

A type of high-energy radiation. In low doses, X-rays are used to spot diseases by making pictures of the inside of the body. In high doses, X-rays are used to treat cancer.



Where to get more information and help

Information and support services for your friend:

canteen.org.au

Canteen helps young people cope with their own cancer or cancer in their family. Visit the website to join our online community, get some answers and chat to a counsellor if you want to.

youthcancer.com.au

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

cancer.org.au

Cancer Council provides information and support to families dealing with cancer. Access Cancer Council in your local state from this national website.

canceraustralia.gov.au

Information and resources provided by the Australian Government, including the Cancer - how are you travelling? resource.

redkite.org.au

Redkite provides emotional, financial and educational help for young people (aged 0-18) with cancer and their families.

campquality.org.au

Camp Quality provides free recreation programs and other support for children (aged 0-14) who have cancer and their siblings.

Useful phone numbers.

Canteen 1800 226 833 Cancer Council Helpline 13 11 20 Kids Helpline 1800 55 1800 LifeLine 13 11 14

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 in here is accurate at the time of publication.



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Thanks

Free copies of this book are available to order or download at the website canteen.org.au or by calling 1800 226 833.

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