WAIT... DID YOU SAY "CANCER"

Supporting your friend when they have cancer



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.



These books were developed through focus groups and one-on-one interviews with young people.

Please note the advice in these books works for most people, but may not be right for everyone.

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Cancer? Are you serious?

Everything is ticking along as normal, then boom, the world is tipped upside down.

Someone you know – a best friend, school friend, boyfriend, girlfriend, teammate, housemate, work friend – has cancer. Talk about unexpected.

You might be wondering...now what? What am I supposed to say? What am I supposed to do? How can I help? Do they even want help?

Being the friend of someone who has, or has had, cancer is not always easy. It can be scary and confusing and throw you way out of your comfort zone.

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

Since your friend was diagnosed with cancer, they have 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 the whole thing pretty weird.

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

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

"As a young person, your friends are the most important element in your life and cancer doesn't change that."

Tammy

Your reaction: This affects you too

You might be surprised at how much this situation might affect you too.

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

Finding out that your friend 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 you or someone in your family could get sick too, or that you could catch cancer from your mate (you can't).

You might also feel a bit upset about some changes in your own life. It might seem like your friend has changed since they found out they have cancer and you can't talk to them like you used to. Different things might be important to them now and you might really miss the way things were.

There is no right or wrong way to feel. Every person will deal with the news differently.

You don't have to pretend to understand what your friend is going through, or feel bad for not being able to fix this for them.

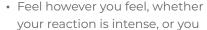
You are not the only person who can support them and you don't have to be there 100% of the time. It's OK for you to spend time doing your normal things too.

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



they are feeling and sometimes hard to say the right things. It makes me feel sad but extremely lucky at the same time."

Jamie (a friend)



As a friend it's ok to...

don't feel much at all.

- Say 'no' and not do anything you feel uncomfortable with.
- Not take responsibility for other people's problems.
- Ignore people who say insensitive things.
- Have your own life, laugh and have fun.
- Not compare your reaction to others.
- Make mistakes.
- Change your mind.
- Talk to someone and get support when things feel hard.

"My friends were shocked, saddened and a couple were very distraught...I felt a bit guilty sometimes, to be causing them so much pain. But it was also quite nice, knowing that they cared."

Max

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 is 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 Glossary at the back.



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 most of the time, especially in young people, cancer just happens with no explanation.

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 or 'normal' 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 you catch cancer from someone else?

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

Can cancer be cured?

Most cancers can be treated and survival rates are increasing all the time.

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. The outcome is different for every single 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 the treatment isn't working.

Is cancer painful?

People with cancer are not necessarily in pain.

A tumour might cause pain 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 make 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.

"I don't think my friends understood that my treatment was going to go on for years not weeks."

Bailey

What is it like to have cancer?

Cancer can mess with a person's life big time. It can impact on their body, relationships, feelings and even their picture of what the future will look like.

Finding out that you have cancer can make the earth feel shaky, like everything suddenly becomes rocky and uncertain. The whole situation might feel very unreal and at times completely overwhelming.

Here are just some of the things your friend might be dealing with.

"I don't think any of my friends really understood how much it affects a person's life, and when they saw me look physically sick it really scared them." Bailey

The physical stuff

Tests and treatments

Cancer affects every person in a different way.

Depending on the type of cancer your friend has, they will need different tests and treatments. Many of these can be scary and not exactly pleasant.

Your friend might have to face a bunch of needles, inserted tubes, scans and X-rays as well as surgeries and medications. They might not have the full story about what to expect or get much of a say about what will happen, which can make things even more frightening.

Side effects

The unintended results of these treatments are called side effects and let's be honest, they really can suck.

As well as hair loss, your friend may experience some of these changes:

- Weight loss or gain.
- Vomiting and nausea.
- Feeling tired and having no energy.
- · Mouth sores and swallowing problems.
- Weakened immune system that means a cold or other infection can make them very sick, so they might have to avoid crowds, pools and other places where infections can spread.
- 'Chemo brain' getting forgetful and finding it hard to think clearly or remember things.
- Amputation in some cases, when it is absolutely, totally 100% unavoidable, doctors might have to amputate a limb or other body part to stop the cancer spreading.

Life stuff

Cancer doesn't only affect a person's body, it can throw their whole world out of whack.

There will probably be heaps of changes going on in your friend's life. Some will be huge. Some not that noticeable. And not all of them will necessarily be bad.

Here are some things that might be going on for your friend:

Missing out on doing normal young person things

Cancer might leave your friend feeling like an outsider from the world of young people. They just might not have the energy or time for parties, birthdays, sports practice, driving lessons or hanging out with friends and they might feel like they're getting left behind.

Looking different

I'm too fat, too short, my hair's too curly...most young people have issues with their body image at some point.

But someone with cancer might have some big things to add to the mix like scarring, weight gain, baldness and a body that won't move the way it used to.

Your friend might be really upset or embarrassed about how they look during and after cancer.

When your friend is ready, you could help them to work out exercise and healthy eating plans that will help them get their strength and confidence back. In the meantime, maybe you can help them to think up some snappy comebacks for the people who stare and make silly comments.

Loss of independence and control

When a cancer diagnosis hits just at the time you are starting to build your own life and depend less on your folks, everything can shift off track.

Parents can get a bit overprotective when their child has cancer and want to do everything they can to make it easier. They may not realise that your friend still needs some space and privacy and might want to make some decisions on their own.

Change in perspective

Your friend has probably had some pretty huge challenges thrown their way and some of them might have been really serious and difficult to deal with. They may have changed their outlook on life. Things that you think are really important may not matter so much to them any more.

Relationships

Everyone close to your friend will be affected by what's happening and will be dealing with stuff in their own unique way. Fights can become more common when families are stressed and they don't all handle stress the same way. Life with cancer can put pressure on even the most loving couples and add an extra challenge to dating new people. Your friend might be finding what is – or isn't – happening in their love life a huge source of worry.

School

Get this: your friend might actually miss going to school. Yes, school can be a hassle, but it makes up a massive part of your 'normal' life.

But coming back after being away can be daunting. There's the worry that people might tease or stare and that keeping up with the work will be hard. Teachers can usually help if they know what is going on.

Being treated differently

Lots of young people with cancer say that one of the hardest parts is suddenly feeling like the odd one out. 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 feel as normal as possible.



Emotional stuff

Every young person who has cancer will feel differently about what is happening, but it's likely that most will go through some major ups and downs.

Your friend might be swinging from one emotion to another or feeling a confusing mix of things at once – it is actually possible to be happy AND miserable at the same time!

Some days your friend's feelings might be so intense and out of control that they feel completely overwhelmed.

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

All feelings are normal and understandable. There is no 'right' or 'wrong' way to feel. 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:

- relieved
- confused
- shocked
- guilty
- scared
- jealous
- sad
- numb
- uncertain
- worried
- over it
- frustrated
- lonely
- angry
- annoyed
- left out
- embarrassed
- hopeful
- nothing at all

"I wish my friends understood that I am going to be vulnerable and moody and upset, so please just accept me for how I am and love me no matter how I react or act."

Sarah

How can I help?

It can be super hard to understand what your friend is going through and to know what help they might need. You may not even be sure whether they want help or 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. It can be a comfort just to know you care.

You don't have to take on a lot of responsibility for looking after your friend. And you don't have to be able to make everything better. No one can do that. But it can mean a lot to someone who has cancer just to have some company – people who are willing to be there with them whether they want to scream, cry, talk, or just laugh.

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.

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

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

Visit them

It can be really lonely and boring to be stuck at home or in hospital and missing out on things. Try to think of things to do together that aren't too tiring – like watching TV, playing video games, looking at photos, or reading magazines. But remember, they might not always be up for visitors. Check in first and just give it a go another time if they turn you down.

Offer to help in specific ways

Don't wait for your friend to ask for help - they probably won't. Suggest practical things you could do like, "I'll bring you a coffee" or "Want me to come over on the weekend and hang out?"

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

A letter or card, flowers or a plant, chocolate, their favourite food, a book or magazine...

Talk to someone

If you're not sure about what you should be doing or worried that your friend is struggling with their feelings, talk to someone who can help – like a teacher, doctor, nurse, chaplain, or counsellor.

Call a helpline

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

"My school friends bought a bear for me and wrote well-wishes all over it...it was the single nicest thing I have ever experienced."

Max

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, or has had, cancer.

You might worry:

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

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

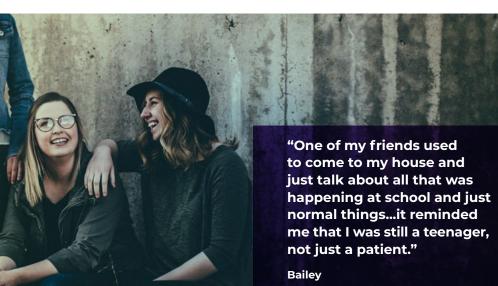
"I don't want to call in case I'm interrupting something or they're feeling too sick."

"We're not really that close. They might think I'm just being nosy..." "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.

Why talking can help

It can be scary as anything to talk to friends about your personal thoughts and feelings. But most young people who have cancer find that it really does help to talk if you can.





Here are some other things to think about:

- You don't always need to know what to say. Your friend might just find it a relief to vent.
- Not talking about difficult stuff doesn't make it go away. Little worries can grow into big fears when they tumble around in your head.
- Putting thoughts and feelings into words can make them easier to understand and seem easier to handle. Other people can help you see things from a different perspective.
- Your friend might feel lonely or ignored if they can't talk about what is happening.
- Talking to your friend can help you feel closer to each other and give you some ideas about the kind of help they might need.

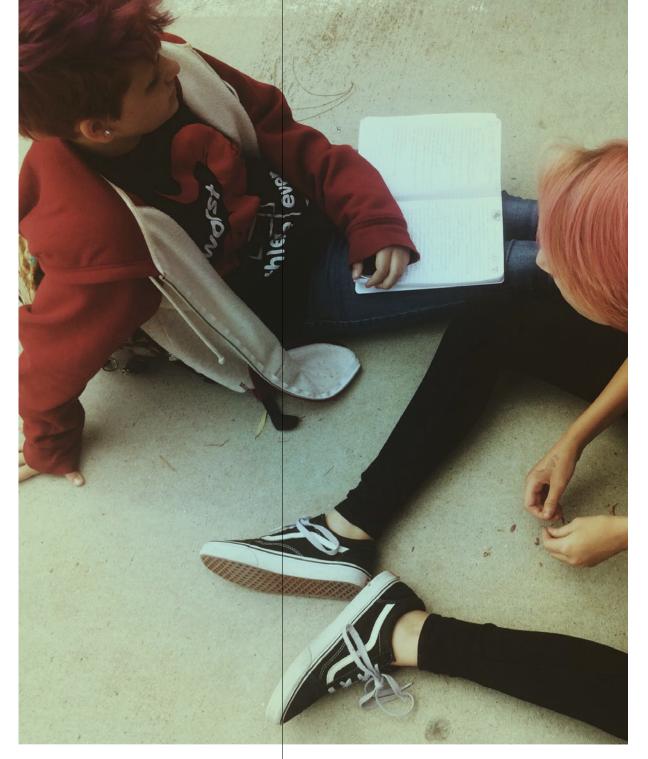
What should I say?

Just relax and be yourself. It's better to say, "I don't know what to say" than 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).
- Your friend is not expecting you to have all the answers or to offer advice. Just let them know you care.
- You don't have to be cheerful and positive. It's OK to let them know you find this hard too.
- It's OK to say the word 'cancer'.
- It's OK for there to be silent moments. Don't rush to fill them up.
- You don't always have to talk about serious stuff, 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 will definitely not want to talk about it.

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.



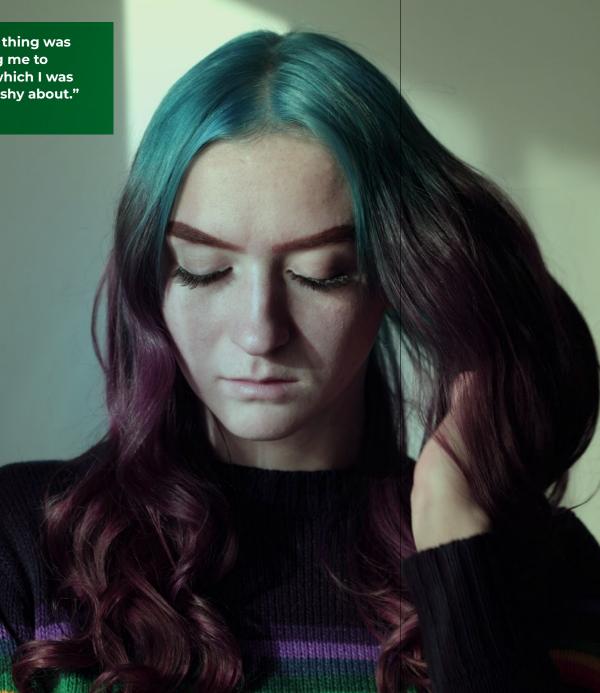
Tips for listening

If your friend does want to talk:

- Don't change the topic, or interrupt.
- 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.
- Encourage them to talk to others too, especially if you are concerned about what your friend tells you.

"The least helpful thing was friends pressuring me to take my wig off, which I was embarrassed and shy about."

Alex



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. You'll be fine." – Cancer is unpredictable. 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." – 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.

"Cheer up. It could be worse." – Cancer is a big deal. It's OK for your friend to be freaked out and think that the whole thing sucks.

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

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

Further down the track

Often people get heaps of support when they are first diagnosed, but later on it can seem like everyone has forgotten about it or thinks that they should be 'over it' by now.

Cancer can go on for a really long time. And its effects can linger even after treatment is finished.

When treatment ends:

- When your friend has finally finished their treatment, their hair grows back and they go back to school, it's easy to think that everything will snap back to normal. But 'normal' may not look exactly the way it did before.
- There might be lasting physical effects that will never go away and things they won't be able to do anymore, like mucking around, playing sport, or staying up late.
- Your friend might have trouble getting a job, or studying because they still have issues with concentration or energy.
- They might have had to rethink their plans or dreams for the future.
- Their outlook on life might be different.

Even their identity or sense of who they are can change. Maybe before cancer they were the joker, or the sporty one, or the academic, but cancer has altered this.

- There might be ongoing uncertainty and fear that the cancer will come back. There will never be a guarantee that nothing bad will happen.
- Roles and relationships in their family might have changed.
- They might feel guilty for surviving when others didn't.
- They might not "trust" their body and be worried when they have aches or pains.
- They might worry about telling new people and being treated differently.

Beyond cancer

Some people say that an experience with cancer never actually ends. There are so many things that continue to impact their life that there isn't really an 'after' to cancer at all.

The way your friend feels about their experience will be really unique.

Some people might want to talk about it a million times. Some people might feel uncomfortable talking about it at all. Other people will just want to put it all behind them. It can be important not to ignore what has happened, however long ago it was. Keep checking in with them and asking how they are going, even ten years later.

If cancer comes back

There is a very small chance that cancer can come back after a period when it seemed to be gone. This is called a 'relapse'. It happens because some cancer cells were left behind despite the treatment they received.

The cancer may still be curable, but it can feel like the end of the world to have to go through it all again. Your friend might feel many of the things they felt when they were first diagnosed – their feelings might even be more intense this time.

Your friend will need as much support now as they ever have.

Here are some thoughts to offer them:

- Hope is flexible. There is always something to be hopeful for.
- You have gotten through this before and you can do it again.
- You are not alone.

"When my friends were first told I had cancer they were really helpful and wanted to just drop everything and see me. But after about the first month most of them backed right off and didn't keep the link of communication with me."

Bailey

Friendships may change

Some friendships will grow stronger through an experience like this. But other friends will drift apart and some friendships might end.

A lot of people say that a crisis shows you who your true friends are.

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 now.

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.

"Some have stayed friends, others haven't. The ones that have stayed have definitely become closer."

Kym

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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.

Cancer Hub

Dealing with the immense challenges of cancer is often overwhelming and can take a significant toll on the mental health and wellbeing of your friend.

Finding support shouldn't be yet another challenge on the list. Cancer Hub makes it easier for your friend to get the practical and emotional support they need. All in one place.

Visit cancerhub.org.au or call 1800 945 215 today.

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.

Talk to someone:

Canteen 1800 835 932 Kids Helpline 1800 55 1800 LifeLine 13 11 14 Cancer Council Helpline 13 11 20

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.



References

Cancer Council NSW (2018), Cancer in the School Community: A guide for staff members. Available at cancercouncil.com.au

Irish Cancer Society (2017), Lost for Words: How to talk to someone with cancer. Available at <u>cancer.ie</u> Macmillan Cancer Support website. Emotional support for family and friends. Available at <u>macmillan.org</u>. <u>uk/cancerinformation</u>

Macmillan Cancer Support (2021). A guide for young people looking after someone with cancer. Available at be.macmillan.org.uk

Thanks

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

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Canteen is here for you if you're 12-25 and cancer has turned your world upside down.