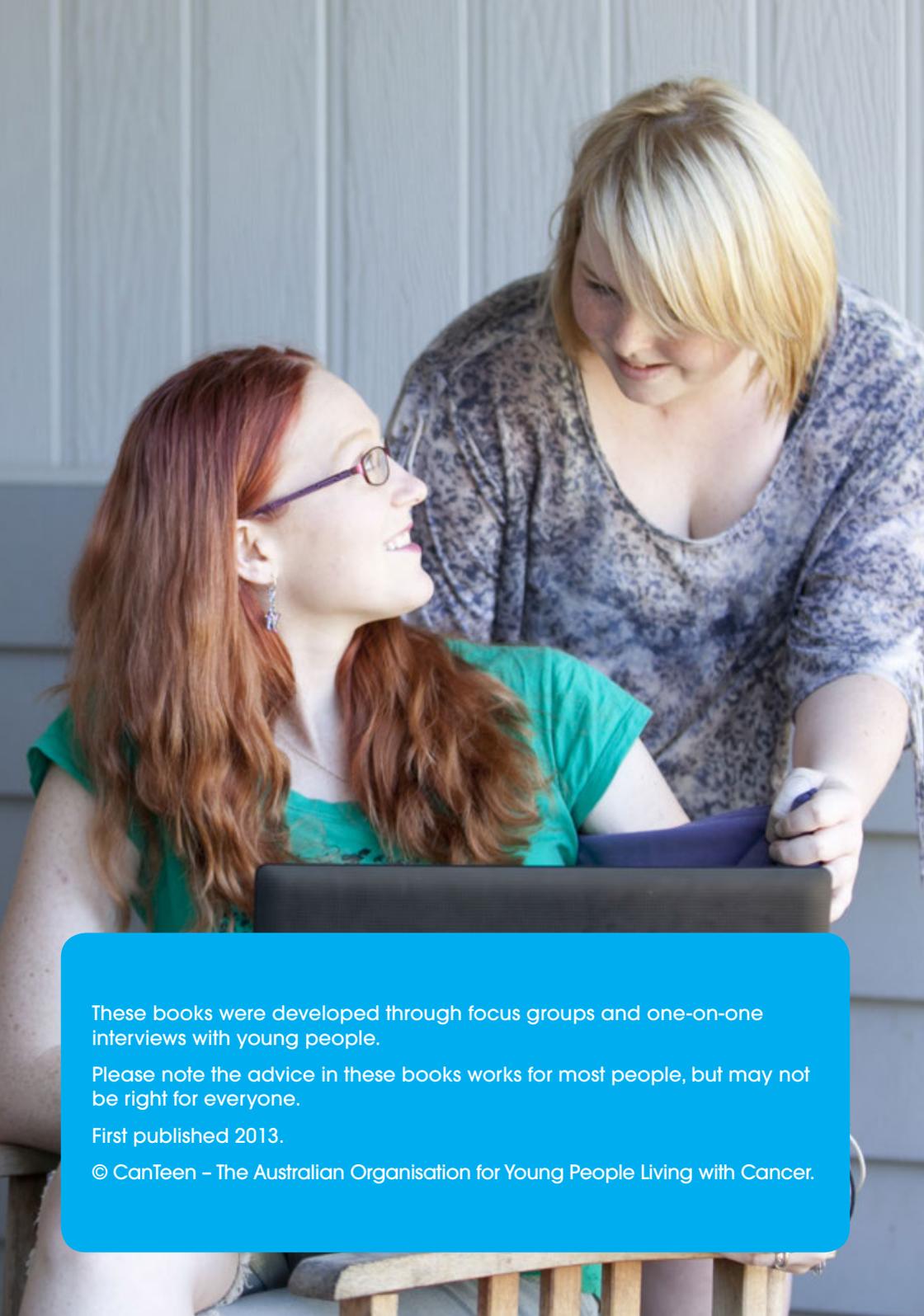


Wait... did you say “cancer”?

A guide to supporting your friend when someone in their family has cancer





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?

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.

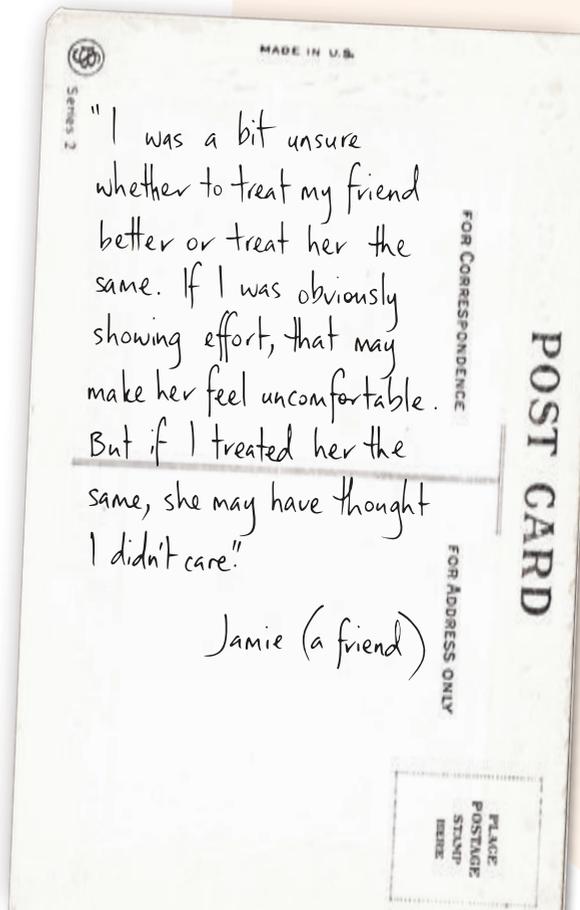
But your friend might need people around them now more than ever.

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 the whole thing pretty weird.

But this booklet 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 with them through the ups and downs.

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



Your reaction

Whether you know the person who has been diagnosed with cancer really well or not at all, you might be surprised at the ways this situation can affect you too.

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

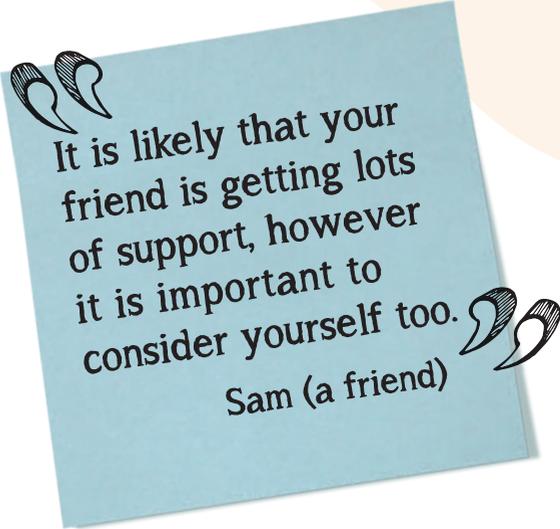
Finding out that your friend's mum, dad, brother or sister has or has had cancer can bring up some huge, scary questions about health, life and death that you might not have thought about much before. It may make you worry that someone in your family could get sick too.

You might find that there are also some changes in your own life that are a bit upsetting. 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.

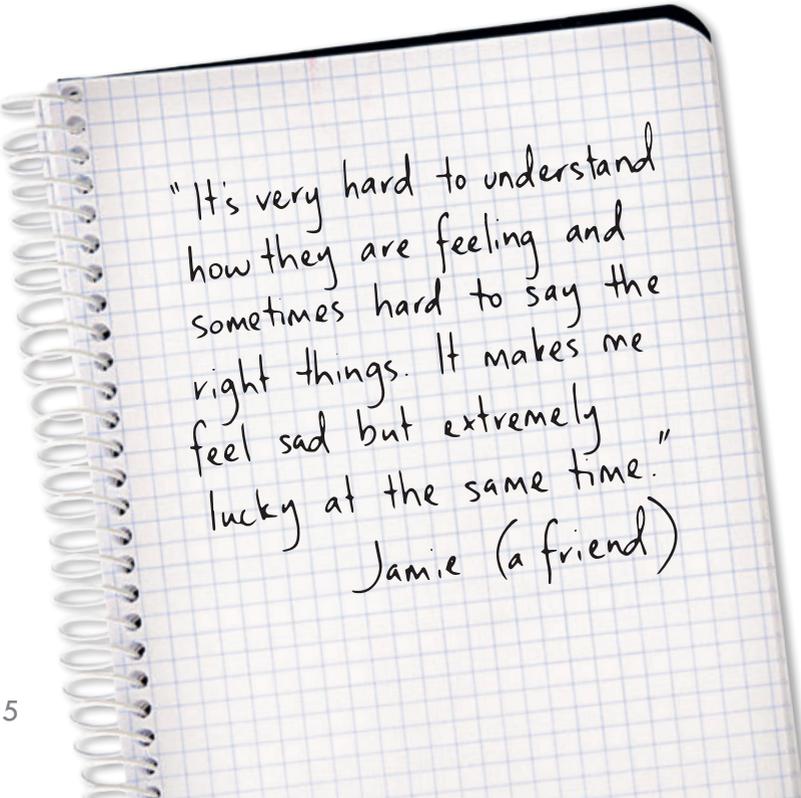


It is likely that your friend is getting lots of support, however it is important to consider yourself too.

Sam (a friend)

As a friend it's ok to...

- Feel however you feel, whether your reaction is intense, or you don't feel much at all.
- Not compare yourself to others.
- Say 'no' and not do anything you feel uncomfortable with.
- Make mistakes.
- Change your mind.
- Not take responsibility for other people's problems.
- Ignore people who say insensitive things.
- Get help for yourself if you are having trouble with your own feelings.
- Talk to someone and get support when things feel hard.
- Have your own life, to laugh and have fun.

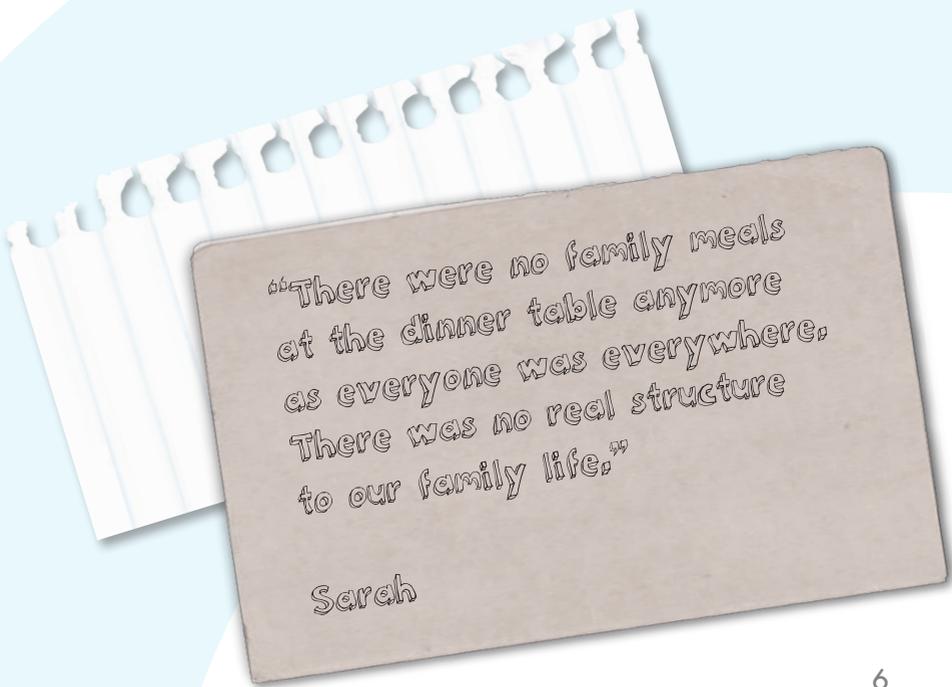


"It's very hard to understand how they are feeling and sometimes hard to say the right things. It makes me feel sad but extremely lucky at the same time."
Jamie (a friend)

So, what is cancer anyway?

You've heard of cancer but haven't really thought much about what it actually is, right? Don't worry, most people haven't. So, in case you were "away that day" in science class, here's the short version:

- Everything in our bodies is made up of tiny cells. If our bodies were a house, the cells are the bricks.
- Cancer is a disease of 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.



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

Sarah

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.

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 (so go easy on the bald jokes).

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.

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

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.



☹️ When I first told my best friend, her head 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

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 questions 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 of the changes will be huge, some of them not that noticeable and not all of them necessarily bad.

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

Disruption to the routine.

With trips back and forth 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, the old "who does what" can change.

Your friend might have to take on more around the house - 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 jealous of friends who don't have to do the same sorts of things.

Home alone more.

Sounds like fun, right? But it might 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.

"I WISH MY FRIENDS
UNDERSTOOD THAT IT'S
TOUGH, ONE BATTLEFIELD
TO ANOTHER." - JACK

With my Mum having cancer it was like
I took over from Mum. It was like I had
to stay even stronger for everyone.

Jane

PP

I wish my boyfriend could understand that it affected my school work. He couldn't understand how I could feel school wasn't important at the time, especially as I was in Year 12. DD

- Zoe

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.

"The kids" or "the 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.

"WHEN MY BROTHER WAS SICK I WAS LEFT IN THE DARK... I FELT VERY LEFT OUT AND CONFUSED."

- EMMA

"Sometimes I couldn't understand why everyone was always making a fuss over her. I used to think that everyone loved Melanie more than me because she was sick and it made me feel sad." - Amber

Everyone is dealing with things differently.

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

Families might fight and argue more when they are under pressure and are not all handling it the same way. 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.

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.

☺☺
It's so hard with everyone's different personalities and how they deal with the shock. ☺☺

Jane

Emotional stuff

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.

Being treated differently.

People can sometimes become over-protective 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.

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!)

“When Dad got ill, I felt drained being in his presence. I wasn't just a visitor; I lived with him and all the other gritty parts that came along with the illness.

Jane

“Treat us normally. No one likes to be singled out or given special treatment. Being treated the same as always keeps a form of stability going for us.”

- Zoe

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

SHOCKED CONFUSED

relieved **LUCKY** **OK**

Scared **JEALOUS** sad **NUM**

FRUSTRATED lonely **ANGRY** **N**

LEFT-out **GUILTY**

uncertain

ANNOYED

worried

PROUD

EMBARRASSED

hopeful

nothing at all

It can be exhausting to go through big emotional ups and downs. Sometimes your friend's feelings might become so intense that they feel completely out of control.

They might also worry that their reaction isn't normal and that people will think they are weird. They may not know anyone else who has been through a similar thing and be unsure about how they are supposed to act.

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.

“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 special treatment at all 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.

"My friends were my escape. When I was with them I could have fun and not think about what was happening with Melanie."

Amber

"I would have liked more time with my friends. I think they felt I needed to be with family all the time when I really needed balance." - Chris

Here are some suggestions of things that might help:

Stay in touch.

Send messages, emails and texts, forward them links, write on their Facebook page. Just call to say "Hi" and let them know that you haven't forgotten about them.

Ask about them.

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

Invite them places.

The movies, your place, the gym, play sport, get coffee or any other awesome distraction away from Cancerville.

Gifts.

Who doesn't love an out-of-the-blue chocolate bar? Or any little thing that will let them know you're thinking of them - a magazine, some TV shows, a new music playlist...

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 bringing their assignments home from school, giving them lifts or helping run errands.

Read stories of other people going through a similar thing.

There are heaps of stories from young people who have a parent or sibling with cancer at nowwhat.org.au.



I would feel a bit pushy calling someone to ask if they can help out. The best thing was people offering specific things at specific times like, "Shall I come over this Saturday and help clean up a little?"



Lizzie

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 12-24 who have a parent with cancer - go to canteen.org.au

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.

Some days after school, I felt as though I was coming home to work. To clean and pack and stack and cook and wash and run errands. It would have been helpful if my friends organised an outing so I could escape.

- Zoe



☁
I didn't really tell that many people about it. I always thought that I would be burdening people if I told them. On the outside I was a picture of well-adjustment, but on the inside I was hurting. ☁

- Jo

Talking to your friend

Hands up who's not that great at knowing exactly the right thing to say at the right time? Right, most people. 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 make them feel worse?"

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

"I want to tell them about this thing that happened today, 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.

Don't worry too much about upsetting your friend. Even if you say something stupid, they are still your friend and they'll get over it!

Why 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.

You don't always need to know what to say. Your friend might just find it a relief to get things off their chest.

Here are some other things to think about:

- Not talking about difficult stuff doesn't make it go away. Little worries can grow into big fears and stresses when they tumble around inside your head.
- Putting feelings and worries into words can make them easier to understand and seem easier to handle.
- Your friend might feel isolated and lonely if they can't share what is happening.

PP I'd talk to my bestie about things that were particularly annoying and she'd provide new perspectives or comment that she agreed, which made me feel better and that it was a normal way to feel. *DD*

- Zoe

"I often had the urge to ask, "How are you feeling?" or, "Are you OK?" but I didn't because I didn't want to provoke any more sadness from her."

- Jamie
(a friend)

“Sometimes if you have something on your mind, just to say it to somebody makes you feel that you’re not alone.”

Anna





"It does help
to talk with
friends, but
sometimes you
just need your
friends there
and to not talk,
to take you
away from the
hard emotions
and for them to
be distractors,"

Sarah

What should I say?

Tips for talking (from young people who have a parent or sibling with cancer).

- Sometimes I want to talk about it, sometimes I really don't want to talk about it. Just make it clear you're there to listen if I do.
- Just check in and say "How are you going?" sometimes, then I can talk about how I feel if I want to (or not if I don't).
- I'd rather hear you say, "I don't know what to say" than something you don't mean, or for you to avoid me altogether.
- Please don't always wait for me to bring it up. I'm worried you're sick of hearing about it.
- Don't focus on the cancer...
- Or ignore it either.
- Please don't bug me for the gory details...
- Or make jokes about how my parent or sibling looks or acts now.
- I know you can't fix this, I don't expect you to provide advice.
- You don't have to put on a brave face. You can let me know that you find this hard too.
- We don't always have to talk about serious stuff. I want to talk about normal things and have fun sometimes too.
- Please don't be offended if I don't feel like talking or if I talk to someone else.

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.

"It is OK to ask questions and if you say the word 'cancer' you don't have to look horrified or feel bad for bringing it up."

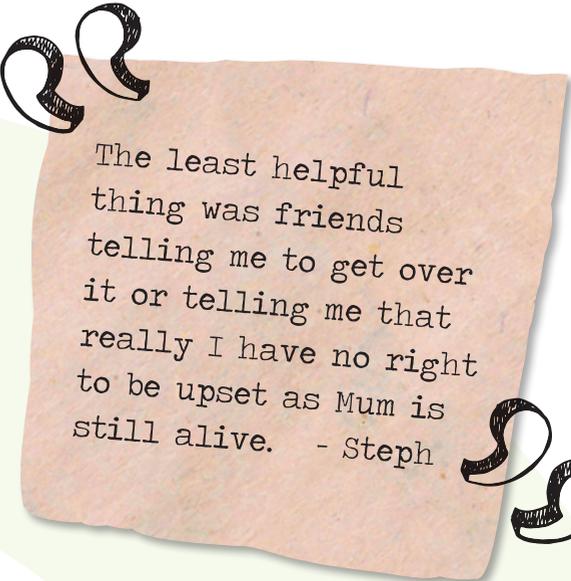
Anna

What should I not say?

Oops, that came out wrong! 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.” Even if you’ve been through a really similar experience, your friend is the only person who really knows how they feel.
- “Don’t worry. She/He’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.” You don’t have to put your friend on a pedestal and make them feel like they have to be perfect or hide how weak and scared they 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 is a big deal and they have a right to be freaked out.
- Just be yourself and go with what feels right. We all make mistakes, so don’t beat yourself up about the things you shouldn’t have said or could have done better.



The least helpful thing was friends telling me to get over it or telling me that really I have no right to be upset as Mum is still alive. - Steph

Further down the track

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 is finished.

When treatment ends.

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

A trip to Planet Cancer is massive and it might have changed your friend and their family in some ways...

- 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.
- Even their identity and sense of who they are might be different.
- There 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.

"When my friends found out my sister had cancer they were really supportive. But after a week or so they expected it to go away and stopped talking about it."

Tara

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.

Sometimes friendships 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 now.

You will also develop new interests and ideas 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.



I think it was important not to ignore what has happened however long ago it was, to acknowledge and understand as best as possible.

Sam (a friend)





"In some ways it feels like my friends and I have drifted apart and then in some other ways it feels like we are closer than we have ever been before. My cancer journey has affected them in ways that they would never show me."

- Danny

☞ You will notice that their perceptions may change, they may see people differently as they have become more mature from having to take on greater responsibilities... ☞

- Zoe

Glossary (decode the medical jargon!)

Benign:

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

Bereaved:

A person who has a loved one who has died.

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 canteen.org.au to join our online community, get some answers and chat to a counsellor if you want to. You can also email support@canteen.org.au or call 1800 835 932.

youthcancer.com.au

This site is especially for young people with cancer and their families. It provides information and links to services for patients throughout Australia.

canceraustralia.gov.au

Information and resources provided by the Australian Government, including the Cancer - how are you travelling? booklet: canceraustralia.gov.au/publications-resources/cancer-australia-publications/cancer-how-are-you-travelling

cancer.org.au

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

redkite.org.au

Redkite provides a range of services for young people (aged 0-24) with cancer and their families. They provide emotional, financial and educational assistance.

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 835 932

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.

References

The following were useful in putting this book together:

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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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