WAIT... DID YOU SAY "CANCER"

Supporting your friend when their family member has died

canteen

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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When a friend's parent or sibling dies from cancer

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

Every cancer story is different. However it played out in your friend's family, they have probably already experienced a lot of big changes, heaps of uncertainty and a huge range of strange and confusing emotions.

But the death of a parent or brother or sister from cancer is not the end of the story. It can be the start of a new journey through grief that will bring some of the toughest challenges your friend will ever face.

It's not always easy to be the friend of someone who is grieving. You might 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.

Most people who have lost a loved one find that things do eventually get easier and they learn to live with their grief. But it can be a very rocky and lonely path.

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 who is grieving 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!

Your reaction: This affects you too

Whether you knew the person who died really well or not at all, you might be surprised at how much this situation affects you.

Hearing that someone in your friend's family has died can really freak you out. Even though we all know that everyone is going to die eventually, people don't really think about dying or death all that much.

Being reminded that people we know and love can die can be really scary. It can bring all these big confusing thoughts into your head; like about what death looks like and what, if anything, happens after.

You might also feel a bit upset about some changes that have happened in your life since your friend's parent or sibling died. You might feel like your friend has changed and you can't talk to them like you used to anymore.

Everyone around you might be acting strange and you might really miss the way things were.

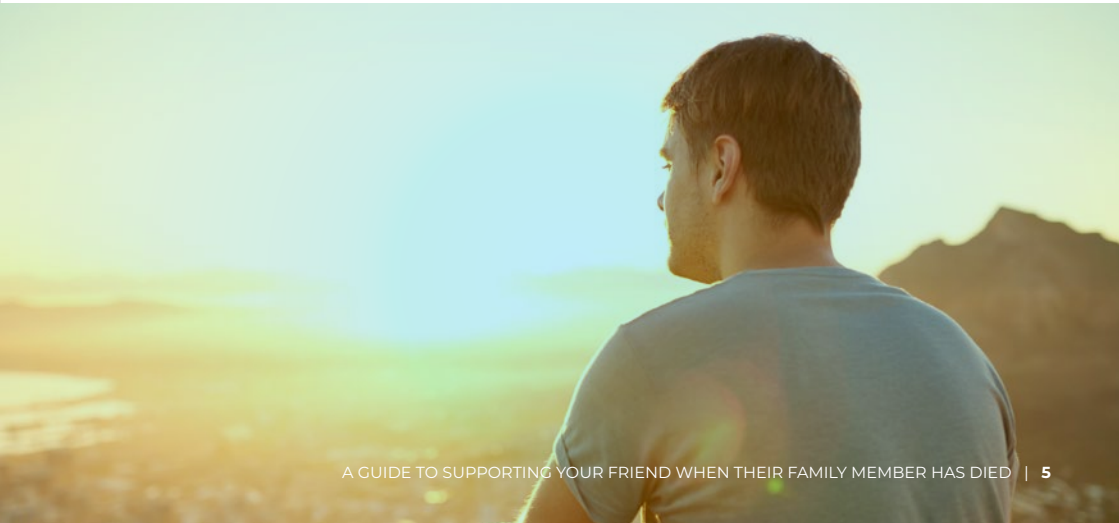
It's also really common to not feel that strongly at all about the death of someone in your friend's family. This doesn't mean you're not a caring person.

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 your friend 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.



As a friend it's ok to...

- Feel however you feel, whether your reaction is intense, or you don't feel much at all.
- Talk or not talk about how you feel.
- Say 'no' and not do anything you feel uncomfortable with.
- Make mistakes.
- Change your mind.
- Ignore people who say insensitive things.
- 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)

What is grief?

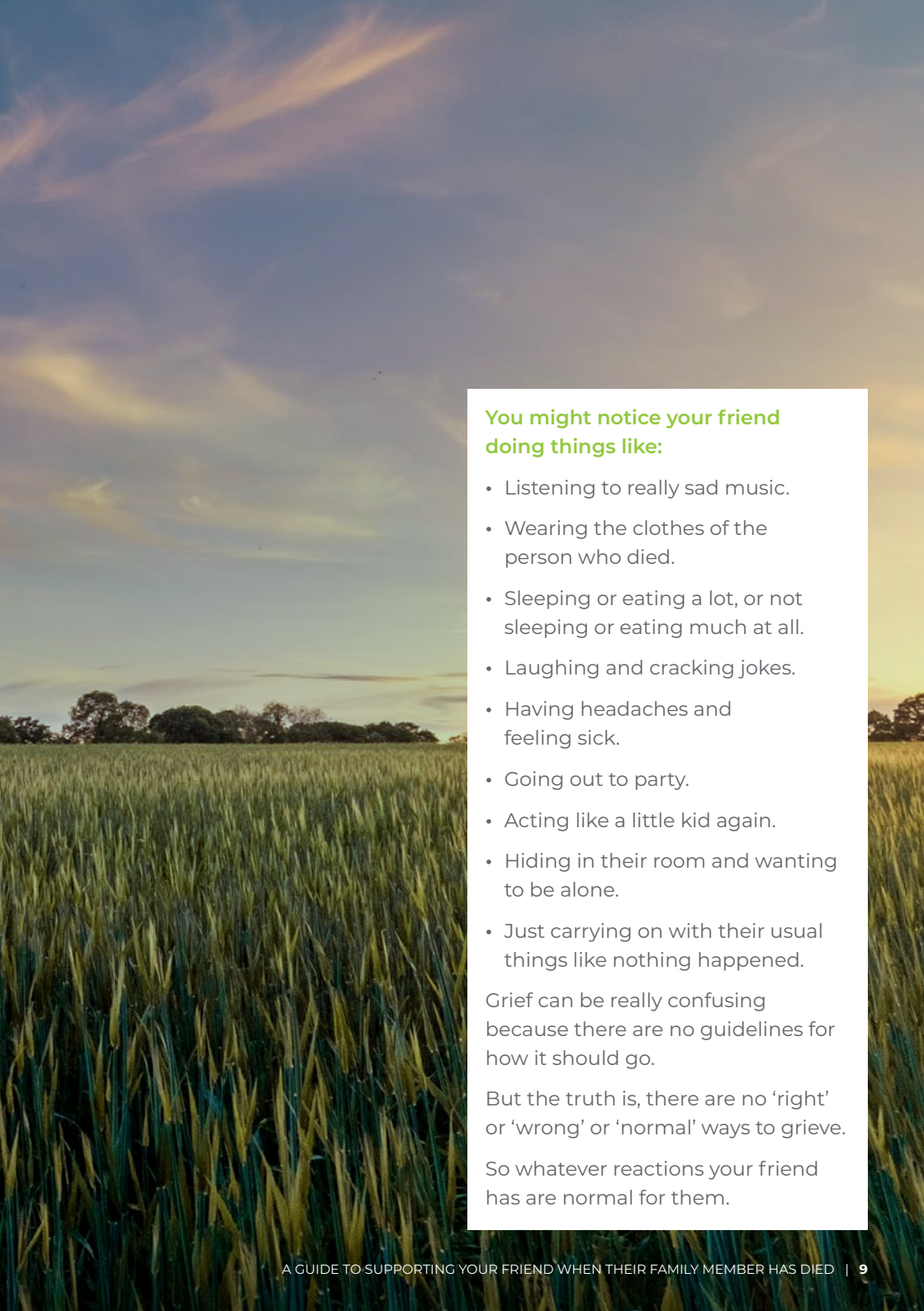
Grief is the reaction we have to the loss of someone or something that is important to us.

Grief shows up differently in every single person. It can include feelings, thoughts, actions and physical reactions.

People who are grieving don't always look exactly the way they do on TV; wearing black veils and crying all the time.

Lots of people don't cry at all when someone dies. If they don't cry it doesn't mean they don't care. Grief just affects people differently.

You might think that some of the things your friend does when they are grieving seem a bit surprising, especially if you've never really been around a grieving person before.



You might notice your friend doing things like:

- Listening to really sad music.
- Wearing the clothes of the person who died.
- Sleeping or eating a lot, or not sleeping or eating much at all.
- Laughing and cracking jokes.
- Having headaches and feeling sick.
- Going out to party.
- Acting like a little kid again.
- Hiding in their room and wanting to be alone.
- Just carrying on with their usual things like nothing happened.

Grief can be really confusing because there are no guidelines for how it should go.

But the truth is, there are no 'right' or 'wrong' or 'normal' ways to grieve.

So whatever reactions your friend has are normal for them.

How long does grief last?

You might have heard that there are 'stages' of grief that a person moves through until they are over it. But that's not really how it works.

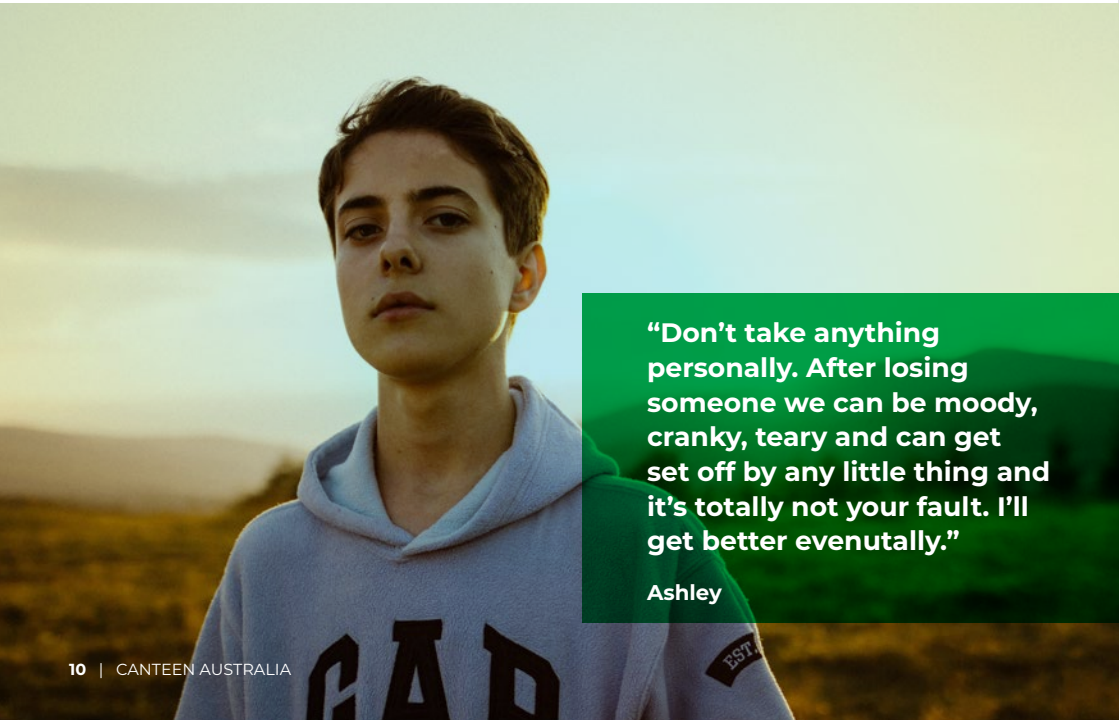
There is no timetable for when a person should start or stop feeling certain things.

It's more likely that feelings of grief will come and go in waves. Some days your friend will feel fine and like they are getting back on track. Then something will trigger a memory and they might be knocked over by a wave of grief so strong they don't know which way is up.

There is no easy way to go through grief. A person just has to ride with each up and down as best they can.

It may seem a bit frustrating to hear, but grief never really ends. Your friend will never get over the death of a parent or sibling. There will always be a space in their life that nothing else can fill.

But over time there will be more good days than bad ones and they will gradually start to feel happy again. This doesn't mean that they don't miss the person who died any more, just that they are getting used to them not being around.



"Don't take anything personally. After losing someone we can be moody, cranky, teary and can get set off by any little thing and it's totally not your fault. I'll get better evenutally."

Ashley

Grief is not just about death

You can feel grief over anything you have lost, not just people.

Your friend might have experienced a lot of losses, big and small, since someone in their family got cancer. On top of their reaction to the death of someone close, they might be dealing with things like:

- The loss of their old routine.
- Having less time to hang out with friends.
- Having more responsibilities at home.
- Changes to the family dynamic.
- Feeling distant with members of the family.
- More family fights.
- Parents working more.
- Less money.
- Having to move house.
- Falling behind at school, uni or work.
- Missing out on a planned holiday.
- Loss of a sense of security and having new worries, like that someone else in their family will die too.

When someone dies, people don't only grieve for the loss of that person, but the loss of the future they imagined.

Your friend might be feeling grief that their parent won't be there to see them graduate, that they will never see their sibling grow up and get married one day.

The bigger these losses feel for your friend, the harder they can be to adjust to and the stronger their grief will feel.

It might take a while, but things will eventually settle down into a new pattern and feel 'normal' again, even if normal doesn't look the way it did before.

Understanding feelings

When someone dies, the people who were close to them may experience all kinds of emotions. These will come and go and change over time and might be mixed together in confusing ways.

Sometimes the feelings brought by grief can be so overwhelming that the person feels like they are going crazy.

In the weeks, months and years after somebody dies, your friend might feel...

Numb:

No feeling at all. Some families know in advance that their loved one is going to die from cancer. In other families, it will be completely unexpected. Either way, it will likely come as a massive shock when it happens. For a while they might feel empty and distant, like they are looking at their life from space. They might find it hard to believe that the person is really gone and keep expecting them to walk into the room at any minute.

Sadness and despair:

Maybe even be worried that they will never feel happy again.

Anxious:

Freaked out about what will happen next and how they will possibly get through it.

Angry:

At the person who died for leaving them behind; at the adults around them for not telling them more about what was going on; at themselves for not being able to prevent it; or maybe at God or the world for being so unfair.

Relieved:

That their parent or sibling doesn't have to suffer any more, especially if they had been sick and weak for a really long time. Your friend might also be relieved that there will be space in the world for them again, after the attention and energy of their family has been focused on caring for the person with cancer for so long; and relieved that the stress and worry is over.

Guilty:

About past arguments or difficult relationships they had with the person who died, or for not getting a chance to say 'sorry', 'thank you' or 'goodbye'. Guilt and regret is common, but it's not always helpful to dwell on past mistakes. Nothing your friend said, did or thought caused their family member to die.

Embarrassed:

About how they are acting or feeling in their grief. Or for being different to everyone else now.

Your friend might be the only person they have ever known to experience the death of somebody close and they might worry that their feelings are not normal.

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

“I am going to be vulnerable and moody and upset and feeling lost. So please just accept me for how I am and love me no matter how I react or act.”

Sarah

“It would have been nice to have friends keep tabs on me, just to make sure I was OK.”

Jo

Everyone grieves differently

Grief affects everyone differently, even when they are grieving over the same person.

Your friend might compare their reaction to the reaction of other people in their family and feel like they are expected to react in a certain way. They might even feel like they have to hide or hold back their grief so they don't make other people upset.

But you can't just turn grief off. If you try to bottle it up, it can get stuck and feel even stronger for longer. It's important that your friend accepts their grief and lets it out in whatever way they need to.

No matter what anyone else says or does, they have the right to:

- Grieve in their own way for as long as it takes.
- Be included in things as much as they want.
- Ask questions about what happened and get honest answers.
- Talk about the person who died.
- Forgive themselves for things they said or did (or didn't say or do).
- Not try to be strong and brave.
- Not step up to take the place of the person who died.
- Have their own personal beliefs about life and death.
- Make some changes when they are ready and go on having a happy life.

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.

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.

Your friend is still the same person, even though they might be moody and acting differently. Make it clear that you will be here for them no matter how they act - whether they want to scream, cry, talk or just laugh and forget about it for a while.

Here are some suggestions by other young people who have lost a loved one to cancer:

In the first few weeks or months:

Don't ignore it.

When you find out, acknowledge what has happened. Send a message, leave a voicemail, Facebook them, pop over for a quick hug.

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 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 1am 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 chocolate bar...

Offer to help in specific ways.

Don't wait for them to ask, they probably won't. Try to think of practical things you could do – like lifts, babysitting, shopping or picking up assignments from school.

Offer to tell people.

So they don't have to say "My.....died" a thousand times. (But always check first. Your friend might want to tell certain people themselves - or they might not want anyone to know.)

Go to the funeral.

Or memorial service to show your support. They might need help organising things, or thanking people after. Share your memories of their loved one. Your friend will love to hear how loved and respected their parent or sibling was by lots of different people.

Help them collect memories and stories.

Anything that reminds your friend of the person who died will become really precious. You could help them make a scrapbook, photo album or memory box full of little knick knacks, tickets, cards and jewellery. You could help them ask neighbours and extended family for their stories and record them on video.

Encourage them to talk about the person who died.

A lot of people will be too scared to mention them at all, but sharing memories and stories is important.

Don't feel guilty.

That your family isn't going through something this tough. They won't be upset or jealous.

"Friends can help by organising events that take the person's mind off things. My friends and I would organise a dinner get together, go to the cinemas or chill out at someone's house for the day."

Emma

Further down the track

The next few months and years.

Often people get heaps of support in the first few days and weeks after someone dies, but later on it can seem like everyone has forgotten about it or thinks that they should be 'over it' by now.

Your friend might find that when the initial shock wears off it really sinks in that someone they love is missing and that they have to start a new chapter of their life without them. Even though it might look from the outside that things are getting back to normal, this is when the pain of grief really hits and your friend might feel more alone than ever.

Don't forget about it.

Continue to check how your friend is going from time to time. Accept that they will still have bad days, even ten years on...

Talk about the person who died.

If you knew them, tell your stories. If you didn't, ask questions.

Let your friend talk about what happened.

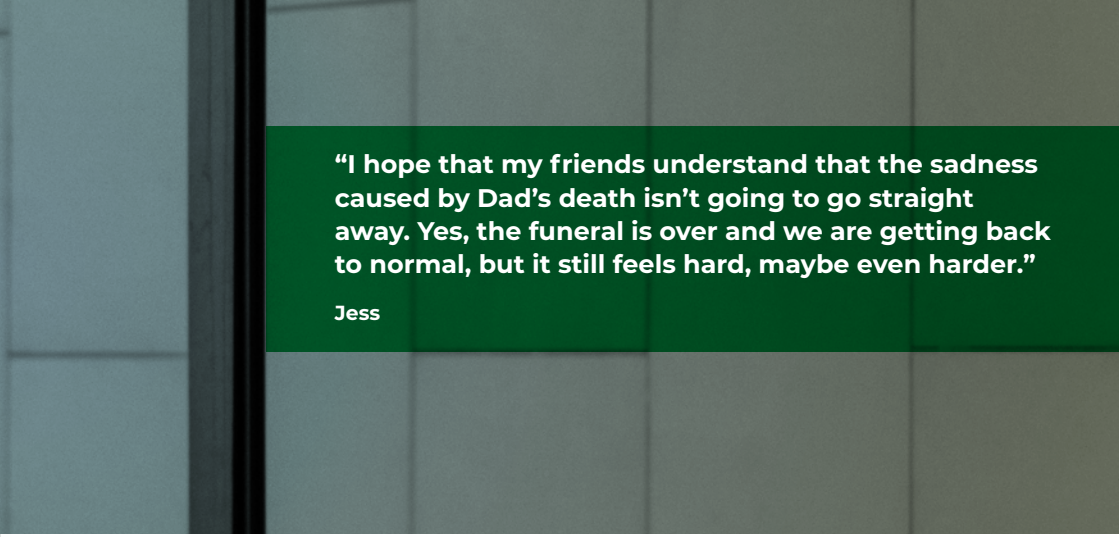
Let them talk about it a million times if they want. But don't hassle them to talk if they don't want to.

Encourage your friend to get out and do things.

Don't let them drop out of life. Hanging out with friends, doing regular activities and having a life separate from the family will give their mind a rest and help to put some structure back into the craziness.

Help create rituals.

Rituals are special activities people do to remember someone who died and mark special occasions and anniversaries. These could be



“I hope that my friends understand that the sadness caused by Dad’s death isn’t going to go straight away. Yes, the funeral is over and we are getting back to normal, but it still feels hard, maybe even harder.”

Jess

formal ceremonies or ones you make up yourself – like lighting a candle, planting a tree, cooking a particular meal or going on a special trip.

Suggest they connect with others in a similar situation.

It can be really helpful to talk to people who truly get what it’s like to lose someone close. Canteen provides free events and programs for young people who have lost a parent or sibling to cancer. Visit canteen.org.au for more.

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 parent, family doctor, teacher, nurse or chaplain will be able to help you find one. Canteen offers free counselling for young people aged 12-25 who have lost a close family member to cancer. Call 1800 226 833 or email support@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.

Accept that their grief is normal.

Don’t make your friend feel like they are acting weird. Remember that grief shows up in people in unique and surprising ways.

Times when your friend might need extra support

Even years later, your friend will have moments when they miss their parent or sibling as much as if they were here yesterday.

Some of these moments you might be able to prepare for, like:

- The anniversary of the death, the cancer diagnosis, or the funeral.
- Family events like Christmas, holidays, birthdays, Mother's Day, Father's Day.
- Special occasions that highlight the absence of the person who died - like weddings, graduations or the birth of babies.

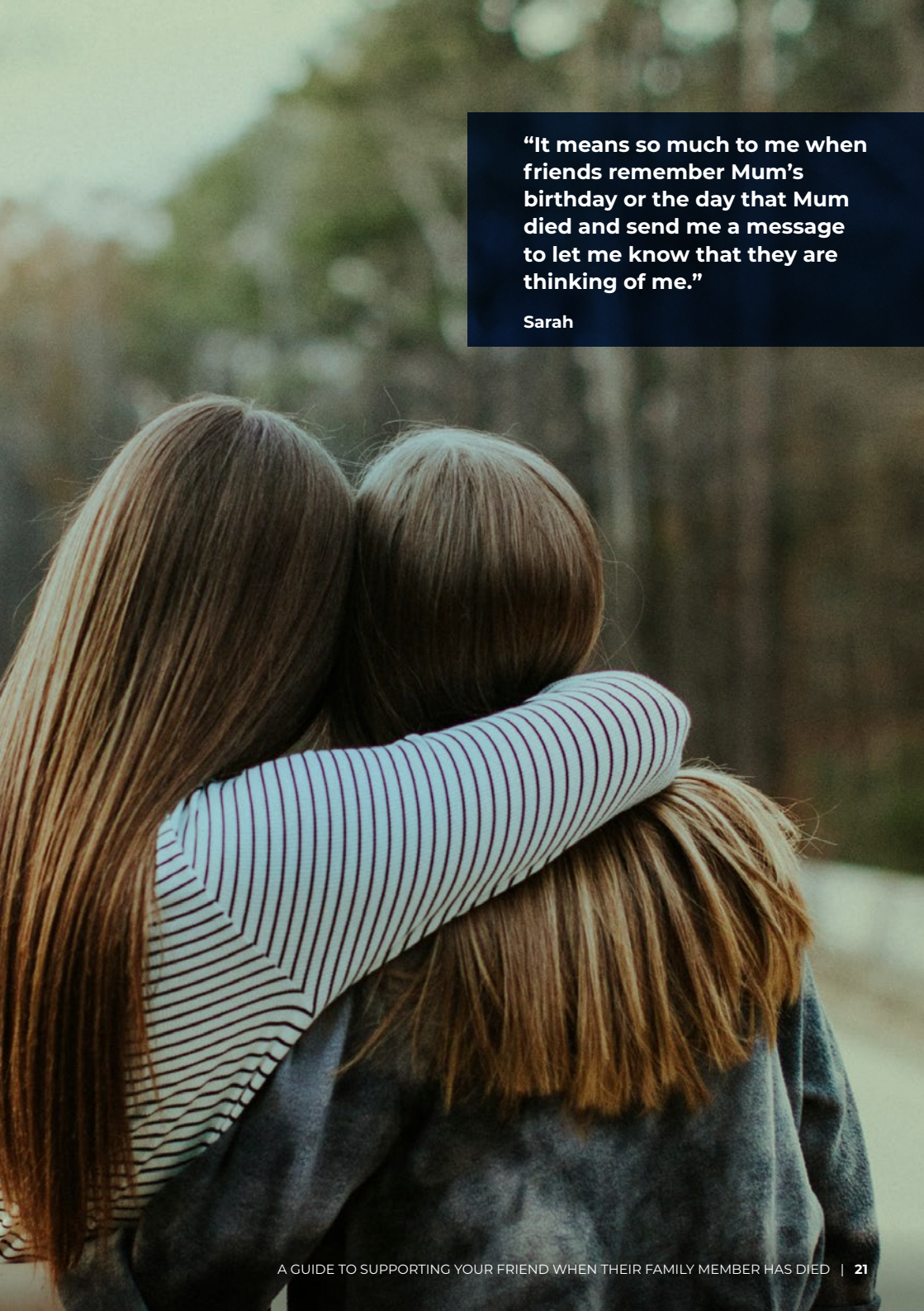
Try setting a reminder for these dates in your calendar so you can check in with your friend and make sure they're going OK. Acknowledge how important these days are and let them know it's OK to be sad if they are.

Other times, memories will be triggered by unexpected everyday things like:

- Seeing, smelling or hearing something that reminds your friend of the person who died.
- Seeing their toothbrush in the bathroom, or the empty seat at the table.
- Someone asking your friend how many siblings they have, or what their parents do.

You can't stop these 'bad days' from happening, or take away the pain they cause your friend.

Don't try to distract them from their feelings. Over time, these moments won't happen as often or knock them around as much.



“It means so much to me when friends remember Mum’s birthday or the day that Mum died and send me a message to let me know that they are thinking of me.”

Sarah

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 is grieving the death of a family member, even if you just want to talk about normal things.

You might worry:

"I don't know if I should bring up what happened...or talk about anything EXCEPT that?"

"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 who are grieving find that it really does help to talk.

"I think that it would be good if friends asked more questions about it to show they really do care... And it gives me the opportunitiy to talk more if I want to or just give brief answers if I don't."

Sarah

Here are some things to think about:

- Not talking about difficult stuff doesn't make it go away. Your friend might find it a relief to get things off their chest.
- Your friend might feel isolated and alone if they can't talk about this huge thing that is happening. They might want to bring it up but are worried that people are sick of hearing about it.
- Talking can help a person see things in a different way, or be reassured that their feelings are normal.
- Talking about and sharing what has happened can make you feel closer as friends.

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 name of the person who died.
- It's OK to say the word 'died'.
- It's OK for there to be silent moments. Don't rush to fill them up.
- Sometimes your friend will just want to talk about normal things and to catch up on the goss.
- It's never too late to acknowledge what happened. Better to say something about it late than never at all.

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.

"When friends didn't mention anything about my mum and just pretended that it hadn't happened it made me feel angry and upset. My whole life had changed and been turned upside down and inside out, I wasn't OK and it wasn't OK to pretend that everything was fine."

Sarah

“If you sound out your thoughts and problems to a friend you feel much better. No one should have to battle through anything on their own.”

Jo

Tips for listening

If your friend wants to talk:

- Don’t interrupt or change the topic.
- Don’t judge or try to change their feelings. Saying things like, “Don’t talk like that” or “You should have told me” might make your friend worry that their reaction is wrong.
- Ask questions to show you’re interested.
- Be patient.
- Don’t jump in with your own experiences of illness or death.
- Keep whatever 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 a person who is grieving.

Best to avoid:

- "I know how you feel" – You don't, because you're not them. Only your friend really knows how they feel.
- "He/she is in a better place" or "It was God's will"– They may or may not believe that, but the only thing that matters now is that their parent or sibling is not here.
- "You're being so brave" – Don't put pressure on your friend to appear strong and hide how scared they might really feel.
- "I understand, my dog died last year" – Even if you have gone through a really similar thing, it doesn't always help to compare. Every experience is different.
- "Cheer up" or "He/she wouldn't want you to cry"– This might make your friend worry that their grief is lasting too long or that their reaction is over the top.
- "Everyone dies. You have to get on with your life." – Your friend's life has changed forever. They are not going to get over this.

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 friends will drift apart and some friendships 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 their old ones.

At the same time, while your friend is dealing with their own personal grief, you will be getting on with your own life. 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, crisis or no crisis.

“In some ways it feels as if my friends and I have drifted apart and 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

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.

ARVUS
GUARANTEED

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.

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: canceraustralia.gov.au/publications-and-resources/cancer-australia-publications/cancer-how-are-you-travelling

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 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.

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