

GUIDES  
TO THE  
FLIPSIDE



canteen

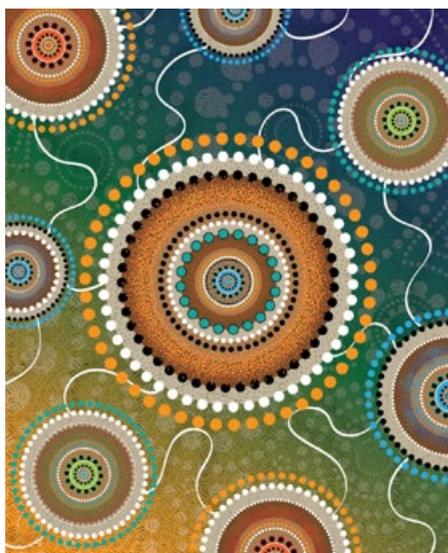
**DEALING  
WITH YOUR**

**PARENT'S  
CANCER**

## ACKNOWLEDGEMENT OF COUNTRY

Canteen acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of this land. We pay respect to Elders past, present and future. We are committed to providing inclusive and appropriate support for Aboriginal and Torres Strait Islander young people, their kin and community. Indigenous Australians are respectfully advised this 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.*



## ABOUT THIS BOOK

When a family member has cancer, it can affect the whole family. Life may change quickly and in many ways. It's natural to have lots of questions and feelings – you might be thinking, now what?

This book is specifically aimed at young people whose parent has been diagnosed with cancer, it could be something you want to read on your own or could also be helpful to go through with a family member together. This book intends to help you understand some of what has or may happen and what challenges you and your family could be facing, it could even be useful to read if your parent has finished their treatment.

The booklet contains cancer specific information, practical tips and suggestions for how Canteen or other support services may be helpful. Getting the right information and support can make a big difference when cancer enters a family's life.

For ease of writing, in the booklet we have used the word 'parent' when referring to the person who has cancer in your family. While we have used the word 'parent', your family might include two parents living separately, one parent, be same-sex, gender-diverse or blended, the parent may also be a foster carer or grandparent. We hope you can think of and use the information below in a way that works for your family.

When cancers in your life, Canteen is in your corner. Visit our website [canteen.org.au](http://canteen.org.au) for more information how Canteen might be able to help.

# CONTENTS

## GETTING SUPPORT

Getting support .....	9
Support Services .....	10
Online support .....	10
How Canteen can support you .....	10

## HEART STUFF

Finding out .....	13
People do survive cancer .....	13
Shared experience with others .....	14
You haven't caused your parent's cancer .....	15
(Correct) knowledge is power .....	15
You can get support .....	16
Talking about cancer .....	17
Your parent has got what? Who to tell .....	20
Sharing on social media .....	21
Let's talk about feelings .....	22
Your relationship with your parent with cancer .....	23
Your relationship with your siblings ..	24
Friends, partners, and other family ..	26
Managing family conflict .....	26
How you may feel .....	27
How your parent feels .....	28
How can I help in my family? .....	29
I don't always want to be with my parent. Is this normal? .....	29
When your parent is having treatment .....	30
Travelling for treatment .....	31
Possible ways to look after yourself ..	32
Taking care of yourself .....	34
When things seem to be too much ..	34



## PRACTICAL STUFF

Practical stuff .....	39
Study and work .....	39
Money matters .....	40

## MEDICAL STUFF

Getting the right information .....	43
Dr Google .....	45
Life after treatment .....	46
Check-ups or follow-up care .....	46
Getting back to normal after your parents' cancer .....	47
Dealing with pressure from others to 'move on' .....	47
Understanding grief and loss .....	48
Things that can help .....	48

## HEAVY STUFF

If treatment doesn't work .....	51
Finding out .....	52
Who says they will not get better? ..	55
How you and your parent may feel ..	55
Talking about advanced cancer .....	56
How can you help? .....	56
Having palliative care .....	58
Saying goodbye .....	63
When seems too hard .....	64
Memories and stories .....	64
Making plans about end of life .....	68
Choosing where to die .....	69
Changing the place of care .....	69
The last few weeks .....	73
When your parent dies .....	75
Funerals or memorial service .....	76
Should I go? .....	78
Grief .....	78

## MORE INFORMATION

More information and support .....	81
Websites .....	81
Acknowledgements .....	85

## A note about language

Families are all different. We use the term 'parent' to refer to the person who had cancer in your family, but we know that person could be your biological parent, a non-biological parent or another important adult. While we have used the word 'parents', your family might include two parents, one parent, you might have grown up with extended family, or your parents could be same-sex, gender-diverse or part of a blended family.

The term sibling could also refer to a biological, adoptive, step or foster, cultural or another connection where the person is referred to as your sibling.

When cancer's in your life, Canteen is in your corner. Visit our website [canteen.org.au](http://canteen.org.au) for more information and support through this tough time.

# GETTING SUPPORT

## GETTING SUPPORT

Getting the right sort of information and support when your parent has cancer is very important. Your parent's cancer experience may last for a long time and the kind of information and support you need may change overtime.

We hope you have people in your life that are in your corner, that you trust, and that will try to be there for you as best they can. These people may come from all different places:

- Parents (with or without cancer)
- Siblings
- Your partner
- Other relatives
- Friends
- Psychologists, counsellors
- Social workers
- Teachers
- GP
- Spiritual and religious leaders, and community leaders
- Support groups
- Online support



## Support Services

Through your parent's treatment you may hear about different places, like Canteen, that work with and support young people facing a cancer experience.

They may also tell you about other services that are more specific to the type of cancer your parent has (e.g. Breast Cancer Network Australia, Prostate Cancer Foundation).

Different support services offer different things, for what you and your family are needing help with there is likely a service that can help. A challenge can be knowing where to look.

Cancer Hub – an initiative by Canteen, Camp Quality and RedKite – is a one-stop shop to help you access all the different practical and emotional support you and your family may need. Visit **cancerhub.org.au** or call 1800 945 215.

## Online support

There are online communities for young people impacted by cancer such as Canteen Connect, which is available 24 hours 7 days a week (**canteenconnect.org**) – it includes forums you can join with other young people who have experienced or are experiencing cancer similarly to you, or who have their own cancer experience.

## How Canteen can support you

Getting the right information, advice and support can really help. Canteen is in your corner. We can put you in touch with a team member who will support your time at Canteen including offering individual counselling support if you would like this and connecting you with other young people through our programs and events who will have their own cancer experience.

Find out more at **canteen.org.au/parentcancer**

# HEART STUFF



## FINDING OUT

You may have found it hard to focus or concentrate since you found out your parent has cancer; this could be because you are having more thoughts or other things are on your plate that weren't previously there as much. Here are a few things that might be helpful to know:

### People do survive cancer

Some people will have medical treatment for their cancer and can get better relatively quickly. When we write about treatment, we mean things that you may already heard about, like Chemotherapy ("Chemo") or Radiotherapy ("Radiation"). Treatment can be very tough with the side-effects that people experience (low energy, possible hair loss).

There are other people with cancer who will need to have treatment for a longer time. Although the plan is for them to have longer treatment, there should still be periods where things feel more ok where the side effects may not be such a problem despite the treatment continuing.

Many factors will affect the outcome of your parent's cancer (you may have heard the word used "prognosis" being used to explain things) including the type or stage of cancer and whether the cancer has spread in their body ("metastasis").

There are new and better ways of diagnosing and treating cancer being discovered all the time, it may be reassuring to remind yourself when you're feeling uncertain or afraid that people can get better and do survive cancer.



## Shared experience with others

While no-one will feel the same way as you and each cancer experience is different, it could be helpful to know that around 21,000 young people find out their parent has cancer each year.

Peer connection and knowing that other people share a similar experience can be a powerful thing to know, it can also be that other people who have been through a similar thing can share their ideas

about what was helpful for them to get through.

Canteen has a strong history of promoting the importance of peer connection and support, one of the main things we offer young people is getting to know and share experiences with other young people. Canteen has an online community where you can chat with other young people who get what you're going through. To join the Canteen Connect community, visit [canteenconnect.org](http://canteenconnect.org).



If you choose to become a client of Canteen we have day events and overnight programs that you can join with other young people to have a shared experience and develop connection around your experience with cancer - We have found with other young people that this can be an empowering and helpful experience for them, some young people have stayed with Canteen for many years.

## You haven't caused your parent's cancer

Lots of things cause cancer, many of which doctors and researchers don't yet fully understand. But we do know that your parent having cancer has nothing to do with anything you said, thought or did. You may wonder or feel that it is your fault; something as big as cancer can bring up lots of tricky thoughts or feelings for people. When these types of thoughts or feelings come it could be helpful to gently remind yourself that it is not possible that you caused the cancer for your parent, it's not scientifically possible.

## (Correct) knowledge is power

Learning more about the type of cancer your parent has and its treatments from a trustworthy source can take some of the fear out of it and be a comfort.

If you're wondering about anything at all, try asking your parent or other family member, it could also be that

your parent's medical team may be able to answer questions. See **page 43** for a list of suggested questions.

Trying to find knowledge and information from known or trusted sources is also important, your parent may have been given information that you are unaware of so it could be worth asking them.

Cancer Council has a lot of up-to-date information about cancer types and treatments - [cancer.org.au/cancer-information](http://cancer.org.au/cancer-information).

Having feelings is ok. Knowing that your parent has cancer is one of the hardest things you'll ever have to deal with. Every family member will react to the diagnosis in their own way. Your thoughts and feelings may be overwhelming, but we do know that both things do come and go for people like waves at the beach. Feelings and thoughts rarely stay the same for long periods.

It's okay to feel what you are feeling. You may feel scared or sad. It can be that when feelings are hard to get out or it's hard to find the words to explain how you're feeling, that trying to speak to somebody who you think may help can be super important rather than keeping it all inside. This may be your parent or other family member; it could be a friend or other trusted person in your life.



## TALKING ABOUT CANCER

Cancer can be hard for anyone to talk about. Your parent might find it difficult to know how to talk about their diagnosis or treatment with the family, they might be worried about upsetting you or even themselves.

How your family talks about cancer can depend on how your family has communicated or related to each other before cancer entered your lives. Cancer is unlikely to suddenly change this, but we do know that trying to find out new ways of talking together within families can be helpful when tough problems like cancer enter a family's life.

If you are a young person who hasn't previously wanted to ask a lot of questions about their parent or how they are going, it may be that your parent is assuming this is hasn't changed for you with them now having cancer. Asking questions can be tough, but it could be a signal to your parent that you are wanting to know more about what is happening for them. If this is something you find tough, we hope that it becomes something you can start at least trying to do.

The talking tips on the next page may be helpful for you and your parent:

### You can get support

Health professionals like social workers or psychologists are trained to listen and can help by talking and linking you with support if this is needed. If your parent is in hospital or a medical team is coming to your home, most major hospitals and medical teams should have support people available to you, just ask whoever the family's main contact person is for the treatment (often this is a nurse).

Canteen provides a free and confidential counselling service

(check out [canteen.org.au/counselling](http://canteen.org.au/counselling)). You can also ask your family doctor/GP to recommend a counsellor or psychologist near you, there may also be low-cost youth specific counselling or support services in your area, these will come up on an online search.

A GP can write you something called a mental health treatment plan to see a counsellor or psychologist that can make sessions more affordable under Medicare. Speak to your GP or look at the Medicare website for further information.



## Tips for talking about cancer

- Think about what you want to ask and what you want to say before you start. You could even write it down and then read it out.
- It may feel hard and uncomfortable at first and there may be some awkwardness. It could be helpful to try to sit with this and remind yourself in the moment that it's normal.
- Send a text message or email letting them know that you'd like to talk, there may be a best time for this to happen.
- If it's getting too hard to talk, it could be helpful to not feel that you must bring up everything in the one conversation. It is normal that you and your parent could cry or show other emotional responses in the conversation, you may need to take breaks.
- Checking in with each other at points in the conversation can be helpful to see if the person is happy to continue talking, hopefully your parent can help guide this.
- Do something at the same time as talking, e.g. going for a walk together or doing something that you like doing together, like watching TV. This can sometimes take some of the pressure out of stressful conversations.
- It could be hard to do in the moment but try not to worry too much about saying the wrong thing. It can take time to work out the best way to talk to each other.



## But what if talking is too hard?

Sometimes talking is too hard. Maybe it's not the right time or you don't know what to say. If you still want your parent to know how you're feeling, you can:

- send a text message, email, or letter
- share songs that say it for you
- find quotes or cards that say what you might be feeling
- draw pictures, write, or play music
- keep a journal; it can be private, or you can share it with your family.

If you or your family can't talk about cancer, it may help to speak to a support service or person like a Canteen team member or family counsellor. They could help by giving you ideas on how to communicate with each other, this could particularly be helpful where there has been a lot of difficulty before now in your family relationships.

Contact Canteen ([canteen.org.au/](https://canteen.org.au/) counselling) for information about our counselling services, which includes parent support that can help parents' problem solve how to talk to their children about cancer. If the communication problem feels too large, it could be that searching for a family-specific psychologist or therapist in your local area could be important for your family to start getting more specialist help.

## Your parent has got what? Who to tell

Deciding who needs to know and what to say to people can be difficult. You might be worried about how they will react.

It's up to you and your family who you tell about your parents' cancer and how much to share. The truth is that some side effects to cancer treatment (e.g. hair loss) may make it hard not to tell others.

### Reasons why it might be helpful to tell:

- You may need to take time off from study and work to be with your parent.
- It could help for other people to know what is happening to offer their support to the family, they may be helpful in ways that you weren't aware of before speaking to them.
- Due to stress, worry, or extra responsibility, your energy levels may be lower than usual. If you're unable to do the same level of things you used to like catching up with friends, it could help to let people know to keep up these connections.
- There is a lot of evidence behind the benefit of sharing emotional experiences with other people and trying to talk openly about emotions.

### Reasons why it may not feel right to tell:

- You feel embarrassed talking about your parent having cancer, especially if it affects private parts of their body (such as breasts or testicles).
- You don't want to repeat the same story and answer the same questions over and over.
- You may feel conversations about cancer already dominate your life, maybe school/work is one of the only places where you don't have to talk about your parent's cancer.

### It is completely up to you and your family who you tell and why.

#### Who do you have to tell?

There is no law in Australia that says you must tell your school, university, or TAFE (or workplace). However, it might help in certain circumstances to let people know. For example, if you're finding it hard to concentrate or not keeping up with homework or assignments, you can ask your teachers or student centre for adjustments to your learning, they may be able to extend assignment dates or allow for longer exam times. In schools, this is usually called applying for Special Considerations to make allowances for your study requirements. See **page 39** for more details.

You may want to plan what you want to say. Try to anticipate questions that might be asked and

how you might answer them. You don't have to give specific details if you prefer not to, they may ask for a letter from a doctor or medical certificate and if you are applying for special circumstances a form will likely need to be completed.

You could also ask your parent or another family member to tell friends or teachers for you if you don't want to tell them yourself. Make sure the friends and teachers understand if you want them to keep the information private.

If you're working, telling your boss or the human resources (HR) manager can make it easier to take time off if you need to go with your parents to treatment.

The ways an employer may be willing to support you could be reducing work hours or allowing flexible work arrangements, including working remotely. It is worth knowing that some workplaces will only be flexible to a limited degree. See **page 39** for more details.

Send an email if you don't know your teachers, lecturers, or bosses very well; this may make it easier to inform people and it becomes more an information record. You can use the email templates on Canteen Connect ([canteenconnect.org](http://canteenconnect.org)).

The tips in **Talking about cancer on page 18** may help you tell people that your parent has cancer.

### Sharing on social media

Some people use social media to let people know their parent has cancer. On the upside, this can be a fast way to tell lots of people and means you don't have to say the same thing over and over. On the downside, once your post is 'out there', it could be shared widely, and people may make comments you find unhelpful. You may decide to share in closed/private groups.



## LET'S TALK ABOUT FEELINGS

Every family will respond to cancer and be affected differently. It may change your relationship with your parent, or it may stay the same as to how it was before. Living with a parent who has cancer can affect your life in many ways such as changes to your expected routines and roles in the family.

How the changes affect you individually or changes things in the family will depend on several things, such as whether you're living out of home or your position in the family.



### Your relationship with your parent with cancer

As a young person, your relationship with your parent(s) is evolving. You could be at the stage where you're becoming more independent and spending more time with friends. The challenges of cancer might mean you grow closer or drift apart from family members.

Try not to expect your family relationships to change overnight – if there were things you argued about before it doesn't mean you will suddenly agree now that your parent has cancer.

When your parent has cancer, it's easy for the diagnosis and treatment to become the focus of family life. You may feel they don't have enough time or energy for you as they did, they may become forgetful when they're undergoing treatment.

Seeing your parent sick, in pain, tired and maybe looking or acting different is going to be hard. You may feel guilty if you get angry with them or want to do things they don't agree with or want to spend time doing other things like hanging out with friends.

Talking with parents about how you're feeling about the cancer and the changes that have come along with it, may make things feel a little easier for you at home. While this isn't always easy to do, it could help to give it a go.

See 'Talking about cancer' on **page 18** for tips on how to talk with your parent.

Your parent may want you to talk to a health professional like a social worker, psychologist, or counsellor. Sometimes this can happen when the parent isn't sure what is happening for their young person, parents can feel that they're not hearing from their young person what is happening for them, the parents may be worried or unsure.

It can be hard to find words, or feel like you're being listened to in families, but trying to explain what you are needing to your parent can be super helpful. This may mean that you do not want to see a counsellor, you just want to talk to your parent more, or you may think it may be just as helpful to start seeing somebody to talk about things away from your family.

Trying to find ways to communicate around love, trust and emotions in families is known to be very important things for families to try to work towards.

### Support for parents

Your parents may be interested in checking out Canteen's support services for parents. Go to **[canteen.org.au/parents](https://canteen.org.au/parents)** for more information.



## Your relationship with your siblings

If you have a sibling, they might be an important source of support. They may be the only ones who really get how hard life is right now because they're living it too.

Your sibling might be coping with your parent's diagnosis differently to you and this could cause tension. If you never got along well with your sibling, the stresses of cancer may not change that. Some siblings find that the experience brings them closer together. However, just like the relationships with your parents, it is very individual what could happen, and each family is different.

You may have to take on some extra responsibilities with younger siblings, you may find yourself cooking more meals – you might be

okay with this or find the change tough. They may also find it hard; they might feel like you're becoming another parent.

Family planning done together around new roles and responsibilities may be something your family could consider doing (if not already).

Changes and stressful events can lead to families going back to old ways of doing things, it might be that your parent(s) could benefit from being reminded where you're up to in life and what you are needing as a young person. We know that early teenage years is a particularly difficult transition times for families, where parents may still be parenting their child as a child - but the child is at an age where they want to become more of an individual.

## If you're older ...

Your relationship with your parents has probably changed as you've gotten older.

You might feel like you now have more control of your life because you're earning your own money, spending more time with your friends, and have moved out of home. You might enjoy the freedom of doing your own thing.

But a cancer diagnosis might mean your parent asks you to help around the house or look after younger siblings more than you previously did. It's common to feel like you're caught between your own needs and the needs of your family.

If your relationship with your parent was tense or distant before, their diagnosis can change the dynamics again. It's tough to be expected to do more just as you're starting to feel more independent.

It can also be that you are being expected to now take on too much, or you could start being seen as what is called a young carer. This basically means a young person who is taking a lead caring role in their family.

Support for young carers is available, there may also be adjustments that can be made in the family so that you're not having to take such a lead role and you can get back to doing some of what young people do and not have to take a parent-type role in the family.

If not done in a way that is supportive of the young person's needs as a young developing person, young carers are known to experience difficulties with attending school or financial challenges that other young people their age may not.



**“I was involved in most discussions, although I generally didn't give any input, I listened intently. I felt privileged to be involved and treasured the respect my parents had for me and my maturity at such a young age.”**

**Melissa**

## Friends, partners, and other family

The other important people in your life may provide great support, others may find the situation overwhelming. You might feel like your friends or partner don't understand what you're going through, your relationships may change or feel different.

Some things to keep in mind with other people could be:

**They may not know what to say or how to say it** – One thing you could try is letting them know it's okay to ask or talk about the cancer.

**They may unintentionally say things that upset you** – If this happens it's okay to let them know how you feel. To try not to sound

like you are blaming them, use an 'I statement'. For example, 'I feel upset when...' instead of 'You make me upset when...'.  
**They may ask tough or silly questions** – Sometimes you may not want to answer questions. It's okay to let them know that you don't feel like talking right now or there are some things you're not ready to talk about.

**They will continue to have their own lives** – They may talk about other things happening in their life, it may feel you're being left out or even behind, letting people know this is something that is coming up for you can be important. You may be able to come up with ways together to bring you into their life in different ways.

## Managing family conflict

The pressure of your parent having cancer may cause tension. This may be because everyone is coping differently, or someone feels they're doing more than someone else. Keep in mind the following:

- expect and accept that family members will experience things differently.
- divide tasks according to each person's age, abilities, and interests.
- try using online tools or apps to schedule tasks and create plans.



All these emotions are natural, and it's common to feel differently from one moment to the next. If you think you're 'stuck' in one, you could try talking to a Canteen clinician, by phone or face to face.  
[canteen.org.au/counselling](https://canteen.org.au/counselling)



## How you may feel

Finding out your parent has cancer is likely to bring up a lot of different feelings for you. Some you may have expected, and others may come as a surprise. It may not always be easy to explain how you feel.

The main thing to remember is that there is no right or wrong way to feel.

Many young people describe the experience as an 'emotional rollercoaster' – you're going through huge ups and downs and feeling like you have little control over things.

Common emotions other young people who've found out their parent has cancer include:

- feeling scared
- angry
- sad
- guilty
- jealous of others
- or lonely

Particularly when you first hear that your parent has cancer, it is important to know that you could experience something called shock. Shock is a response in the body when a sudden illness or injury has been experienced, it can also be a mind-thing that happens when sudden or unexpected news is heard, and your brain and body becomes really overwhelmed.

Shock can include things like feeling shut off from reality or the world around you, it may lead to your heart racing fast, short breathing, or dizziness.

If this is something you had experienced when you first heard about your parent's diagnosis, it could be helpful to know that just because it's happened once doesn't mean it will happen again, it is just that your body got really overwhelmed when hearing the news.

If it happens again or returns, it could be something more anxiety related, and it could be helpful to start getting help with this through a mental health counsellor or psychologist through your GP. It could be something that a team member clinician at Canteen could also help with.

If you're finding things hard, you're not alone. Do any of these thoughts seem familiar?



## How your parent feels

It's common for people to describe the days and weeks after the diagnosis as a whirlwind. Your parent is likely to have similar emotions to you, adult emotions are the same as young person emotions, however this may look differently from how you show emotions.

Knowing how other family members feel about the diagnosis could help you develop more understanding of what they are also going through. It can help for families to try to talk about emotions and to have understanding about how other family members show their feelings.

It is important to know that looking sad or crying may be a way that family members show how they are feeling. This is a normal response, however if the sadness doesn't seem to be changing or the crying seems like a lot, it could be that the person is experiencing depression.

Depression is something that commonly develops for people with cancer, it may be that the person isn't noticing the change in themselves. It can show itself through low energy and tiredness or loss of enjoyment in things, or lots of sadness that isn't going away. It can be that some signs of depression show itself the same as how people's bodies respond to cancer treatment.

It could really help to check in with the family member who are showing worrying signs like this, it may they need to see somebody like their GP.

## How can I help in my family?

**Try to be flexible** – It's likely that family routines and schedules may change, doctors' appointments may be rescheduled, treatment is planned then the plan changes; just knowing this and trying to sit with the change could be helpful.

**Help at home** – If your parent can't do as much as they used to whilst they are having treatment, it possibly could help to share the workload with other family members. Relatives and friends may also be able to help. Try and divide up the responsibilities fairly between the rest of the family.

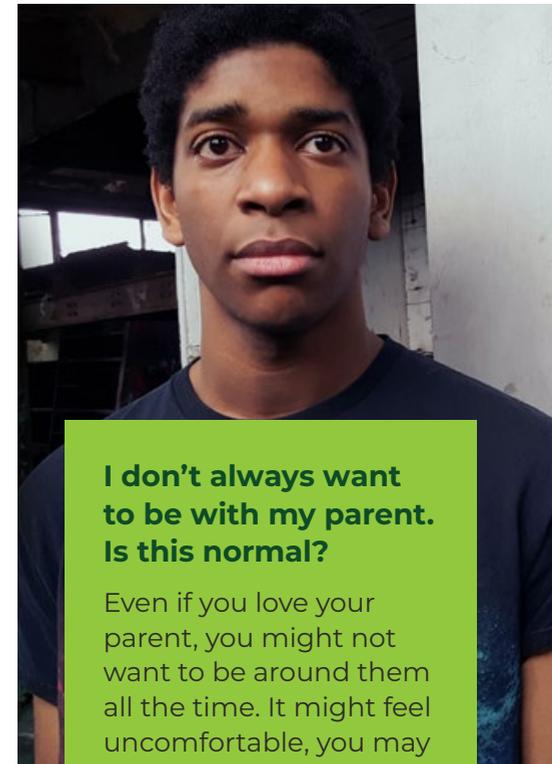
**Spend time with them** – Your parent might appreciate you doing something without being asked, even a small gesture (like making a cup of tea) can make a big difference.

**It's ok to talk about normal things** – These conversations can be a good distraction from thinking about cancer, just because there is cancer doesn't mean the conversations you usually would have as a family need to stop.

**Keep your distance if you're sick** – When someone is being treated for cancer, they can get infections more easily. That's because treatment can reduce the number of white blood cells that fight infections, making it easier to catch colds or the flu.

An infection could make them sicker, so they may need to stay away from crowded places or people who have an illness they could catch. You can help by:

- washing your hands with soap and water regularly to avoid spreading germs
- letting your parents know if you've been in contact with someone who is sick or has a cold
- not coming in close contact with your parent if you get sick
- checking with the doctors or nurses if you are worried about infections that may harm your parent.



### I don't always want to be with my parent. Is this normal?

Even if you love your parent, you might not want to be around them all the time. It might feel uncomfortable, you may be a little guilty, but it's okay to spend time with your partner, friends or doing other things.

## When you parent is having treatment

Having treatment for cancer may mean your parent has to go to hospital. This may be for surgery, chemotherapy (chemo) or radiation therapy (radiotherapy), or other procedures. If your parent has surgery, they may need to stay one or more nights in hospital (this is called being an inpatient).

Hospitals can be busy and noisy places, which can feel overwhelming. Knowing what to expect can help make visiting the hospital less stressful.

Treatment for cancer can be a long process. Chemotherapy and radiation therapy means going to hospital every day for a few weeks or months (outpatient). These visits can last for a few hours. If it feels ok, you could offer to go with them, once you're there you may be surprised to find it different to be how you thought it would be, this may be a comfort.

### Before the visit

It is okay to ask what you might see and hear when you visit, such as:

- What machines, tubes, drips, or other equipment will your parent be connected to?
- Are you allowed to touch them?
- Will the treatment change how they may look?

Given the visits can be long, it could help to bring along some things to entertain you.

### When visiting is too hard

You may not be able to visit because you're juggling other things in your life like study or work. Hospital visiting hours may make it hard to fit it all in. Try not to worry if you can't visit all the time, or planning-ahead may now be something that you have to think more about.

Sometimes visiting the hospital can feel difficult. If it feels too much to visit, you can stay in touch with your parent in other ways like texting or video calling. If you continue to feel like you can't visit, it may help to talk to someone trusted or a health professional about what you're feeling and why you're not visiting.

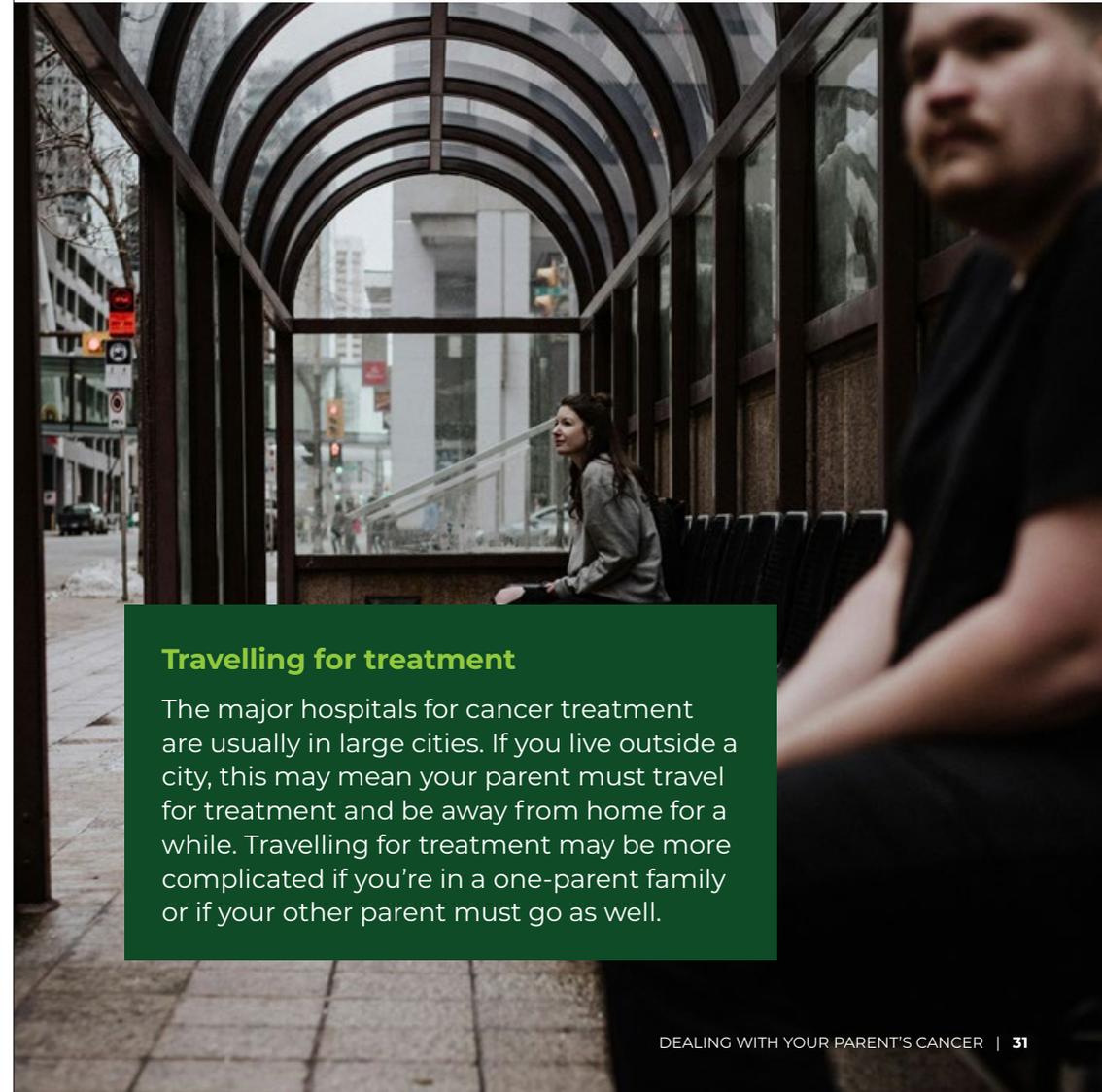
If it is difficult to visit, here are some things you could try:

- Make the visits short
- Visit at quieter times
- Let your parent know when you get there and how long you are planning to stay

It could be a lonely experience for you and your family, or it could also be a time when you find out more about who your village is. You may have heard of the idea that "It takes a village to raise a child", meaning that it takes more than just the family to raise a child, it takes everyone else who is important in the family's circle to be there.

Using other words, it could be said that "It takes a village to get a family through cancer".

It could be your village is made up of people in your extended family, friends, school, community groups etc – Your village is your own experience of community.



### Travelling for treatment

The major hospitals for cancer treatment are usually in large cities. If you live outside a city, this may mean your parent must travel for treatment and be away from home for a while. Travelling for treatment may be more complicated if you're in a one-parent family or if your other parent must go as well.

## Possible ways to look after yourself

We all have things we do to look after ourselves and try to deal with difficult situations when they come up for us. This may be things you're aware that you're doing, or even unaware. These things we do can also be called other things like "Coping Strategies", "Relaxation Strategies", "Self-Care" or "Emotion Regulation Strategies".

When your parent is diagnosed with cancer it could help to have a clear idea about what makes up your "Toolkit" for looking after yourself and facing tough times.

Some people are aware of what their toolkit is, other people may not be. At the least it could be helpful to be thinking about what these things are, sometimes writing up a list can be helpful, and an idea might be to stick it up on your bedroom wall.

**If you're unsure of ideas, or want some more, here are a few things you could try:**

- **Talk to someone** – Talking can help clear your head and reduce worries, it can be a great way to think through problems out loud with somebody else.
- **Exercise AND rest** – Exercise and activity is proven to reduce stress, it releases a chemical in your body called endorphins that are proven to improve people's moods, it doesn't matter what the exercise is – It could be a walk or even a mountain climb! On the other hand, rest and sleep are both also super important to keep things on track with your body and how you're feeling.
- **Get creative** – Things like writing, drawing, painting, photography, scrapbooking, collaging are all great ways to let out how you're feeling, it can make our minds less cluttered when they feel jumbled or too fast, it can slow things down.
- **Keep doing things you enjoy** – Doing things you enjoy may help keep things feeling as normal as possible.



**"Cry if you want to. Don't worry about what people think, they'll deal."**

Erin, 21

**"I watched a lot of movies and TV shows. Focusing on these fictitious stories somehow helped me escape reality and forget about my problems."**

Melissa



- **Try something new** – What could this be?
  - **Join an online community** – You might want to check out Canteen Connect ([canteenconnect.org](http://canteenconnect.org)), it could help to chat with other young people going through something similar to you.
  - **Try mindfulness** – This is all about being in the moment and can help you manage stress. There are several apps that can help you get started with mindfulness, including headspace ([headspace.com](http://headspace.com)) and Smiling Mind ([smilingmind.com.au](http://smilingmind.com.au)).
  - **Sensory toys or tools** – Play with a pet or squeeze a stress ball, there is a lot of science behind sensory play and tools are effective in calming our bodies. It could help to develop your own sensory toolkit, to make your own toolkit you could base ideas on each of the 5 senses: touch, smell, hear, see, and taste – you may also be somebody who prefers one sense over another.
- **Plan!** – Use a weekly planner and a to-do list to keep track of tasks, especially if you have taken on extra roles in the family. Being more organised could help you feel more grounded and more in control.

## Managing other people's expectations

You might think (or people might be telling you) that you should be doing or acting in certain ways, like trying to 'be positive'. It can help to be optimistic, but you don't have to feel happy and hopeful all the time, try to feel confident that you know what is going to be best for you and your family.

**It could help to remember it's okay to:**

- not be perfect all the time
- not feel brave all the time
- not feel positive all the time
- And it's ok to do things your way

## TAKING CARE OF YOURSELF

Stress and worry can show up in a few ways, this may include sleeping troubles, changes in eating patterns, headaches, trouble concentrating, or withdrawing from family and friends.

### When things seem to be too much

Feeling sad, down or upset is completely natural when your family is dealing with cancer. If these feelings stick around and

you're feeling this way most of the day, or for a length of time that doesn't feel right, like over 2 weeks, then this could mean that you might have developed or are developing a more specific mental health problem, like depression.

It can be confusing to work out what a normal response to a parent's cancer is and when it becomes more of a mental health problem, checking in with an adult, GP or even your Canteen key worker could be a good place to try to start work out what's what.

### Depression

When you're going through something big like cancer, it can be important to look out for some of the warning signs of depression and check in with yourself regularly. Common symptoms include:

#### Mood

- feeling sad or grumpy nearly every day
- feeling guilty and blaming yourself for things that you might not usually
- feeling hopeless and helpless
- unable to feel good or not enjoying things you used to like
- trouble concentrating, remembering things, and making decisions
- believing that you can't cope and that things are out of control

#### Behaviour

- not interested in activities that you used to like
- crying a lot
- not wanting to spend time with friends and family

#### Physical

- not feeling hungry or eating too much
- sudden changes in weight

- change in sleep habits, e.g. waking up during the night or sleeping more than normal
- feeling physically sick, e.g. stomach aches, nausea, or headaches

If you are experiencing depression, it probably won't go away on its own, but getting the right support for it can help and it is very treatable.

A good first step is to talk to your parent and doctor. They could help you arrange to talk to a psychologist, counsellor, or social worker if this is needed. **Canteen's online Community, Canteen Connect**, is available 24/7 for you to get support from other young people who are going through similar situations to you. If you're a client of Canteen your key worker may also be able to support you with counselling, which may be enough to help.

If you have thoughts of suicide or hurting yourself in other ways, call **Kid's Helpline** on **1800 55 1800**, **Lifeline** on **13 11 14** or the **Suicide Call Back Service** on **1300 659 467**. If it is more urgent, you can call **000**, go to your nearest hospital emergency department, or find the nearest mental health crisis service in your area by searching online. For other phone numbers and websites check the 'More information and support' chapter on **page 81**.

### Self-harm or non-suicidal self-injury

This is when people can hurt themselves on purpose to try to deal with strong physical or emotional pain and distress, it can happen by the person cutting their skin and could also be things like drinking alcohol too much.

If self-harm is something that is happening for you, it can be hard to know how to get help. People can feel lots of different and challenging things about themselves when it's happening, it can be important to get the right help and to not feel judged or blamed.

Online there are several very good resources and websites that suggest ways to help if self-harm is happening for you, e.g., Beyond Blue or headspace, it may also be best to reach out to a family member and your family GP as a good first place to start.

[beyondblue.org.au/mental-health/suicide-prevention/feeling-suicidal/self-harm-and-self-injury](https://beyondblue.org.au/mental-health/suicide-prevention/feeling-suicidal/self-harm-and-self-injury)

[headspace.org.au/explore-topics/for-young-people/self-harm/](https://headspace.org.au/explore-topics/for-young-people/self-harm/)



# PRACTICAL STUFF

## PRACTICAL STUFF

When your parent has cancer, you may have to deal with tasks or practical things in the family more so than you did before.

### Study and work

School, study, or work don't stop because your parent has cancer, and keeping up with study and work while your parent is sick could be a challenge for you.

#### Study

##### School

Challenges you may face with school could include:

- finding it hard to concentrate or stay motivated during class or study
- feeling more tired than usual
- having less time to do homework or study
- not wanting to be around other people as much as you used to or having days where you're wanting to be quieter or alone.

While you might not want to be treated differently, it can help to let your teachers know what's happening at home. You're in control of how much you tell them. There could be options for your

studies to be supported through 'Special Consideration' that allows for things to be put in place to help with your learning.

#### Tertiary study

If you're at university or TAFE, you might want to let your lecturers, tutors or department heads know what is happening in the family, they may be able to work out ways to support your learning.

Most universities and TAFE campuses have student services that provide counselling and support. These services could be other support options to help you get through the tough times.

#### Work

What you tell your boss or work mates about your parent's diagnosis is up to you. You don't have to tell them at all.

Check with your supervisor, manager, or human resources manager about your rights for leave, they may also be able to support you in the workplace in other ways.

For more information about your rights at work, visit the Fair Work Ombudsman website at [fairwork.gov.au](http://fairwork.gov.au).

## Money matters

It could be that with your parent's cancer the family's finances may be impacted, it could also be you're having to help organise things at home more than you previously would, it could be you're helping more with:

- the payment for household expenses like bills or groceries
- purchasing things like medications for your parent or younger siblings
- it could be that if your parent is off work, you may also have to help with things like Centrelink which is a place that provides families with income support

Where to get more information:

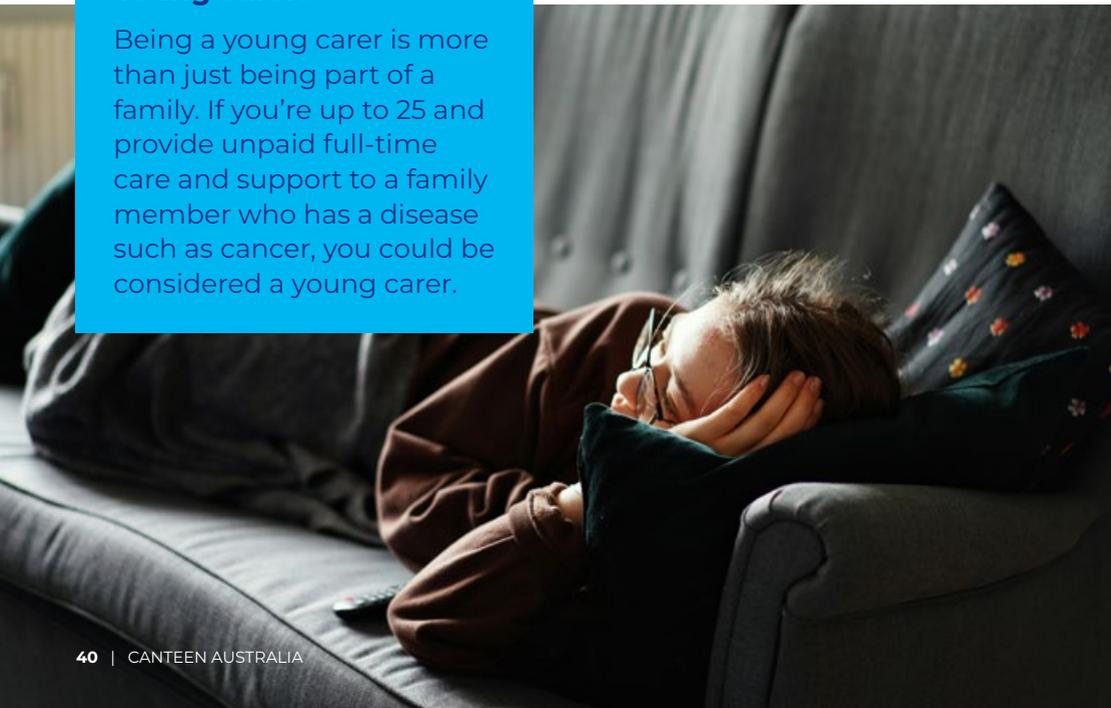
- talk to your parent or other family
- ask the social worker or nurses at the hospital
- if there's ever any issues with making payments, try to get onto it as soon as possible, leaving it may make things harder to deal with in the long run
- check out websites and support services in the 'More information and support' chapter on **page 81**.

Juggling being a carer with everyday life can be a challenge. The Young Carers Network is part of Carers Australia and provides information, counselling, referrals, and a break from caring (respite care). To find out more, visit [youngcarersnetwork.com.au](http://youngcarersnetwork.com.au).

## Young carers

Being a young carer is more than just being part of a family. If you're up to 25 and provide unpaid full-time care and support to a family member who has a disease such as cancer, you could be considered a young carer.

# MEDICAL STUFF



## GETTING THE RIGHT INFORMATION

Feeling that you don't know what's going on with your parent and their treatment can be stressful. Finding out about cancer is a good way to understand what is happening and what is going to happen, it may take some of the stress out of what's happening. You might want to know why your parent has cancer or if you will get cancer too. Information can help clear up some of the confusion, it could reduce the fear of the diagnosis and could help you feel a little more in control of things by being more involved.

Everyone in your family will deal with the diagnosis in their own way. Some people want to know every little detail all at once, others want general information a bit at a time. You can ask more questions as time goes on. Whatever you choose is okay.

You're probably used to getting information from the internet or social media. But because everyone's cancer experience is different, the information may not always be relevant or right. Ask your parent, their doctor, the nurses, the social worker, or other family members or people you trust questions, they may be able help clear up misunderstandings.

If they use medical words you don't understand, ask them to explain. Here are some questions to consider:

### About the cancer

- What kind of cancer does my parent have?
- Where is the cancer? Has it spread to other parts of the body?
- Will my parent get better?
- Is there a chance that I might get this cancer too?
- Is the cancer going to be painful?

### About the treatment

- What is the best treatment for this type of cancer?
- Are there other options?
- Where will my parent have treatment, and can I go with them?
- What are the side effects of the treatment?
- Will the treatment change the way my parent looks, feels, or behaves?
- How often do they have treatment and how long does it take?
- How will we know if the treatment is working?

If you have questions not listed here, use the space below to write down any other questions you may have.



### When you want to know more

If you want to know more about cancer and how it's treated, as well as the possible outcome (otherwise known as "prognosis"), you can try asking the health professionals involved in your parent's treatment, like the doctors or nurses. Knowing what to expect may help you feel a little better about what is happening for your family.

By law your parent's health care team will need their permission to discuss specific details about the cancer with you. This is called doctor-patient confidentiality.

Some doctors and nurses (and other health professionals) can be very approachable, others not so much. If you ever feel like you're not being talked to in the right way, please try not to be offended. It probably has nothing to do with you and may relate more to the busyness of the other person.

With your parent's permission, the doctor can share information with you. But if your parent has asked the doctor not to share some details, then the doctor must obey their wishes.

### Will my parent get better?

Some people want to know this information, others prefer not to know. The outcome or prognosis is the doctor's opinion of how likely it is the cancer will spread and the chances of your parent getting better. This is a difficult question to answer. No doctor can give an exact prognosis – it can be an educated guess based on what usually happens to someone in a similar situation to your parent. The doctor's answer may be in years, months, or weeks. The time may end up being shorter or longer.

If your parents are told that their cancer can't be cured, this means that treatment has stopped working and they are unlikely to get better from the cancer. You can read more about this in the 'If the treatment doesn't work' chapter.

It's a good idea to have support at this time – the 'Chat to a Counsellor' function in the Canteen Connect app may be one place you would like to try.

### Information overload

When you're stressed, upset, or scared, it can be hard to take in and understand new information, especially at the beginning.

#### These tips may help:

- make a list of your questions before appointments.
- write the answers down.
- ask people to repeat things if you don't get it or send a follow-up email with your questions.
- ask people to explain what they mean using simple words.
- ask where you can get more information.

### Dr Google

The internet is a great source of information, but we know that not all information online is true. Here are some tips for finding reliable information on the internet.

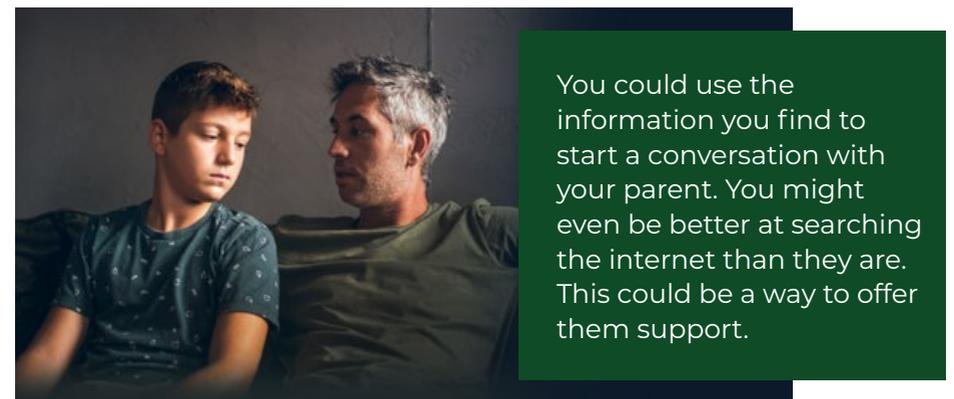
#### Always check the source of the information – Information online

can be misleading or out of date. For cancer organisations with accurate and up-to-date information, see the 'More information and support' chapter on **page 81**.

**Don't believe it all** – When your parent has cancer it's natural to look for other treatments they can try. Keep in mind that personal posts on forums, blogs or social media only relate to one person's experience.

**Search the right stuff** – There are over 100 different types of cancer. The likely outcomes are different for every cancer and different for every person and will vary depending on the stage and where it is in the body.

**Search websites you trust** – There are many reliable cancer organisations that have accurate and up-to-date information. A list of these reliable sources is on **page 81** in the 'More information and support' chapter. Canteen can also help you to access the right information. Visit [canteen.org.au](http://canteen.org.au).



You could use the information you find to start a conversation with your parent. You might even be better at searching the internet than they are. This could be a way to offer them support.

## Life after treatment

When your parent ends their treatment, you might think that life will go back to normal. But normal may not look exactly like it did before. They will probably feel relieved the treatment is over but at the same time they could also be worried that the cancer may come back. This chapter explains what happens when your parent finishes treatment, tips on getting back to 'normal' (or creating a new normal) and dealing with loss and change.

After treatment your parent with cancer enters a phase called 'survivorship'. But going from 'patient' to 'survivor' isn't easy. Surviving cancer is more

complicated than just having treatment. Your parent might still be dealing with side effects from treatment such as tiredness and feeling down. And they may need time to adjust to the changes cancer has made to how they look and feel.

## Check-ups or follow-up care

After your parents' treatment ends, they'll need to have regular appointments to manage any side effects, look for early signs of any issues or check that the cancer hasn't come back. This is known as check-ups.

- At first, appointments should be sometime between every 3–6 months. Eventually they may only need check-ups about once a year.

- What tests you have at the check-ups will depend on the type of cancer and treatment.
- It's natural for your parent (and you) to feel scared or anxious before check-ups. These feelings can be known as scan anxiety (or you and your family may want to come up together with your own words to explain the experience).
- Down the track, the doctors will look out for and support your parent with any 'late effects'. 'Late effects' are side effects of treatment that might not show up until later in life, and include lung, heart, kidney or liver problems, tooth decay and problems thinking clearly and concentrating (chemo brain). They don't mean the cancer has returned.

## Getting back to normal after your parents' cancer

Your family may expect that life will return to how it was before your parent was diagnosed with cancer, but some things may be different.

Your parent has just dealt with a life-threatening disease. Their life has changed. Everyone will need time to adjust. This is often called the 'new normal' (or you may have your own preferred words to explain this as well!).

## You might feel:

- relieved that your parent is okay.
- confused that your parent looks fine but still feels tired or isn't 'back to normal'.
- worried the cancer will come back.
- happy that cancer may now not be such a focus of the family.

You might find it helpful to chat with or read stories by other young people whose parent is a cancer survivor. Again, this is something Canteen can help with. Canteen Connect ([canteenconnect.org](http://canteenconnect.org)) has an online community, it is also where you can find out about our peer-based programs and events.

## Dealing with pressure from others to 'move on'

Your friends and other people might think everything should be 'back to normal' now that your parent has finished treatment. But this doesn't mean that cancer is no longer part of your life, and things may still feel different or difficult. It's natural to worry about cancer coming back.

A gentle reminder about how cancer could come back, and you're still feeling a little unsure about how things are going to be, could be all people need to recognise it's not something you easily 'move on' from.



## Understanding grief and loss

Grief is the term we use to describe how we respond to a loss. You might think grief is just about when someone dies, but you may also experience grief when your parent is living with cancer. You can experience grief and a sense of loss when you are told about the diagnosis, and other times during and after treatment.

### Other reasons for your grief could include:

- feeling you're unable to have fun like everyone else your age.
- being unable to take part in one-off experiences of being a young person, e.g., going to your first club, not being able to attend your school formal.
- having to pause your plans to go to university or TAFE because you were taking care of your parent.
- missing out on a planned holiday or not being able to plan holidays because of treatment.
- not celebrating special occasions like birthdays in the same way.
- missing your 'old' parent – if it feels they're a little different from how they were before cancer.

## Things that can help

- It's important to find ways to take care of yourself and to develop ways to look out for yourself throughout the grief process, another way to put this is "for you to find ways to grow around your grief".
- Go easy on alcohol and other drugs. While you might feel like they help you cope with stress and intense emotions, they can start to have negative effects particularly if you start using them more than you usually would.
- Seek comfort from your cultural, spiritual, or religious traditions. Even if you're not into traditional religion, you might find you are developing an interest in other beliefs and types of spirituality. This can be a way to find meaning in what can be a very tough situation.
- Find ways to grow around your grief and try not to get 'stuck'. See 'More information and support' on **page 81** for support services that can help you.
- Get in touch with Canteen. We can offer individual grief counselling and an online community for you to connect with young people in the same boat as you ([canteen.org.au](http://canteen.org.au)). As a start you can also contact Kids Helpline ([kidshelpline.com.au](http://kidshelpline.com.au), 1800 55 1800) if things are feeling a little too much.

# HEAVY STUFF

**“I wish I had known that even though Dad wasn’t going to be here, I would become the strong person I am today and be able to create a happy life for myself. A life that I can happily say he would be proud of!”**

**Melissa**



## **IF TREATMENT DOESN'T WORK**

In this chapter you'll find information about a very difficult situation – a parent who has advanced cancer. Sometimes, cancer may come back (recurring) or spread to other parts of your parent's body (metastasis). Or the cancer may have been diagnosed at an advanced stage. You can skip this chapter if the cancer was diagnosed

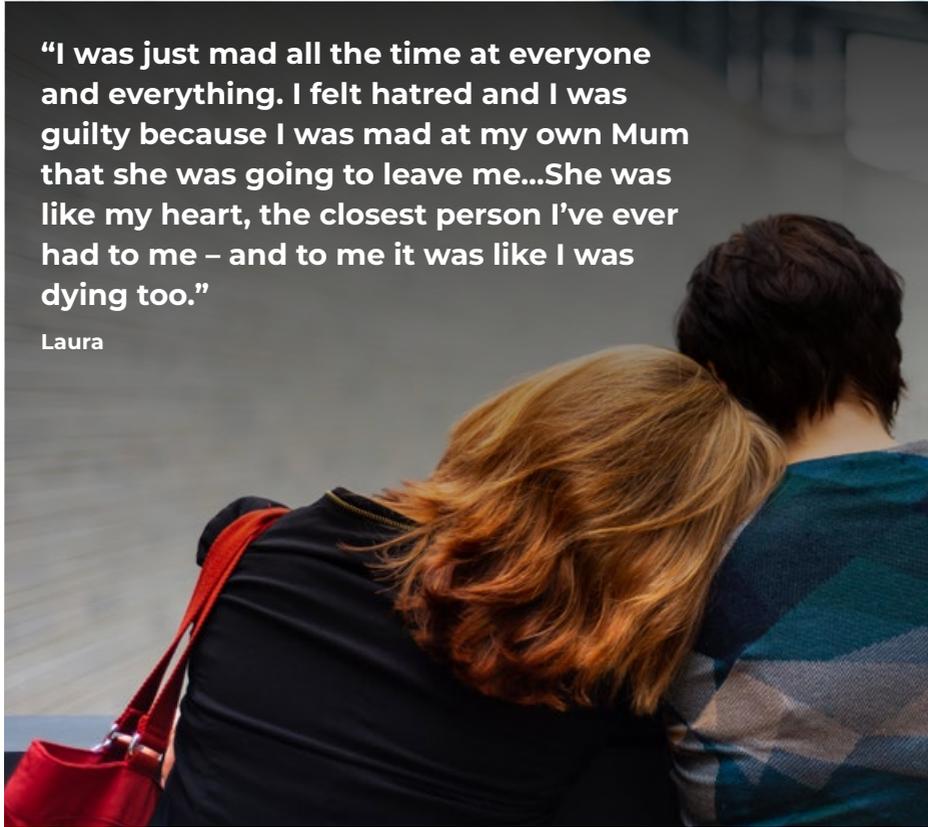
at an earlier stage and treatment has helped control it.

Sadly, not all cancer can be cured. Sometimes treatment doesn't work, and your parent may not get better. At this point, the focus changes to helping your parent be as comfortable as possible.

There might be certain things here you're not ready to think about yet. That's okay, you may prefer to talk to somebody or put this booklet away and come back to it at a later date.

**“I was just mad all the time at everyone and everything. I felt hatred and I was guilty because I was mad at my own Mum that she was going to leave me...She was like my heart, the closest person I’ve ever had to me – and to me it was like I was dying too.”**

Laura



## Finding out

### Taking it in

Learning that your parent is not going to get better could lead to similar feelings to when you first found out your parent had cancer, you may be shocked or have disbelief, it may feel like you’re a little distant and removed from the world around you.

Even if your parent has been feeling sick, having more tests or spending a lot of time in hospital, you may

have thought they would get better. You might find it hard to accept that there are no treatments left to try.

### Ask for more information

If you want to understand more about what’s happening with your parent, you might need to ask. The questions on **page 43** may help you think about what you want to ask your parents. You can also search the Internet for reliable information (see **page 45** for more details). If you need tips on taking in new information, see **page 45**.

### In the loop

Parents can want to protect their children from bad news because they may not want you to worry, it could also be very hard for them to talk about what is happening for them. If you suspect that something is wrong, you may fill in the gaps with your own guesses, which may be worse than finding

out what’s really going on. We imagine this may make you feel stressed, worried, or left out.

It could be worth trying to loop yourself in more by mentioning to your parent that you can feel something might be up, you could suggest to them it may help for you to know a little more as you’re already feeling quite worried.

**“I had no idea what was going on. All I knew was that Mum takes a handful of tablets every day. The first I heard that it was really bad was when Mum went into hospital as terminal. We didn’t think there was much wrong before then. I would have liked to know what was going on.”**

Megan



### People are living longer with advanced cancer

More and more people are living with advanced cancer for longer periods of time – this can be for many months or years. And there are treatments that can help your parent feel better.

### Managing uncertainty

Living with advanced cancer is a time of uncertainty. You may not be sure what's going on or how long your parent might be around. Or frustrated that the doctors have no clear answers.

### You can get support

Canteen provides a free and confidential counselling service supporting young people through their family's cancer experience (check out [canteen.org.au/counselling](http://canteen.org.au/counselling)). You could also ask your doctor to recommend a counsellor or psychologist they might know.

You can also connect with other young people at Canteen Connect ([canteenconnect.org](http://canteenconnect.org)) who could be experiencing or experienced something like what you're going through.

**“My younger sister (age 12) was not told of the terminal nature of Dad’s illness until about a month beforehand. She later expressed to me that she wished she had been told about it earlier. I suppose my family was hoping she would just sense what was happening so they could hold off telling her, everyone was worried how she would cope. But looking back, it would have been better to be open with her upfront, she wanted to know.”**

Lizzie



**“Mum had a rule that if I asked, then she would tell me. However, if I didn’t ask, then she wouldn’t tell me. Therefore, I had no idea my Dad only had 6 months to live. Perhaps this was because she was trying to protect me, as I was so young.”**

Chris

### Who says they will not get better?

When treatment doesn't control or shrink the cancer, their doctor (oncologist) may say there's nothing more they can do to treat the cancer, meaning they believe that your parent is more likely to die from the disease.

It's not possible for a doctor to say exactly how long a person will live for with incurable cancer. They may give you an estimate, but your parent may live longer, or unfortunately, for less time than they predict.

Your parent may decide to stop treatment. Often a patient knows before anyone else that they are not getting better and just can't face going through it all again. It doesn't mean that they are giving up on living, just that they are admitting the treatments are not working.

In some states of Australia there are new laws relating to something

called Voluntary Assisted Dying, which allows for people living with a terminal medical condition (where it is definite they will die from the disease of illness) to choose to end their life. A reason why somebody may choose to do this is to reduce suffering at the end of their life.

### How you and your parent may feel

Nothing can fully prepare you for the emotional rollercoaster of being told your parent might not recover from cancer.

You both may be experiencing some of the similar feelings you had when your parent was diagnosed with cancer – see **page 27**. When you're living with the stress of advanced cancer, it's important to find ways to share how you're feeling, it could be helpful to revisit what got you through the early stages – see **page 19**. Sometimes your emotions can be strong and confusing. Read 'When things seem to be too much' on **page 34** for signs of depression.

## Talking about advanced cancer

Many people say it helps to talk about the diagnosis but don't know how. Your parent may find it difficult talking about what advanced cancer means because they don't want to worry you more, or you may be also be worried about upsetting your parent by asking questions. They may also just not be able to find the words to talk about something so very hard.

This will be a challenging time for the family and it could help to talk about how you're feeling. This might particularly not be easy if you're not used to talking about your feelings as a family. It might help you to remind yourselves that it's never too late to share how you feel. If you prefer, you could talk to a family member or friend, or you could consider professional help from a counsellor, they could even help plan family conversations with you.

## How can you help?

**Treat them the same** – Your parent is still the same person and it's okay to laugh and argue with them sometimes. And every conversation doesn't have to be about cancer. Talking about study, your friends or work can help them to feel included in what's going on. You don't have to pretend to be happy all the time.

**Talk about dying** – Most people find it hard to talk about death and dying, and use words like 'passed away' or 'gone away'. If you're okay talking about dying, it may help your parent feel less alone. They may be able to answer any questions you have about how they're feeling.

It can help to talk about the practical aspects of dying – where your parent would prefer to die, who they would like to be around them when it happens, what they want their funeral to be like or what might change after they die.

Asking these questions doesn't mean that you want your parent to die or that you have given up hope. You and your family can also talk to the palliative care team about how they can support the family.

**Follow their lead** – If your parent doesn't want to talk about dying, you need to respect their wishes. They may think talking about it will be too much for you or that if they do it will make death happen sooner. It may even be disrespectful in your culture to talk about dying. As the cancer progresses, your parent might be tired, trying to put on a brave face, or overwhelmed by sadness. The cancer or medicines may have changed how they think or behave. Your parent might cope by withdrawing from family activities. Try not to take their behaviour personally.

If your parent wants to talk, listen. You don't have to pretend it's not happening by saying things like, 'No, you're not. Don't talk like that'. It's okay to be upset and afraid together. You could say something like, 'I know this is hard. But it would help me to talk about what's happening'.

**Spend time together** – Young people have said that even though it's difficult to see their parent unwell, they find comfort in spending time together. Think

of things you can do that don't take much energy, like watching a movie or listening to music. Expect that some days your parent will be too tired or sick to talk. They may seem irritated or distant. This may make you feel hurt, disappointed or worried.

If your parent is feeling too sick to spend time with you, it doesn't mean that they don't want to. There may be ways to show you care – like writing notes, bringing them small gifts, or just sitting by their bed.



## Having palliative care

When it no longer seems likely that your parent will get better, the focus of treatment shifts from trying to treat the disease to helping them to live as comfortably as possible. This type of care is called palliative or supportive care.

If your parent is referred to palliative care, it's natural to have questions. One of the most

common questions is, does this mean my parent is about to die?

Palliative care can help people whose illness has not responded to treatment and it's likely it cannot be cured. Palliative care does not aim to make someone's life shorter or longer. It aims to make them comfortable. This could be for weeks, months or years. It can be at home or a hospital.

**"I thought 'palliative' was a cancer ward. I thought the nurses just wanted to keep an eye on her. It didn't cross my mind to ask what it meant."**

Lisa



## How palliative care works

### What support does palliative care provide?

Palliative care will help to maintain the quality of life of your parent by dealing with their physical, emotional, cultural, social and spiritual needs. Palliative care also supports the family.

Each palliative care team tailors its services to the unique needs of a family. This may include:



nursing and medical care – to control symptoms and side effects of cancer, like pain and nausea



counselling and social worker services



advice on what to eat



hire of equipment, e.g. special beds, chairs



physiotherapy and occupational therapy



therapists skilled in music or colour therapy, massage or aromatherapy



spiritual support and pastoral care from a range of cultural and religious backgrounds



volunteers to help you care for your parent.



### How do we know when it's time to consider palliative care?

Starting palliative services as early as possible can make things easier for your parent and your family. A lot of people avoid having palliative care for as long as they can because they're afraid that it means they're going to die soon.

Your parent's health care team will probably suggest when it's time to consider palliative care. Your parent can even refer themselves by contacting a local service. And they can stop and start palliative care as their needs change.

### How can we access palliative care?

Depending on your needs, your parent may receive palliative care from their own GP or health care team, or they may be referred to a specialist palliative care team. Services are available in most areas of Australia.

### Is palliative care like euthanasia?

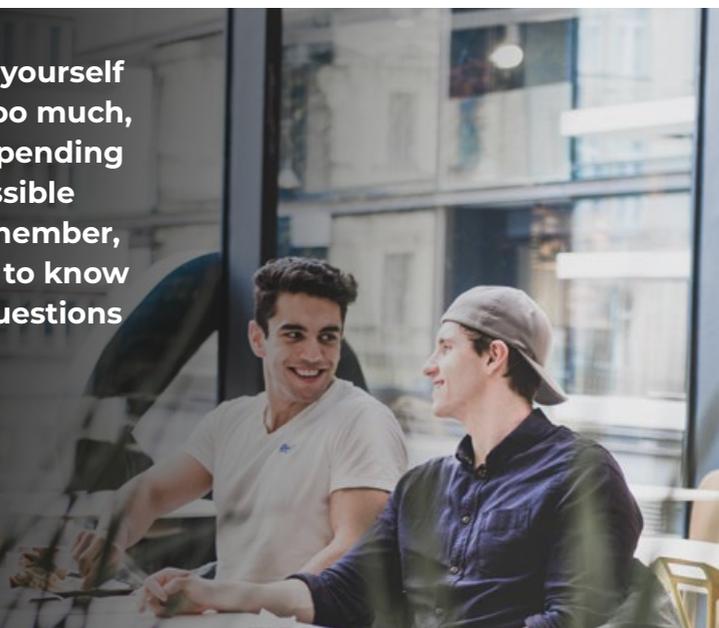
No. Euthanasia is assisting the death of someone who would prefer to die. This is illegal in Australia. Palliative care is also not like voluntary assisted dying, which is when a person with an incurable illness uses medicines specially prescribed by a doctor to end their life. Voluntary means it is the choice of the person to end their life. Laws have been passed in all states in Australia.

### How much will palliative care cost?

Palliative care is usually free in the public health system. It is often funded by the government or charitable organisations. However, in some hospitals and palliative care units (sometimes called hospices) you might have to pay for some in-patient services – check if Medicare or private health insurance will cover the cost of these in-patient services.

**“Try not to distance yourself from the situation too much, you will regret not spending as much time as possible with your ill family member, take the time to get to know them and ask any questions you want.”**

Lizzie



**“They don't have to be in the palliative stage, you can have the conversation just in case. It wouldn't hurt to have this now.”**

Erin



### If my parent is in pain, can it be eased?

Pain management is an important part of palliative care. Most of the time, pain can be managed or improved. A lot of different drugs are used to treat pain and they can be taken by mouth, into the vein (intravenously) or worn on the skin as patches.

Opioids are a group of drugs commonly used to treat strong pain. Morphine is a commonly used opioid. When morphine is used for a long time, the body can get used to the dose. This is known as tolerance. The

doctor may need to increase the dose to achieve the same level of pain control. This does not mean that their condition is getting worse or that they are addicted to the opioids.

There are also other things your parent could try to relieve pain, such as massage, meditation, hot and cold packs, aromatherapy, acupuncture or hypnotherapy. A doctor can tell you more about these.

### Who can I ask if I have questions?

The palliative care team can answer your questions and help you too.

**“One of the hardest parts was imagining life without Dad. The thought was just too painful, thinking of all the things Dad was going to miss out on seeing me do. At the time all I wanted was for him to see me dressed up and going to my Year 10 formal.”**

Melissa

**“If there’s something you want to know, don’t waste time thinking about it, just ask them.”**

Peta

**“Knowing what I do now, I would try not to hold back. If I want to tell someone how I feel, then I would tell them.”**

Eloise

**“I wish I’d asked her what her dreams were. I didn’t think at the time it was such a nice subject to bring up.”**

Steph

**“Let them know how much they mean to you every chance you get as you don’t know when it will be the last.”**

Melissa

**“You feel a bit awkward with the whole ‘I love you’ convo, but you might appreciate it later.”**

Mark

## Saying goodbye

This is a sad and difficult thing to do but a chance to tell them what you’d like them to know.

You might feel awkward having deep and meaningful conversations, when your parent might still be around for months or years. Or you might be worried that they will think you have lost hope if you talk about life without them. But your parent might like to know that you love them and that you’ll miss them.

**Here are some suggestions to get you started:**

- Thank you for...
- I’m sorry that...
- I love you because ...
- I feel proud when you ...
- I forgive you for...
- I hope that...
- If only...
- What scares me the most is...
- A favourite memory I have is...
- You make me laugh when...
- I’ll miss you because...
- Do you have any advice for me in the future?
- What are your hopes and dreams for me?

Whatever way you say goodbye to your parent, it’s a good idea to do it while they’re still as well as possible.

## When seems too hard

When you experience grief before a loss occurs, it's called anticipatory grief or pre-loss grief. When your parent is dying, they and you might experience anticipatory grief for what is about to come. While they are still a part of your life, you grieve the future without them. It's a weird in-between state. Anticipatory grief doesn't make grief after the death any easier or shorter, and the death can still feel like shock.

## Memories and stories

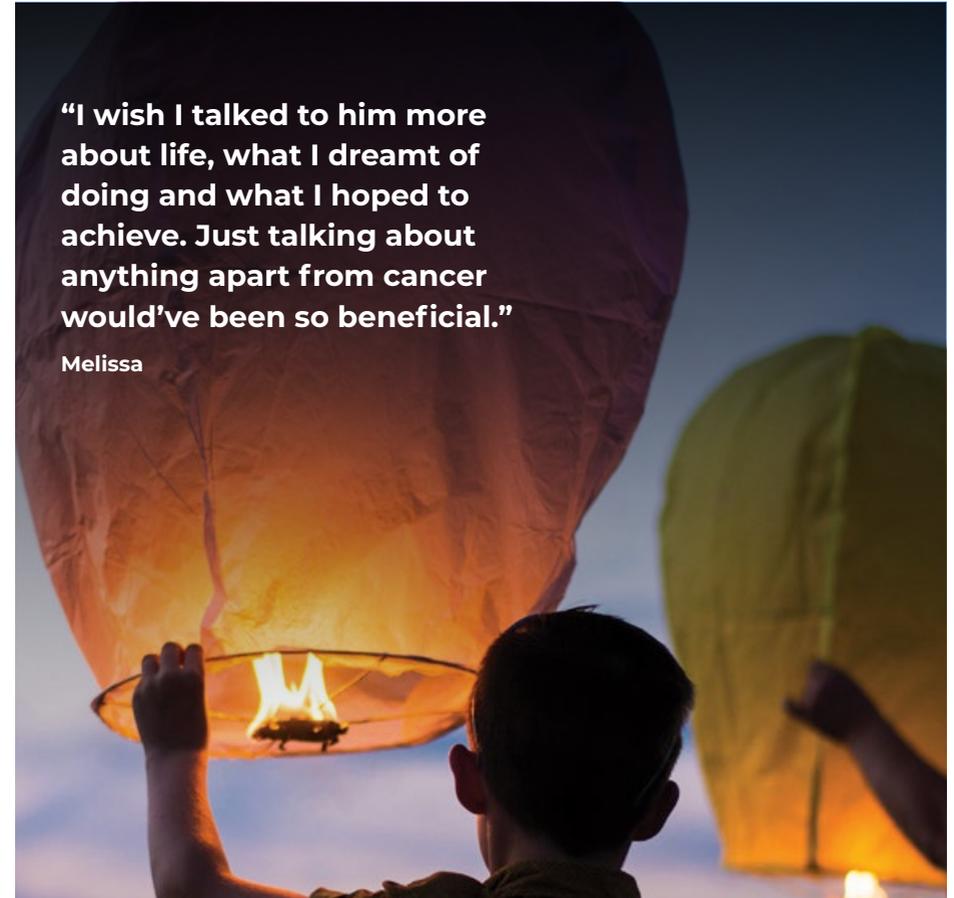
Often when a person is dying, they like to reflect on their past and what they've achieved so that they can see that their life has been important.

Now is a good time to learn more about your parent. You could ask them about their life and share memories. If they don't have the energy to reminisce, you might be able to collect stories from other family members or friends.

Collecting memories and stories might make you both laugh and cry, but that's okay. Knowing that you had the chance to share this special time with your parent should be something you are grateful to have had and can reflect on throughout your own life.

It's natural to find imagining the future without your parent upsetting or, even, impossible. It will be hard to think of the occasions and events they will miss out on or that you wish they could be there for – finishing school or study, your wedding, becoming a grandparent.

At moments like this in the future, you may wonder what your parent would think or say about the situation. You will not be able to predict all of the conversations you might ever want to have with them, but you might want to hear about their thoughts and dreams for you and the future.



**“I wish I talked to him more about life, what I dreamt of doing and what I hoped to achieve. Just talking about anything apart from cancer would've been so beneficial.”**

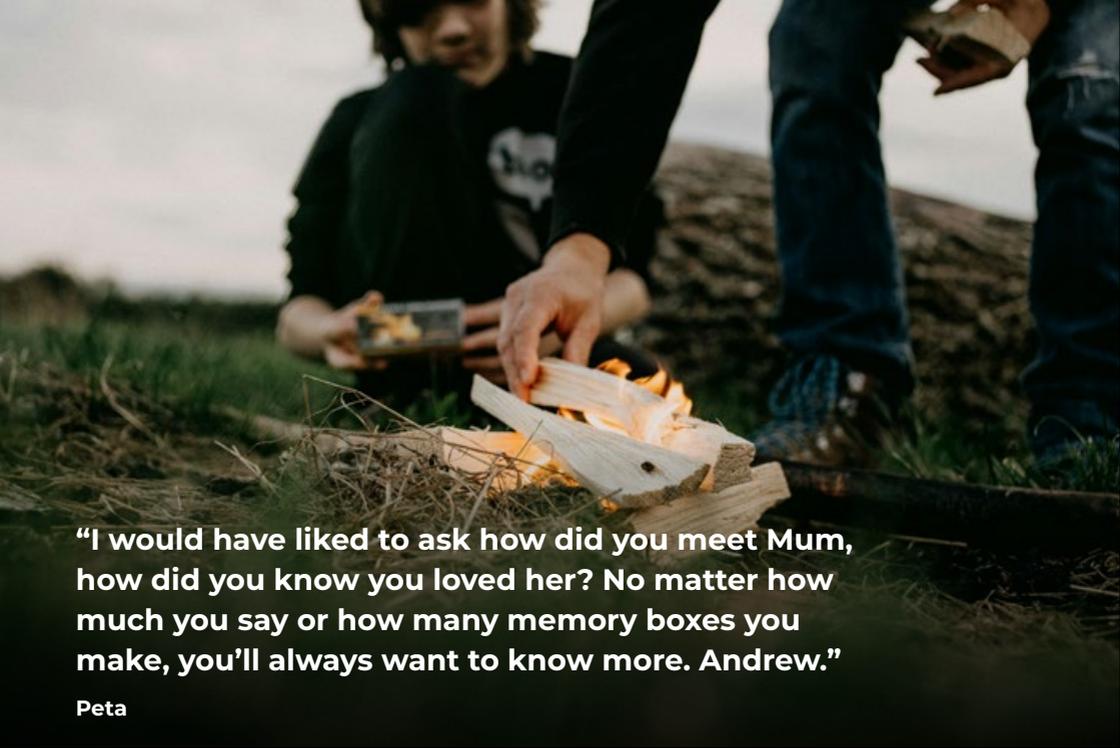
Melissa

**“I'd like to know his opinion on teenage things – like what does he think of me having a boyfriend at 15?”**

Erin

## Questions to ask your parent

- Where were you born?
- Tell me a story from when you were little.
- What did you want to be when you grew up?
- What were you like as a teenager?
- What was your first job?
- Where did you meet [insert partner's name)?
- Who did you first go out with?
- Tell me about when I was a baby.
- What is your favourite memory?
- What is your favourite colour?
- What is your favourite movie?
- What is your favourite place?
- What is your favourite song?
- What is your favourite food?
- What is your favourite quote?
- What is your most important achievement?



**“I would have liked to ask how did you meet Mum, how did you know you loved her? No matter how much you say or how many memory boxes you make, you’ll always want to know more. Andrew.”**

Peta

### Collecting memories

With time, memories of your parent will become precious. You may want to put together things that will remind you of them in the future. This is also a good way to spend time together.

#### Here are some ideas:

- Create a photo album, slide show or scrapbook. You could write a note next to each one about what your parent remembers about that photo.
- Make a playlist of songs that your parent likes or that remind you of them.
- Put together a box of special things, e.g. photos, tickets, cards,

clothes, toys or jewellery, that remind you of them. This is often called a memory box.

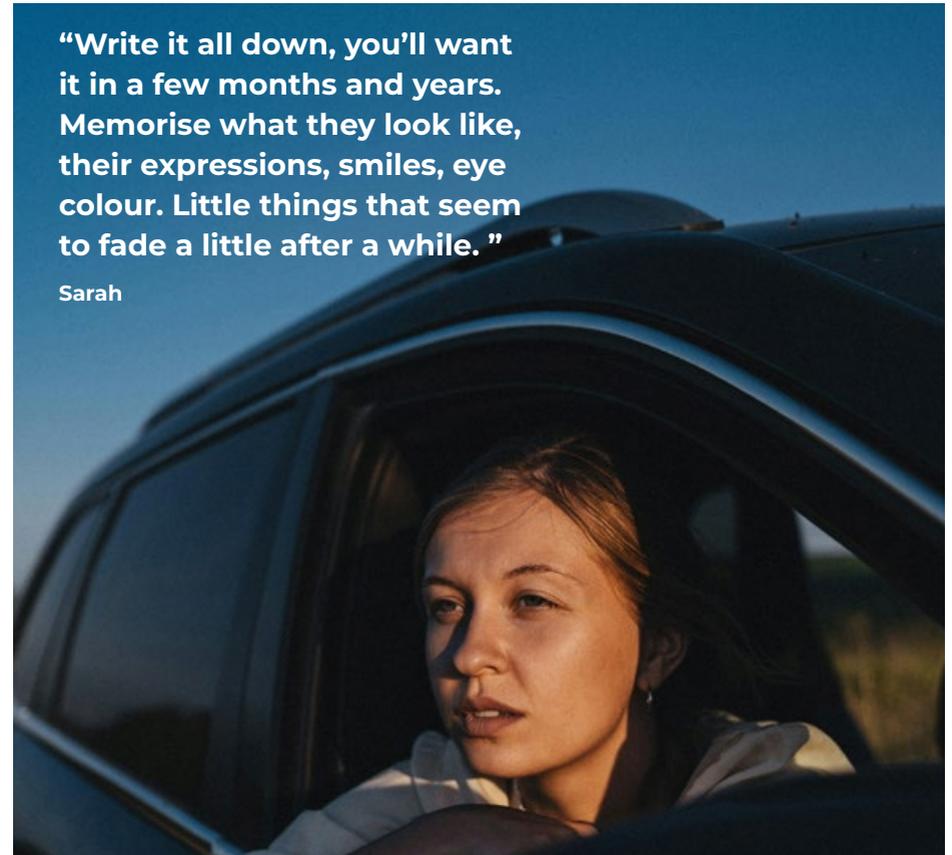
- Keep a journal. You could write down how you’re feeling now. It might help you to maintain a connection in the future.
- Take photos. If your parent doesn’t want you to take photos of them because they look sick, you could take photos of their room, the house or the garden. This will help you remember how your home looked if it changes in the future.
- Record a video or voice message. You could ask them to tell stories about their life or shared memories.

- Make a physical record. Draw around their hand, make a handprint in plaster, record how tall they are, cut a lock of their hair.
- Write a song or poem about your parent, or how you’re feeling.
- Create a family tree. Write down what they know about your family history.
- Collect their smell. The sense of smell can help bring back memories. Ask your parent what perfume, aftershave or soap they use.

Everyone approaches the end of life differently. Don’t worry if your parent doesn’t feel like participating in these activities. It doesn’t mean they don’t care. You can collect memories on your own later. If you don’t want to, that’s okay too. There will be lots of ways to remember your parent. You could also include other important people in your family’s life in this memory making.

**“Write it all down, you’ll want it in a few months and years. Memorise what they look like, their expressions, smiles, eye colour. Little things that seem to fade a little after a while.”**

Sarah



## Making plans about end of life

Your family might find it really difficult to talk about dying with your parent. This might be from fear that if your parent accepts their death, they will give up hope and die sooner. Or perhaps your family has never been comfortable talking opening with each other. This doesn't necessarily change when someone is dying.

Making decisions about the type of care a person would like to have in the future is called advance care planning. Having these conversations is hard but planning ahead for the death will help ensure that your parent's wishes are met.

It's important to write their wishes down and complete documents while they can make decisions clearly. This is known as having capacity. Tell the medical team about the documents, to make sure they get followed when the time comes. While planning ahead can feel sad and daunting, it can make things easier later and offer peace of mind to your parent and family. Remember, choices about their treatment and care can be changed at any time.

Some important things your parent may want to consider include:

- Make an advance care directive – This describes what kind of treatments are or are not wanted, and whether they want to go on life support. Depending on where you live, this could be called Advance Health Directive, Health Direction or an Advance Personal Plan. See [advancecareplanning.org.au](http://advancecareplanning.org.au) for more information.
- Appoint a substitute decision-maker – This nominates a person your parent trusts to make legal, financial and medical decisions if they lose capacity.
- Organ or tissue donation – This may not be possible depending on the type of cancer.
- Ideas for their funeral – Whether they would like their body to be buried or cremated, type of flowers, colour to wear or music.
- Hold a 'living funeral' or 'party' – If your parent is well enough, organise an event to celebrate their life.
- Update or prepare a Will – This is a legal document that states what a person wants to happen to their money and property (estate) after they die. It can also include details of who will look after you (if you are under 18) and your siblings after they die.

## Choosing where to die

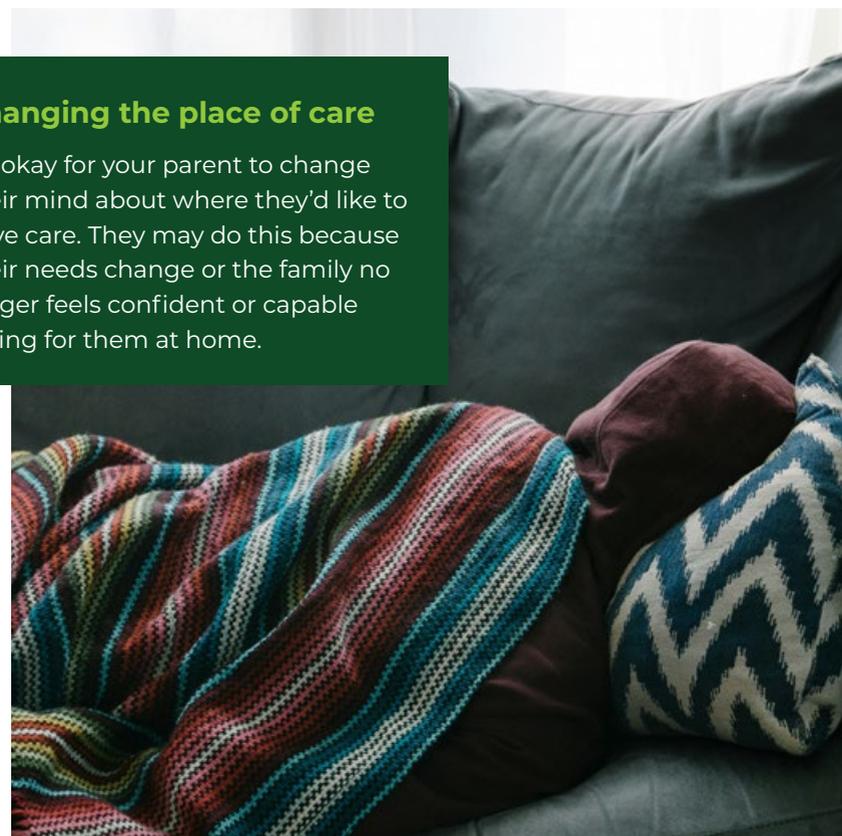
A major decision your parent will have to make is where they'd like to be at the end. It may be important to them to have some control over where they will die. The decision will depend on what your family feels comfortable with, what support they need, where you live, and what services are available. Care may be possible at home, in a hospital, in a palliative care unit (which is sometimes called a hospice), or in a residential aged care facility.

It's important that you are open and honest about how you feel about the decisions for your parent's place of care. Ask for more information if you are unsure about the options.

Your parent may go to hospital or a palliative care unit for a short time for symptom control. Your family may decide that it's better if they stay there or come home. Sometimes things change and your parent doesn't die where they would like or the death happens more quickly than expected.

## Changing the place of care

It's okay for your parent to change their mind about where they'd like to have care. They may do this because their needs change or the family no longer feels confident or capable caring for them at home.



## Care at home

Many people say they would prefer to die at home. They may want to be in a place they know, and surrounded by their family, friends and pets.

Having your parent at home in their final stages can be a special experience. You may appreciate having the time to spend with them. The palliative care team can provide support to make your parent comfortable and help your family care for them at home.

Caring for your parent at home can be physically and emotionally tough. You may want to talk to your family about what care you feel comfortable providing. If you don't want to help with their physical care, there are many ways to help improve their quality of life and offer support – you could bring them some fresh flowers, read to them, play music or light scented candles.

There may be changes in how your parent looks and behaves when they are approaching the end of life. You might find it distressing to see them become weaker and have less energy.

**“The hardest part was the change from child to carer. My Dad could no longer care for me so I had to be more independent and help him... Dad wanted to be home for his passing. I wanted him to be in hospital, as his presence overwhelmed me.”**

Lizzie

**“Living at home throughout the whole ordeal was extremely traumatic. I can recall sitting down to study for my year 12 exams, only to hear my parent in another room wailing and crying. The difficult part wasn't necessarily being able to focus on my study, but was in fact because I was so helpless to do anything.”**

Chris

**“Dad was at home, we had to make sure the house was kept clean, we had to make sure the animals stayed outside. Sometimes if Dad was having a bad day, we had to keep a bit quieter and stay away from his tummy. My little sister and I took turns to stay home with Dad while everyone else went out.”**

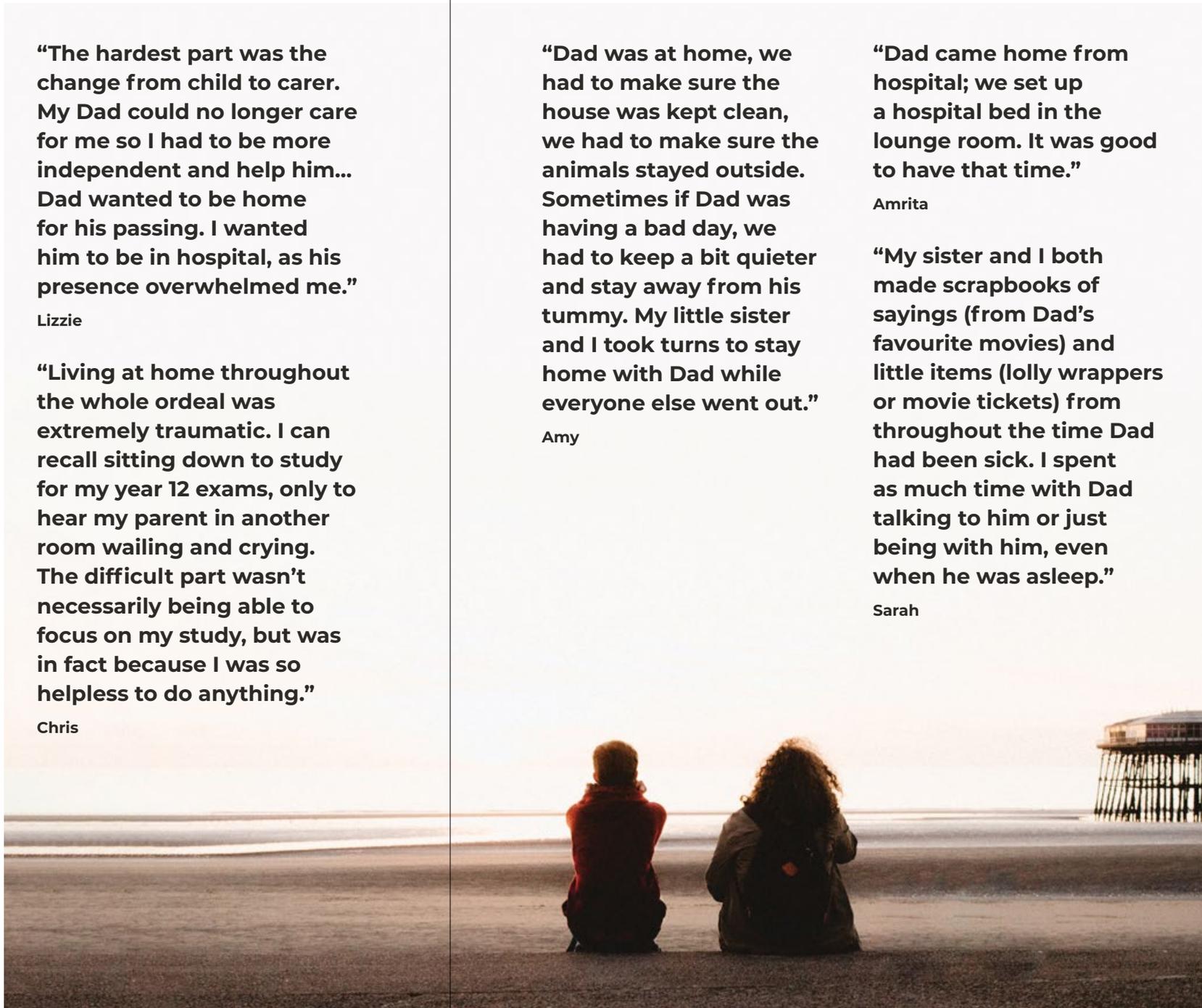
Amy

**“Dad came home from hospital; we set up a hospital bed in the lounge room. It was good to have that time.”**

Amrita

**“My sister and I both made scrapbooks of sayings (from Dad's favourite movies) and little items (lolly wrappers or movie tickets) from throughout the time Dad had been sick. I spent as much time with Dad talking to him or just being with him, even when he was asleep.”**

Sarah



During this time, it's important to take care of yourself. Try to have regular breaks, get as much sleep as you can and eat healthy meals and snacks. This will mean you have more energy to enjoy the time you have with your parent.

Remember, there are services available to help your family care for your parent. A community nurse can visit to give drugs, change dressings and help with washing and toilet needs.

You may be able to stay over with your parent in a hospital or hospice – but try to spend some time outdoors, if that's what you need to do.

**“I felt that the hospice was the best place. It wasn't too impersonal but there were medical professionals nearby.”**

Megan

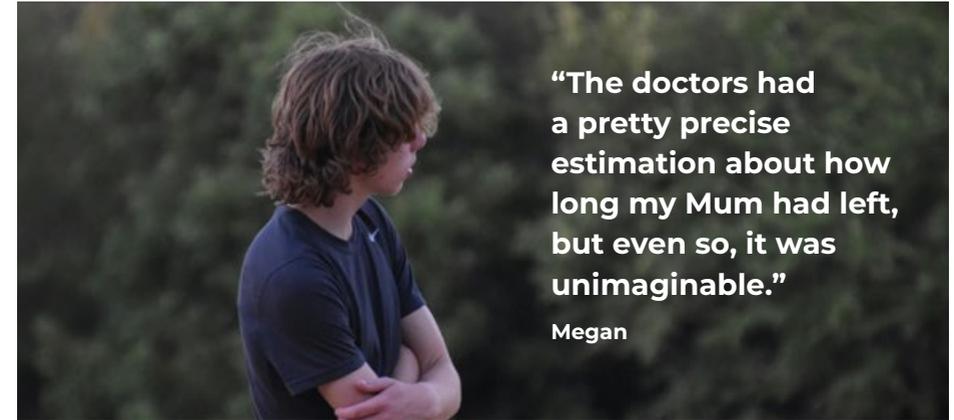
### Care in a hospital

Your family may feel more comfortable if your parent is cared for in a hospital. Here health professionals can look after them and relieve pain and other symptoms as necessary.

### Care in a palliative care unit

A palliative care unit (hospice) is a special ward in a hospital or special facility. It provides care for people with an illness that is unlikely to be cured.

Many palliative care units are often smaller and quieter than hospitals.



**“The doctors had a pretty precise estimation about how long my Mum had left, but even so, it was unimaginable.”**

Megan

### The last few weeks

You might worry about what will happen during the dying process. It can be scary to see your parent sick and drowsy. The distress of knowing that your parent is going to die cannot be taken away, but knowing what is going to happen can help you feel less scared. If you feel like you need a bit more space, this is okay.

The doctor and nurse will do everything they can to make sure your parent is comfortable and not in pain. The time before death is usually peaceful. The body slowly closes down as it starts to 'let go' of life.

No-one can say exactly when someone will die but there are some signs that death is near. Changes happen over a few weeks or days. You may find these changes distressing, but they're a natural part of gradually withdrawing from the world.

Signs you might see include:

- **Sleeping more** – They spend more time asleep and are less alert. It's best to let them sleep and talk to them when they seem most alert.
- **Not talking very much** – They might become withdrawn, talk less and lose interest in things around them. Sometimes it might seem like they don't recognise you.
- **Changes in mood and behaviour** – At times they might be angry or irritable. You may not have done anything wrong and just being there and listening can be supportive.
- **Eating and drinking less** – As your parent gets weaker, they may have trouble swallowing or digesting food. Small sips of water or ice to suck can help dry lips and mouth.
- **Changes in temperature** – Sometimes they may feel cool, other times hot and clammy. This is because their blood circulation is slowing down.

- **Incontinence** – This is when they lose control over their bladder and bowel. The palliative care team can help you manage incontinence.
- **Changes in breathing** – As saliva and phlegm begin to collect in the back of the throat, breathing becomes noisier. This can create a gurgling or rattling sound. They may have one fast breath then no breath for a few moments. You may find the breathing changes distressing, but your parent probably isn't uncomfortable or in pain. It can help to raise the head of the bed with pillows.

It is said that people can still hear and feel touch when sedated or unconscious. So even if your parent doesn't respond to your voice, they can probably hear you. Talking or reading to them, or holding their hand can be a comfort.

If you notice any changes in your parent that you're unsure about, ask the medical and nursing staff for

more information. They can also help manage any symptoms.

At this time, it may feel like life stops. It's common to want it all to be over. This doesn't mean that you don't care. It's a sign that you want your parent to be at peace.

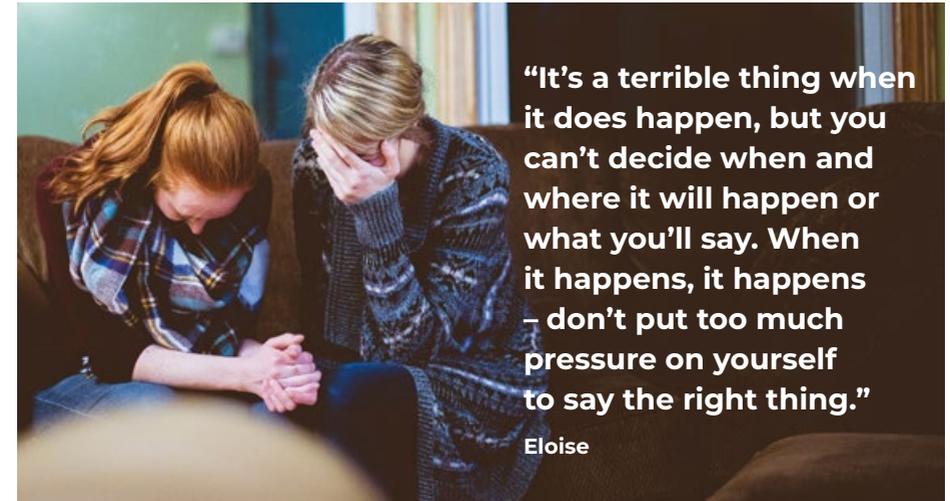
#### Do I need to be there when they die?

This is a very personal decision. It's a good idea to talk to your family about how you feel. Many people want to be with the dying person as a way to show love. This is called keeping a vigil. Your parent may be sedated or unconscious at this time.

You may worry that if you go to school, uni/ TAFE or work you'll miss the moment of death. If you want to be there at the end, ask your family to let you know what is happening. Some people don't want to be there at the final moments, and that's okay. You can say goodbye to your parent in other ways.

**“During the end stages my dad had lost nerve function of one side of his face, so he needed a straw to drink and couldn't talk properly. It made me sad to see my Dad so frail and bald. The once chubby and jolly man was wasting away, and I couldn't see him anymore.”**

Lizzie



**“It's a terrible thing when it does happen, but you can't decide when and where it will happen or what you'll say. When it happens, it happens – don't put too much pressure on yourself to say the right thing.”**

Eloise

### When your parent dies

Knowing what might happen can help you feel more prepared when your parent dies.

Signs that the person has died include:

- breathing stops
- pulse stops
- they do not respond to anything
- their skin feels cool and looks pale
- eyes stop moving and may stay open
- pupils of the eyes stay large, even in bright light
- might lose control of bowels or bladder as the muscles relax

#### What do we have to do?

Wherever your parent dies, you don't have to do anything in a hurry. You and your family can sit with them

and say goodbye. This is a personal time and you can take as long as you need.

Some families wish to sit quietly together and hold their hand, sleep next to their parent, wash and brush their hair, or cut a lock of hair. Some people feel comfortable touching and holding their parent, other's don't. This is a personal decision and it's okay to do what feels right for you.

#### If your parent dies at home

Your parent's palliative care team will tell you what you need to do and who to call.

The doctor will need to come and check your parent and sign a death certificate. But there's no rush to do this. If your parent dies during the night, it's okay to wait until morning before you call the doctor and funeral director. They will talk you through the next steps.

### If your parent dies in a hospital or palliative care unit

It is fine to sit with your parent for a while after they die. There is no rush to call anyone or get anything done straight away. Many families find this is an important time to talk together or pray and say goodbye.

The doctor will give your family a death certificate to give to the funeral director. Your family may want to arrange to have your parent at home for a short time before the funeral. The funeral director might collect your parent's body from the hospital or palliative care unit.

It can be hard to leave the hospital or palliative care unit without your parent. The staff will support you and let your family know what you need to do next.

### Funerals or memorial service

Some people say that a funeral or memorial service is for the living. It can give the family and friends of the person who died a chance to come together and support each other, share memories, laugh and cry, and say goodbye.

A funeral or memorial service is a very personal occasion. What it looks like might depend on your family's cultural and religious traditions. Your parent may also have given you some ideas about what they would like before they died. There is no 'right' way.

Your family will probably start planning the funeral or memorial service within a couple of days after your parent dies. But there's no rush, you don't need to think about the funeral or memorial service straight away.

Most families use a funeral director to help organise the details of the day such as:

- Will it be a burial or cremation?
- When and where will the service be and who will lead it?
- Who will speak at the service?
- What sort of casket or coffin? Who will carry it? Can you decorate it?
- Will the family spend time with your parent before the funeral (this is called a viewing)?
- What personal touches – like music, flowers, photos or booklets – can you add that show your parent's personality?
- Will there be a gathering called a 'wake' after the service? This could be anything from a cup of tea and biscuit to singing and dancing.

Being part of the funeral or memorial service may give you a sense of control. For example, you could do a reading, write a letter or poem, talk about your parent, choose the music, put together photos or a slideshow, or place a photo or memento in the coffin.

To find a funeral director, see 'More information and support' on **page 82**.

**“Something I wish I had of done after Dad had passed away – I had prepared a speech for the funeral but I didn't end up giving it, which I will regret for the rest of my life. I was too worried about being judged and getting upset in front of everyone. That was my one opportunity to share with everyone how much Dad meant to me and I missed it.”**

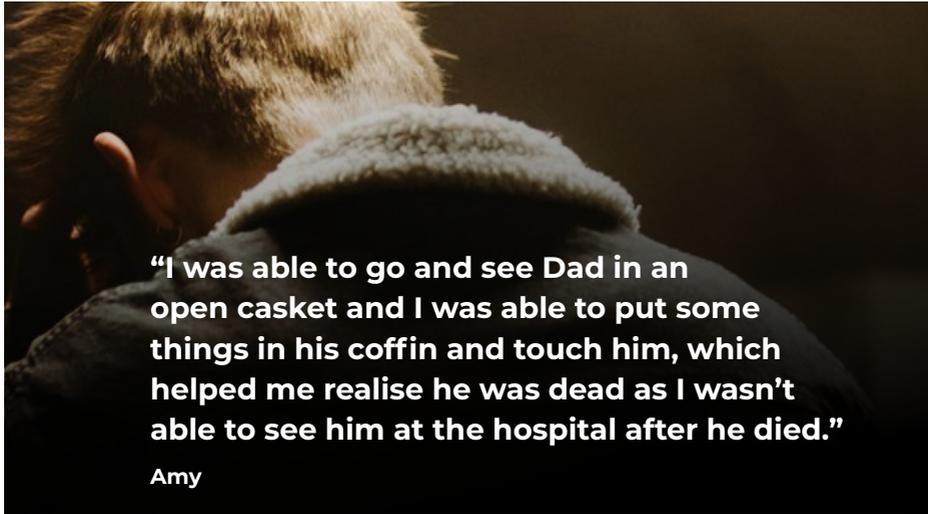
Melissa

**“You think you have prepared yourself to say goodbye, over many, many months and in some cases years. You tell yourself you're ready for them to go, ready for them to be at peace. But when it all comes down to it, in those final days, hours, minutes, seconds, nothing can prepare you for the feelings and emotions you will experience.”**

Rebecca

**“We each made photo boards of Dad for his funeral, which we now have hanging above our beds. I wore my graduation dress Dad got me to his funeral.”**

Amy



**“I was able to go and see Dad in an open casket and I was able to put some things in his coffin and touch him, which helped me realise he was dead as I wasn’t able to see him at the hospital after he died.”**

**Amy**

### Should I go?

You can decide whether you’d like to go to the funeral or memorial service. Attending your parent’s funeral or memorial service may be one of the hardest things that you will ever have to do. You don’t have to put pressure on yourself to act or feel a certain way.

Many young people find going to the funeral helps them. They can share their sadness with their family and friends, hear other people’s memories of their parent and celebrate their parent’s life.

But it’s okay if you don’t want to go to the funeral. Or you may decide you feel more comfortable going to only part of the funeral like the service but not the burial or cremation. There are other ways you can say goodbye. You could plant a tree, light a candle, tie a message

to a balloon and let it go, or visit a special place you used to go to together. You can change your mind at any time.

### Grief

The mixture of thoughts and feelings you have as you deal with your parent’s death is called ‘grief’. The way you show your grief is called ‘mourning’. This will be different according to your culture, religion, family traditions, as well as your personality. The death of your parent is one of most challenging things that will ever happen to you, so don’t feel like you have to act a certain way or say particular things.

Whatever you’re feeling is okay.

Our book *Living with grief after cancer* focuses on how you deal with grief. You can download a copy from [canteen.org.au/resource](http://canteen.org.au/resource).

# MORE INFORMATION

## MORE INFORMATION AND SUPPORT

These organisations and websites can help you deal with a parent who has cancer. We have included some of the most well-known and reliable sources.

### Websites

#### General

##### **Canteen**

1800 226 833

**canteen.org.au**

Canteens helps you find the emotional strength you need to deal with cancer. We make cancer support stronger through connection – with other young people who ‘get it’ and with specialist staff who are always in your corner. We’re here for the tough stuff and for a break from cancer when you need it.

##### **Canteen Connect** **canteenconnect.org**

Canteen Connect is an online community where you can connect with other young people impacted by cancer, check out events and chat to a counsellor.

##### **Cancer Hub** **cancerhub.org.au**

Initiative of Camp Quality, Canteen and Redkite to provide a digital one-stop shop to help families with children aged up to 25 access practical and emotional support.

##### **stupidcancer.org**

US site to empower people aged 15–39 who are affected by cancer.



## Carer services

### Carer Gateway

1800 422 737

[carergateway.gov.au](http://carergateway.gov.au)

Practical information, support and resources for carers.

### Young Carers Network

[youngcarersnetwork.com.au](http://youngcarersnetwork.com.au)

Support for young people up to age 25 who care for a family member or friend with an illness, disability or mental health issue.

## Counselling

### Beyond Blue

1300 22 4636

[beyondblue.org.au/who-does-it-affect/young-people](http://beyondblue.org.au/who-does-it-affect/young-people)

The youth website of beyondblue. You can call or chat online with a counsellor or join a forum to connect with people who are going through similar experiences to you. It has links to other support organisations and fact sheets on depression.

### headspace

1800 650 890

Online and telephone support service for young people who don't feel ready to attend a headspace centre in person.

### Kids Helpline

1800 55 1800

[kidshelpline.com.au](http://kidshelpline.com.au)

Free and confidential online counselling service available by phone or webchat as well as other helpful information on dealing with tough things.

## Lifeline

13 11 14

[lifeline.org.au](http://lifeline.org.au)

Offers 24-hour crisis support by phone, text or webchat.

## QLife

1800 184 527

Provides peer support and referrals about sexuality, identity, gender, bodies, feelings or relationships through an anonymous online and phone counselling service. Available 3pm-midnight.

## Reach Out

[au.reachout.com](http://au.reachout.com)

Online support and information for young people going through tough times. Includes information on depression, drugs and alcohol, relationships, sex and grief.

## Suicide Call Back Service

1300 659 467

[suicidecallbackservice.org.au](http://suicidecallbackservice.org.au)

24-hour telephone and online counselling for people affected by suicide.

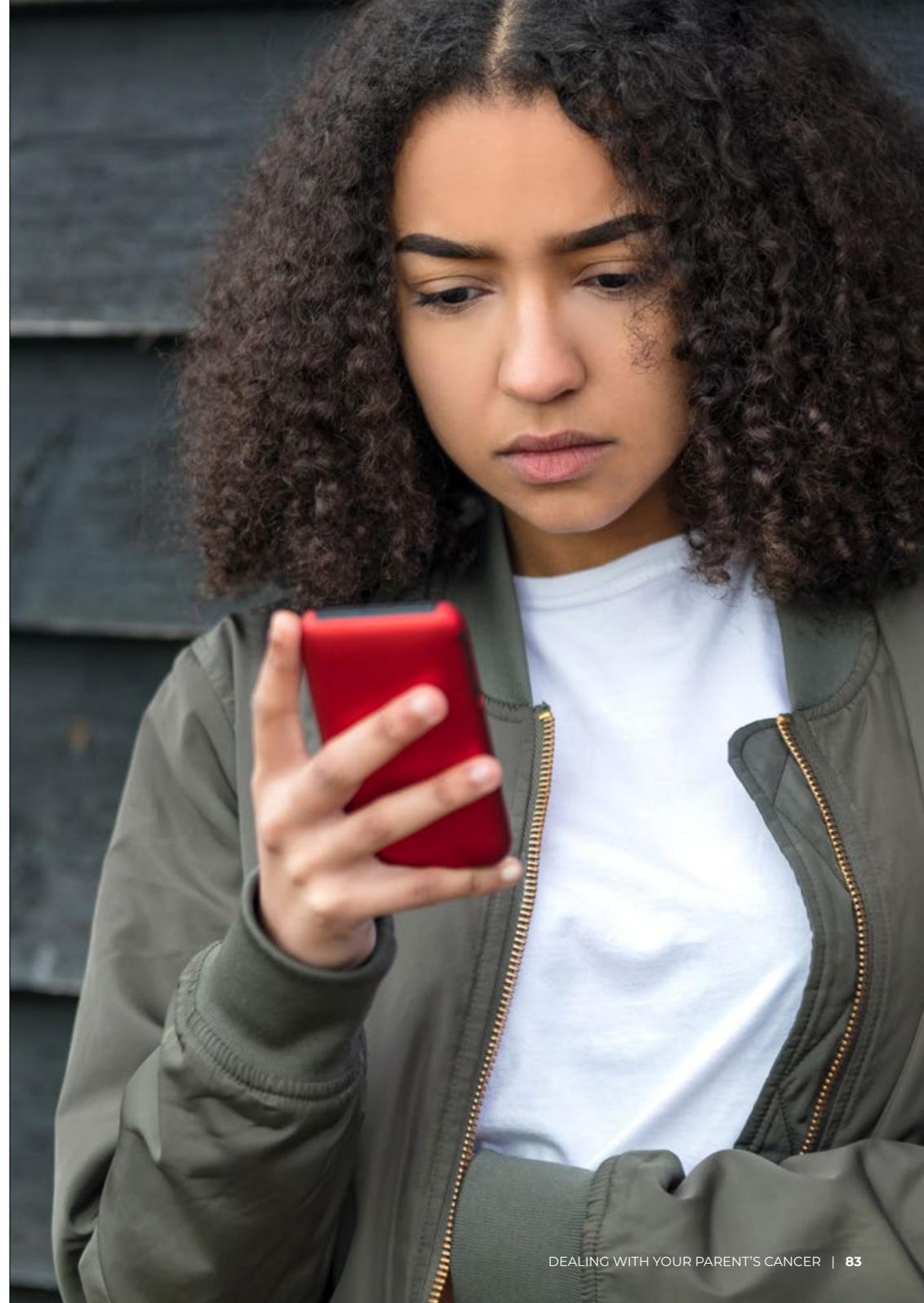
## Funerals

### Australian Funeral

### Directors Association

[afda.org.au](http://afda.org.au)

Use the 'Find a Funeral Director' search to find a funeral director near where you live.



**Funeral Celebrants  
Association Australia**  
[funeralcelebrants.org.au](http://funeralcelebrants.org.au)

Use the 'Find a Celebrant' search to find a funeral celebrant near where you live.

**National Funeral Directors  
Association of Australia**  
[nfa.com.au](http://nfa.com.au)

List of independent funeral directors and information about planning a funeral.

**Legal and financial information**

**Centrelink**  
[servicesaustralia.gov.au](http://servicesaustralia.gov.au)

Offers financial support for people with a long-term illness and their carers.

**Youth Law Australia**  
[yla.org.au](http://yla.org.au)

If you have questions relating to legal matters this website provides lots of answers and also links other legal sites.

**Fair Work Ombudsman**  
[fairwork.gov.au](http://fairwork.gov.au)

Government website with information on National Employment Standards, leave and making complaints.

**Palliative care**

**CareSearch**  
[caresearch.com.au](http://caresearch.com.au)

Australia Government website with resources and information about palliative care and how to find services in your area.

**Palliative Care Australia**  
[palliativecare.org.au](http://palliativecare.org.au)

Information about palliative care services. Includes links to palliative care organisations in your state and provides directories of palliative care services in your area.

**Planning ahead**  
Advance Care Planning Australia  
1800 208 582  
[advancecareplanning.org.au](http://advancecareplanning.org.au)

Information about planning for future health care, including advance care directives.

**Dying to Talk Discussion Starters**  
[palliativecare.au/campaign/discussion-starters](http://palliativecare.au/campaign/discussion-starters)

Palliative Care Australia series of books and cards to encourage people to talk about dying.

**Talk to someone**

<b>Canteen</b>	1800 226 833
<b>Beyond Blue</b>	1300 224 636
<b>Cancer Council</b>	13 11 20
<b>eheadspace</b>	1800 650 890
<b>Kids Helpline</b>	1800 55 1800
<b>Lifeline</b>	13 11 14
<b>Reachout</b>	<a href="http://au.reachout.com">au.reachout.com</a>
<b>Redkite</b>	
<b>Telephone Support</b>	1800 592 410



## ACKNOWLEDGEMENTS

**Dealing with your parent's cancer**

First published 2024. Previously published as two separate titles: Dealing with your parent's cancer and When your parent's cancer can't be cured.

We acknowledge the contribution of young people with cancer, health professionals and the editorial teams who have reviewed previous editions of these two titles.

This book was developed and funded by Canteen, the Australian organisation for young people living with cancer. Free copies of this book are available at [canteen.org.au/resource](http://canteen.org.au/resource). This book is provided free of charge to young people affected by cancer. If you would like to support Canteen's work, please visit [canteen.org.au/donate](http://canteen.org.au/donate).



**Canteen Australia**

**GPO Box 3821,  
Sydney NSW 2000**

**Free call: 1800 226 833**

**ABN: 77 052 040 516**

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