

When your
parent's cancer
can't be cured

Now what?





Hearing the news that your mum or dad's cancer is not going away and that they may have a limited time to live is going to be hard for you and everyone around you.

That's the understatement of the year.

You may find it impossible to believe.

You might feel like you're stuck in a nightmare and will wake up any minute to find out it's not true.

But the sad truth is, cancer can't always be cured. No matter what treatments the doctors have tried or how brave and positive your parent has been, people do die from this disease.

No matter how much preparation you do, you can never be totally ready for something like this. It sucks. You may feel like you have the worst luck in the world. Thinking about life without your parent can be so painful that you may not be able to breathe.

It's not going to be easy. But that doesn't mean that you can't get through this. Many other young

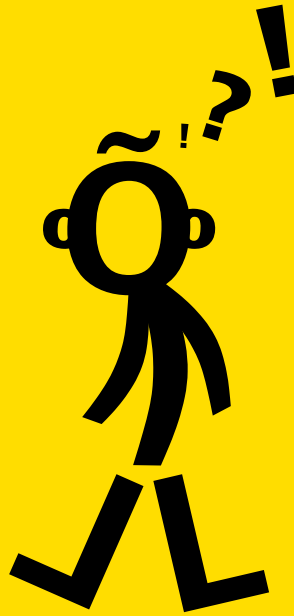
people have been there before and have made it out the other side. We have tracked some of them down and in this book they share their stories with you. Although nothing we say can make what's happening go away, hopefully it will help you to realise that you're not alone.

This book is not an instruction manual on how to feel when your parent is dying. There is no right way to feel and no plan to follow to prepare for something like this. Everyone does it in their own way.

You're not expected to remain calm and composed. Your feelings will change as time passes and different sections of this book will be important to you at different times. So although the pages are numbered, you don't have to read them in order. This book is just something you can dip into when you need to.

You may find reading about these issues for the first time difficult and distressing. Most of us have never talked about 'dying' and 'death' much before.

“ 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** ”



We know this is hard for your parent, but we know that this is really hard for you too. Cancer affects the whole family.

Often “the kids” get forgotten in situations like this. But you have a right to get the information you need and to be included in what's going on. Leaving this book out on the table might be a good way to get the message across to other people in your family that, “Hey, I'm here too!”

This may be a time of massive uncertainty. You may not be sure what's going on, or how long your parent might be around. The most important thing to remember is that you can live while dying. Their illness might shorten their life, but they don't have to stop living until the last breath. This is a book about making the most of that life. They will always be a part of your life after they have died.



There is no easy way to hear that your parent is not going to get better. When you found out, you may have thought, “No, you’re wrong. I don’t believe you!”

Even if your parent has been sick for ages, has no hair and the hospital has become your second home, you may not have expected this. Your parent may have already shown a great amount of strength. Even though they have been really sick before in stages before, they always bounced back. You may have been expecting them to bounce back this time - and find it really hard to accept that there are no treatments left to try.

“

I was very angry and overwhelmed.

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**

”



Doctors make their judgement about the likely outcome of a person's disease (called a "prognosis") based on their knowledge and experience with patients with a similar condition.

When your parent's cancer does not respond to treatment aimed at reducing or controlling it, a doctor may say it is no longer "curable". This means your parent will not get better and it is likely they will die from the cancer at some point.

It is really difficult for a doctor to accurately predict exactly how long they will live. They may give you an estimate, but keep in mind that your parent may live longer, or unfortunately, for less time than the doctor predicts.

A doctor will not give up on your parent. They will always do everything they can to do the right thing for your parent and family. But sometimes, you do have to ask them to tell it to you straight.

It may also have been your parent's decision 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.

What's this 'palliative' thing?



Many people have never heard of palliative care until someone they know needs it.

"Palliative care" is the special kind of care and support provided to people who have an illness that can't be cured.

It is really hard to shift your focus from talking about your parent getting better to talking about them needing palliative care. It can also be really hard to be referred to palliative care and have to start dealing with new people and a new system.

Your family may have developed a really strong and trusting connection with your parent's hospital and feel comfortable with the treatment team there. It is normal to miss them - you have been through a lot together. But it is important to find someone you can talk to openly in the palliative team too. It is often easier if you meet them sooner rather than later. It may also help to talk to a professional counsellor or social worker (whether they are part of the team or not).

But it looks like they are getting better...?

Often when cancer treatments are stopped and palliative care begins, people start to look a bit better. You might find that your mum or dad's hair starts to grow back, they get some colour back in their cheeks and they may even have more energy. If they are looking better than they have for a while, how are you supposed to accept that they are dying?

Cancer treatments can be pretty nasty. There are some quite powerful side effects of treatments such as chemotherapy and radiotherapy that might have left your parent looking quite weak and ill. When these are stopped, the body starts to recuperate. But unfortunately, the cancer will still be there.

Loop

in the

Parents naturally want to protect their children and they may want to shield you away from bad news. You also might feel that you don't want to know what's really happening because the truth would be too hard to deal with and you'd rather try and keep your spirits high.

But cancer is having a huge impact on your life, too, and not being included in what is going on can be even more stressful and scary.

Many young people find that when they understand their parent's diagnosis, treatment and what to expect with changes in their health, they feel more prepared to deal with things as they happen.

“ The hardest part of the experience was being left in the dark about the extent of Mum's health... Mum should have told us or at the very least the doctor should have told us. The children have a right to know the truth about their Mum's wellbeing. Mark ”

When there are gaps in the information you get, you will probably start to fill them in with your own guesses and fears. You might suspect that something is wrong, but often what we imagine is worse than the reality.

“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 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 actually going on.” **Megan**

Even though you might not want to upset your parents by bringing up the tough topics and letting them know you're worried about stuff, most people find that they do feel better when they talk about what is happening.

“ 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 ”

Honesty is really important. Even if you are young, you have a right to know what is happening in your family. And if there is a chance that your mum or dad has a limited time to live, there will probably be things you want to do and say while you still can.

You're walking a fine line

You can never know enough, but sometimes you don't want to know any more.

Andrew

How much you want to know is up to you. Some people want to know all the details and others feel that just the main bits are enough. You might also find that your need for information changes over time. Whatever you choose is OK.

“ 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 ”**

getting answers



If you do want to know more about what's happening with your mum or dad's cancer, you might have to take the lead and just ask. It's never too late to start asking questions. You might have to remind people to be honest and not sugar-coat things.

Here are some examples of questions you might want to ask:

- What type of cancer does my parent have?
- Are there any options for treatment?
- Will my parent get better?

- Have they done everything they can?
- How will my parent be feeling – will there be pain?
- What's a realistic expectation of how long they will live?*
- What will happen when/if she dies?
- What's going to happen to me?
- What about money?

***There's no way to know for sure how long your parent has left. It's very hard for a doctor to predict how quickly someone's disease will progress.**

Advice for others in the same situation:

Have courage, speak up and ask questions.

Andrew

information

When you're feeling stressed and upset, it can be really hard to take in new information. Here are some tips to make things a bit easier:

- Write your questions down
- It's OK to ask the same questions a thousand times if you don't get it the first time
- Write the answers down
- Ask people to use simple words
- Ask where you can get more information
- Don't be embarrassed. You have a right to ask about anything you're worried or curious about. You might have heard the saying "there's no such thing as a stupid question".

"I was pretty puzzled by it.

I was, like, 11. The only thing I knew about cancer was that you lost your hair and that was pretty much it." **Erin**





Who can *answer* my *questions?*

Parents:

Your parents might explain to you what is happening. Some families hold family meetings to keep everyone updated and involved in decisions.

“ My Dad was very open to us about what was going on and very willing to answer any questions honestly. My two sisters and I were very appreciative of this. Lizzie ”

But not all families are good at having conversations like this. There are other places you can go for information.

Doctors and nurses:

You could ask your mum or dad if you can go with them to their appointments. It can help if you are just there to hear what's going on. But you are allowed to ask the doctor questions too if you like.

“I didn't really know what was going on...”

I don't think I saw a single doctor the whole time Dad was sick”. **Brooke**

Social workers:

You might have the opportunity to see a social worker provided through the hospital, through your GP or the community. They can help you talk through the things you are worried about, show you how to find more information, organise family meetings with the medical team and tell you about community organisations and service that might be able to help you.

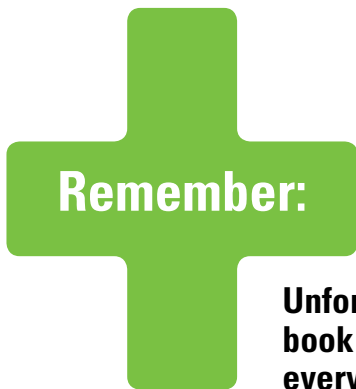
School:

There may be a school counsellor or school nurse who can answer some of your questions – medical or emotional. The librarian may also be able to help you find information or support in books, magazines, videos or online.

The Internet:

The Internet is an amazing place to go for answers. But, as you probably already know, it's also full of a lot of weird and wrong information. Here are some tips to make your Googling a bit more successful:

- **Don't believe it all.** When your parent has cancer you're open to all sorts of miracle cures and treatments. But it's a good idea to check any claims made with your parents or their doctor.
- **Make sure you're searching the right stuff.** There are over 100 different types of cancer. The likely outcomes are different for every cancer and different for every single person. Google is not a doctor; it can't tell you how long your parent is going to live.
- **Always check the source of the information.** Look at who is behind the website and where their info is coming from. A lot of stuff on the internet is out of date, inaccurate or may be just trying to sell you something.
- **Use the web as a starting point.** You could use the information you look up to start a conversation with your Mum or Dad. You might even be better at searching than they are and come up with some questions they haven't thought of yet.
- **Use websites you can trust.** There are heaps of recommended websites that provide information about cancer, palliative care and where to get help listed in the back of this book.



Unfortunately, there is no person, book or website that can tell you how everything is going to work out. Cancer is different for every single person.

it's OK to feel

Realising that your mum or dad's cancer is not going away and that they might not recover will probably be one of the hardest things that you will ever have to deal with. Even if they have been sick for a while, nothing can fully prepare you for this ride on the emotional rollercoaster.

Your feelings might overwhelm you suddenly when you least expect it, or they might be a constant nagging weight that never seem to go away.

“ Your head is all over the place and half the time you're not really sure how you feel. Scott ”

The truth is, there's no right way or wrong way to feel. Feelings will come and go and you will have good days and bad days.

This is not going to be easy. But it might provide some comfort to know that whatever you're feeling right now, it has a name - and it's normal.

“ I was like an emotional cyclone
I felt a huge build up of anger and on top of that was the grief.
Lisa
”

Here are some things that other young people have described...

- **Shock/Disbelief** – This is when you can't believe that this is really happening. It doesn't feel real, like you're stuck in a dream (nightmare is a better word!).
- **Denial** – Sometimes it might feel easiest to pretend that everything's normal. It is a really hard thing to accept that your parent is not going to be around forever.

“ I ignored it all! I didn't talk about it, I carried on like nothing had happened and I was fine. Melissa ”

- **Empty/Numb** – There may be times when you just feel nothing. This doesn't mean that you don't care – it might just be your way of protecting yourself.

“ **A lot of the time I felt numb, I couldn't feel because the pain was too much. I switched off and escaped with food or TV.... there was a big hole inside me that nothing could fill. Lizzie** ”

- **Guilt** – It's common to get the guilts big time when your parent has cancer. You might feel guilty that you're not helping enough, or for complaining about the extra work you have to do. You might feel guilty that that you are still going out and having fun with your friends. You might feel like you should be crying more. Or be thinking about all of the fights and nasty things you've said or thought about your parent. You feel guilty for misbehaving, or even for wishing that all of this would just hurry up and be over.... But it's normal to feel guilty. All of these are normal reactions to painful feelings. Remember that it's not your fault that any of this is happening.
- **Regret** – Try to avoid the 'coulda, woulda, shouldas' – it's hard to dwell on the things that you could have done differently. Instead, try letting yourself off the hook. You can't change the past.
- **Fear** – No matter how brave or grown up you are, thinking about life without your parent is scary stuff! You may be afraid of the unknown, of being alone, or worried about what will happen to you. You might be afraid of your parent getting sicker or

“Dad always treated cancer as it was a person so that we were able to be angry at the cancer and not at Dad for being sick”. **Amy**

that they will be in pain. Admitting you're afraid is usually the first step towards dealing with it. The next step is finding someone to tell how frightened you are.

- **Anger** – What is happening is so unfair and you have a right to be mad! Anger is a normal reaction to situations out of our control but sometimes we can direct anger at the people we are closest to, or it can build up and release itself in harmful ways. Try to find positive ways to release your rage. There are some ideas on page 18.
- **Jealousy** – You might feel jealous that your friends can still go out and have fun, or that they have healthy parents and “normal” lives. You might also feel jealous of your sick parent, who may be getting all of everyone's attention while you are left to look after yourself.

“ **It's really important not to get caught up in jealousy. It almost consumes you. Lisa** ”

- **Sad** – Thinking about your future without your mum or dad in it can be desperately, heartbreakingly sad. It may be hard to imagine right now, but sadness will come and go and things will not always feel so hard.
- **Withdrawal** – There may be times when you feel really down and just want to be left on your own.

“ I sheltered myself away from the world and didn't want to deal with anything or anyone. Lizzie ”

- **Lonely** – Even if you are surrounded by people, you might feel like no one really gets it - not even your brothers and sisters or closest friends. Or you might feel a bit abandoned and left out of what is happening because your parents are always stressed and focusing on other things.
- **Worried** – You may be stressed about heaps of stuff! What will happen to me? Will I get cancer? Will my parent be in pain? Do we have enough money? What about school? Getting answers to your questions and knowing what to expect can really help – so it helps to let people know what you're anxious about.
- **Embarrassed** – Having a parent who is really sick can make you feel different and that can be hard to handle. At times you might just wish things were “normal”.

- **Confused about your identity** – You might start to feel like your identity is defined by cancer and that everyone just knows you as “the girl/guy whose parent has cancer”. It's OK to want a bit more independence, but it can be hard to find a balance. Sometimes you might feel all grown up – taking on heaps of responsibility and dealing with big serious issues. But other times you might wish you could be protected like a little kid again.

“ Everyone kept saying, “You're 18, you're an adult now” ... but I wish people treated me like the child I was. I wasn't ready for everything I was faced with. Lizzie ”

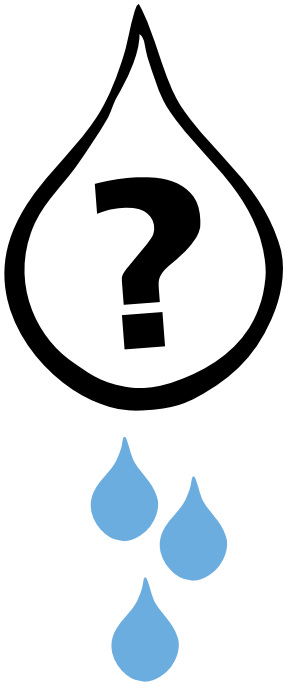
- **Hope** – You might think (or people might be telling you) that you should “think positively”. It can help to be optimistic, but you are not expected to feel happy and hopeful all the time. You might need to redefine what hope means. It's even OK to hope that all of this will soon be over.

“ Things like having hope that they will not be in pain or that you will get to finish the memory box with them are all perfectly OK things to feel hopeful about. Rebecca ”



However you feel, many other young people in your situation have felt the same way.

What's GRIEF



We often only think about grief as something we feel after someone dies. But actually, grief is the normal reaction we feel in response to any kind of loss.

You have probably already experienced many losses since your parent was diagnosed with cancer. You may have lost your normal life, or lost contact with some of your old friends, or missed out on an opportunity to go on a planned holiday. Any of these losses can be really upsetting and it can feel like your life will never be the same.

It's also possible to feel grief when you know you are about to lose something that is important to you, before it happens. This is called "anticipatory grief" and often happens when someone you love is expected to die.

Waiting for the death to happen - and knowing you are helpless to stop it - can be just as overwhelming and painful as after the death has occurred. It can be a really confusing time, with many mixed feelings and you might not be sure how you're supposed to act.

Maybe you think that everyone, including you, should be sad and crying all the time and that there will be no smiles or laughter.

But this isn't the case. It's not all black and depressing, there will be good days and bad days. It's OK to make the most of the good days and still have a bit of fun sometimes.

Everyone in your family is experiencing their own feelings of loss and grief, but they may be showing it in different ways. They may also be trying to hide it. You might find it really scary or upsetting to see your parents so stressed. And you might miss the way things used to be. But grief is normal and things will eventually settle down.

As much as it may not feel like it now, the world in fact doesn't end and you do survive it – somehow. Life won't be the same, but there will still be life.



**“I'd see beauty in the world,
but also the bad stuff.**

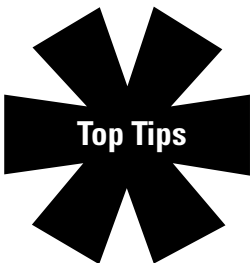
You go back, you go forward. It sucks, but there's no right way.” **Andrew**



“ One thing I wish I'd known at the start was that normality does start to come back into your life. Lisa ”

It can be important that you try to understand and get a handle on your grief so that you have the energy to make the most of your time with your parent and say the things you need to say.

“ I would tell someone else in my situation to relax and ask for help wherever you can. You need to have more understanding for yourself and remember its just one rough patch. This isn't your whole life and you just need to get through this one bit, there is so much good ahead. Lizzie ”



Top Tips

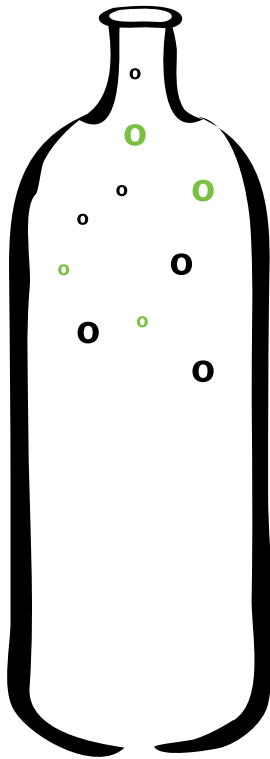
Find someone who is *easy* to talk to and tell them about your worries and fears. When your feelings are out in the open, you don't need to hold onto them.

Letting it out.

“ Sometimes if it was too much I would have some time out listening to music or doing some art and sometimes I just had to get out of the house and go to my friend’s house. Amy ”

When you are living with the stress of cancer in your life, it’s really important that you find a way to let your feelings out and take your mind off the situation. You might be tempted to keep your emotions inside so that you don’t cause everyone else around you extra stress by seeing how worried you are.

But bottling your feelings up doesn’t make them go away. In fact, they will probably only grow stronger. Being worried and frightened all the time can make your mind foggy and your body tense and tired. This makes it even harder to manage through this difficult time.



Managing your strong feelings won’t be quick and easy, but it is definitely possible. Sometimes it may not feel like it, but you WILL get through this.

There are heaps of things you can do to give yourself a bit of an outlet and help you feel more in control of your feelings.

Everyone deals with stuff in different ways. You might have already tried some of these things and find they didn’t work. Keep trying, you will find something that helps you feel better.

“ Take time to do things that relax you.

For me it was playing guitar. Even just getting away for 5 minutes to have your own space and clear your head. Peta ”



Here are some ideas:

- **Talk about it.** Putting your feelings into words can make them seem more manageable. Don't try to deal with this on your own. It doesn't have to be someone from your family or friends, it can be anyone. It may really help to see a professional, like a counsellor or social worker who understands a lot about grief and loss.
- **Listen to music.** Choose a song that describes how you are feeling, turn it up and have a good sing, a yell or a cry. You can also use music to change how you are feeling. Listen to songs that make you feel relaxed and happy. You could also write your own songs or change a few words to a song you like to express how you feel.
- **Cry.** Give in to the waterworks; it can be a big relief.
- **Exercise.** Exercise can release the "feel good" hormones in your body. Make a playlist for your iPod and go for a walk or run. Even some simple stretches can help. When things are getting crazy at home, it can help if you keep doing your normal activities, like sport or dancing.
- **Take a long shower.** Sing, cry or scream while you're in there.
- **Get creative.** No one's expecting a masterpiece, but getting arty can be really relaxing. You could try drawing, painting, photography, scrapbooking, collage or digital art. Getting started is often the hardest part. You could try to show how you are feeling now, or your favourite memory with your parent. Or nothing related to anything at all. Just draw the cat.



"Cry if you want to.

Don't worry about what people think, they'll deal." **Erin**



- **Learn something new.** Ever wanted to try the guitar? Salsa dancing? Yoga? Learning a new skill can help you take your mind off things.
- **Write stuff down.** A long ramble in a journal or blog might be just what you need. You could also write poems, stories or letters to your parents.
- **Read, watch, play.** It's OK to zone out sometimes with TV, movies, books, radio, magazines, board games or computer games.

“ 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 ”

- **Take a break from it all.** Go out with your friends and have a laugh and talk about different things. You're still allowed to enjoy yourself. Don't feel guilty for wanting your own life.
- **If you're religious, pray.**
- **Punch a pillow.** Or chuck a tantrum on your bed. You have a right to be p*ssed off, but it's best not to take it out on other people.
- **Meditate.** Even just taking one minute a few times a day to breathe deeply can release some of the stress and fear from your body. Find a quiet place, sit comfortably and just focus on your breath. If your mind starts to wonder, just keep bringing your thoughts back to your breath until that is all you are thinking about.
- **Set goals.** It can help to have things to look forward to. You don't have to dream up where you'll be when you're 65, you could just think about what you'd like to achieve by the end of the month or year. It could be things about your family or relationships, jobs or education. Think about why you want to achieve something and then write down an achievable action you will do to make sure you get there.
- **Get a bit philosophical.** It might sound a bit funny at first, but taking time out to ponder the 'big picture' might help you get your head around things.

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Escaping into novels was good for a while.

I used to drive out to the beach and just sit there and cry or pray, it was calming and so beautiful there. Sarah ”

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Try this activity:



Three things:

I wish weren't in my life anymore:

- 1. _____
- 2. _____
- 3. _____

I really like and appreciate about my life:

- 1. _____
- 2. _____
- 3. _____

I would like to have in my life that I don't have now:

- 1. _____
- 2. _____
- 3. _____

I can do or change to make things in my life better:

- 1. _____
- 2. _____
- 3. _____

One word or sentence:

To describe you before your parent had cancer:

To describe you now:

To describe cancer:

when it's all too much



“ I had a lot of trouble with my feelings. It was all about Dad at home.

But I was getting ill myself, I was on anti-depressants and I binge ate as a way of coping. This was especially distressing to me because I was enthusiastic about health and fitness, but when I tried to stop I would be overwhelmed by a bombardment of emotion. Lizzie

”

Sometimes, feelings can be so strong, confusing and out of control that you just don't feel like you are coping at all.

It doesn't mean that you are weak, crazy or flawed if things are getting on top of you and you want to escape from it all. This happens to everyone from time to time.

You might feel like you can't say that you're not coping because you feel you have to be strong for your parent. But your feelings are important too.

If you can recognise the warning signs that things are becoming too much, there are things you can do to help you feel better.

Signs you're not coping...

- **Behaving badly** – Throwing tantrums, swearing and talking back to your parents, running away or skipping school can all be ways to hide how hurt and afraid you are. Acting out can also get you a bit of attention when everyone's so focused on cancer that you feel abandoned. Things might feel so hard right now that you just want to act like a little kid again. This is a normal reaction to stress. But everyone is feeling pretty strained right now, so it might help if you let people know when you are in a bad mood so they don't take your outbursts personally.

- **Using drugs or alcohol** – This might seem like a good way to block out the hard feelings. But it really is only a short-term escape and can actually make the stresses of your parent's illness even harder to handle. When you're drunk or high you can say or do things you don't really mean – and sometimes don't even remember. You might look back with regret one day if you spend the time you do have left with your parent in a bit of a haze.

- **Hurting yourself and others** – It's normal to feel angry when your parent has cancer. But there are safe ways to vent it and using violence or deliberately hurting yourself can cause you and your relationships permanent damage.

I went cuckoo. I ran away.

I was bitchy, like a brat. I thought, I'll do what I want!

Erin

- **Using dating and sex to get close to people and ease the pain** – While it's OK to have relationships, hooking up with people before you are ready or with more than one person can put you at risk, both emotionally and physically.

“ I started dating any boy that would go out with me in attempt to fill this big hole that Dad had left. I felt I needed a supportive male in my life. At this time I pushed away all my female friends and focused all my attention on boyfriends. Melissa ”

- **Withdrawal** – You will need some time to yourself every now and again. But you should not try to go through this alone. Your worries and wonders can grow into big fears when you shut yourself off from others altogether.



- **Depression** - You will feel sad and down when your parent is approaching end-of-life. But if the sad feeling goes on for a long time or hurts so deeply that it's hard for you to enjoy anything at all, you might be "depressed".

Signs of depression include feeling miserable, tired and crying all the time; changes to how much you sleep and eat; losing interest in the things you used to like; and feeling hopeless or like you will never be happy again.

Depression is very common. It is nothing to feel guilty or ashamed of.

It is not permanent, but it is not something that you can just "snap out of" either. It is really important to tell someone about it. You will probably have to work at it before it will get better. Trying to get active and do things you enjoy will help you to reduce your depression.

There is no easy way to go through this. Be kind to yourself let yourself make mistakes. Don't punish yourself for your behaviour when you are stressed. No one is perfect in these situations.

"I would tell someone else in my situation to relax and ask for help wherever you can.

Because I had lived with the situation for a while, I started to forget it was unique and be hard on myself for not coping... You need to have more *understanding for yourself* and remember this isn't your while life and you just need to get through this one bit, there is so much good ahead." **Lizzie**

it's crazy at



**It was stressful at home.
Everyone was uptight, upset.**

We all had to pull together and not complain that we had to do the housework. You just do it.

Peta

Cancer can mess with all parts of your life and really change things at home. Your routines will probably change, your relationships might become more strained - or your family might be drawn closer together.

In the later stage of a serious illness, you might feel like your normal life has been stolen from you. You might have to take on a lot more responsibilities and not get to do your usual activities as much. There might be a crowd of people around wanting to help out. Maybe it's been a while since you had a home-cooked meal.

“At home, because our Mum didn’t live with us, the house cleaning and maintenance was up to us.

The house was always very messy. We had to help out with things, like making Dad’s breakfast and giving him morning and evening pills. I wasn’t very efficient, tended to forget his coffee, drop things, bring things in cold.” **Lizzie**

“ I was only eight and I had a great amount of responsibility. For example, I made myself dinner, I had to get myself to bed, and sometimes Mum got so tired I got up and had to help my Dad. Belinda ”

Even if you’ve been living with cancer for a while, most of us find it really hard to deal with such massive changes in our lives. It’s a normal reaction to resent what is happening and it may take a while to get used to the new situation. Eventually, things will settle down and your family will adjust and start to establish new routines and plans for the future. Things may not go back to exactly the way they were before, but it may begin to feel like a new kind of “normal”.

Some of these things might start to sound familiar:

You have to take on extra responsibilities.

You might have to pick up more chores at home, like cleaning, cooking or looking after younger brothers and sisters. You may also be expected to help with your parent’s care.

Most of the time you might not mind and you probably just get on with it. But it’s OK to wish that sometimes you could just go out and do normal fun things.

“ I had to take on a lot of responsibilities around the house, in particular tasks like mowing the lawn and others that usually a Dad would do around the house. Also helping Mum with such tasks as washing, cleaning, ironing, etc. It was really hard as I was only 16 and none of my friends had these responsibilities, so *I did feel a bit hard-done by!* I have now grown up and realised that by helping Mum with these little things while she is at work will allow her to spend more time with us when she is at home and prevent her from becoming too stressed. Amy ”

“

I had to be careful around Dad cos he had gotten so weak.

I was used to my big strong Dad mucking around playfighting with us, but that couldn't happen. **Eloise**

”

Your relationship with your unwell parent changes.

You may find that it becomes difficult to be around your parent as their illness progresses. It can be scary to see them become so weak or in pain and you might prefer to stay away. Or there may be changes to their energy levels or behaviour and they may find it harder to interact with you. You may feel particularly lonely or sad if they are your only parent.

Your relationship with your other parent changes.

Like you, they are probably experiencing a whole range of difficult and confusing emotions. They will be worried about your sick parent as well as stressing about you and your siblings, the bills, work and what will happen in the future. They might not be around as much and even when they are they may seem tired, distracted and always focused on other things.

If you are starting to feel really lonely or neglected at home, you could ask if you could spend some time with another relative or family friend once in a while.

“ **Mum had to start working fulltime. As she hadn't worked since before I was born, it was very difficult for her at first. It was also very difficult for my brother and I as we had always had at least one parent at home to welcome us after school. Mum would not get home from work for another 3 hours.**

Things just didn't feel right. **Melissa** ”

“ **It was lonely, since Dad and Mum were at the hospice most of the time.**

Sarah

”

“I think our family kind of became happier. It sounds so cheesy, but everything happens for a reason.

All the good things that happened after to this were a response to the bad...I really think everyone in my family are better people now.” Erin

Your relationships with siblings change.

If you have brother or sisters, they might be a really important source of support. They are going through this too and may be the only ones who really get how hard it is. But if you never got along well with your siblings, the stresses of cancer may not change that. Everyone in your family will deal with stress and fear in different ways and you may need a truckload of patience to prevent you from losing your cool.

Roles in the family might change, too. Older siblings might start becoming really bossy and protective, which can be frustrating. Or younger siblings might look up to you to look after them while your parents are distracted and you might resent having to be the strong one all the time. You may almost feel like you have become the parent.

If you are having a really hard time dealing with the changes at home, it's important to talk about it with someone. A counsellor or social worker can give you lots of advice. There are contacts in the back of this book of people and places to go for help.

Your family is drawn closer.

A crisis can really bring people together and make them realise what is important. Many young people appreciate the extra time they spend with their family in the end stages of their parent's illness and find that relationships became stronger as they take on dying together.

But every family is different and don't think you're doing anything wrong if it doesn't happen in yours.

You get an army of visitors.

Lots of family and friends might stop by to help with the housework or cook you meals. You know they are just trying to help, but sometimes you might wish you had your privacy back and more time alone with your parent, particularly if you don't know the helpers very well. (They may be really important people to your parents, however, even if you don't know them.)

“ I thought - you don't have the right to be here. You weren't there through the big life-changing journey. Andrew ”

You miss out on doing your normal things.

Everything might be about looking after your parent and your normal activities might not seem so important any more. Or there just might not be the time.

“ We had to be flexible with commitments because of Dad's doctor's appointments and trips to the hospital. Sometimes we had to go to friends or families at strange times because Dad would need to go to hospital. Sometimes we couldn't go out because Dad wasn't working and we didn't have much money. Amy ”

It might seem like your life has been turned upside down and things will never settle down. But, eventually, they will.

Many families find that maintaining as normal a routine as possible can help everyone deal with the changes that will happen as your parent approaches end of life.

This is obviously a really, really hard time for everyone, so try to work together and remember that it's normal to stuff up sometimes. Everyone will be doing their best in a very difficult situation.

“ Once my parent became ill, I wasn't allowed to invite friends around. I also felt scared to expose my friends to the full extent of what was going on at home. I was too *scared to* introduce my friends to my Mum who had no hair. Chris ”

Everyone turned up but I didn't really know anyone.

There were so many randoms. Amar

SCHOOL + WORK + other STUFF

School

For some young people, school might be a welcome relief. It can be a place where you can go and see your friends, do normal things and forget about cancer for a while.

But for others, going to school when your parent is sick or dying can cause a lot of stress.

When you're back and forth to the hospital, taking on more responsibilities around the house and helping to

look after your parent, you might find it hard to find the time or energy for school.

It can also be really hard to concentrate when everything's so hectic. You may miss a lot of classes, slacken off on your homework and start to fall a bit behind.

You might worry about being away from your mum or dad and find that school just doesn't seem that important right now.

“ I avoided school because I didn't really care about it and my mind was elsewhere. I was facing horrible stress, my hair was falling out and I had terrible dandruff, I was breaking out in heaps of pimples and I gained a lot of weight. This did not help me to want to go to school. Laura ”

“At school I wasn't trying, I didn't care, didn't hand in any work.

It's important for teachers to know. It takes the pressure off. They do understand and will give you more time.” **Peta**

“My teacher told me that if I felt that I needed to spend the day with Dad not to feel bad about missing school.

They said it was easy to catch up on school work but not to make new memories.” Amy

Tips to stay afloat:

- Let your teachers know what’s happening at home. How much you decide to tell them is up to you. But you will probably find that they do understand and will try to make things a bit easier for you. They might be able to give you more time for your assignments or let you have time off when you need it.
- Try to get as much done at school as you can, so you don’t have to bring work home.
- Talk to your teachers or a counsellor if you’re being bullied or your marks are starting to suffer.

“ The workload seemed a bit heavy at the time, but the teachers were extremely sympathetic and were willing to be lenient when I needed it. Megan ”

- Try not to stress about your school work. It can wait, if necessary, until things settle down again.

“ My teachers were very understanding because I was able to openly let them know what was going on. Sitting my final year exams I got some allowance for my circumstances and got more lenient marking because I had lost sleep and focus due to living with and worrying over my Dad. Lizzie ”

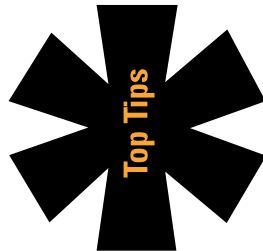
Work

What you tell your boss or work mates about your parent's cancer is completely up to you. There is no law that says they need to know. However, you might find that if you do they will be supportive and understanding, especially if you have to take time off or are just having a bad day.

Just before and after your parent dies you'll probably want quite a bit of time off. You have the right to take time off work, but you should check with your manager about exactly how much.

Most people know you can take paid sick leave (unless you are a casual). But you may not know that you can also take paid carer's leave if you have to look after a family member who is sick, or paid compassionate leave if a family member dies, or is about to die. The Australian government website, www.fairwork.gov.au can tell you all about your rights at work.

Check out the website, www.fairwork.gov.au to learn about your rights at work.



Getting help and support

There are lots of organisations, government agencies and charities out there offering things like financial assistance, carer support, student services, legal advice and medical information. Almost all of these services are FREE and they WANT to help you. Don't be afraid to use them, that's what they're there for.

See the contacts listed in the back of this book to find them.



“ I was lucky as a lot of my friends are like extended family as I have known them since I was little and they felt like they were going through it too. We laughed together, we cried together and when I was feeling down, they would boost me back up again. **Samantha ”**

Some friends are great at being there for you and holding you up when your feelings come and hit you like a bus.

But sometimes, friends don't really know how to handle what is going on. They might stop calling you or inviting you out and it can feel like they're not there for you when you need them.

“ I couldn't talk about it. You bring it up once and they say "I'm sorry" and that's it. It was too awkward. I felt I would be there for them if something happened but they weren't there for me. **Amar ”**

“True friends
are the ones who *don't bail*
when it's getting hard.” **Peta**



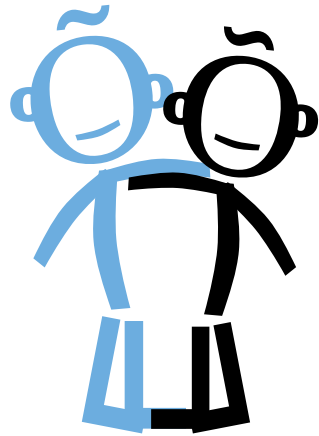
You find out who your true friends are.

Ignoring it is not good enough for your best friend. **Erin**



A lot of friends don't really understand the whole cancer thing and don't know what it's like to have a parent who is sick or dying. But even when you know this, you might feel really hurt and let down when your friends aren't very supportive.

You might also find that you have less in common with your friends now. You are going through some massive changes in your life and you might find you are not as interested in what your friends talk about anymore. You might feel a bit jealous that your friends still have "normal" lives and think they sound a bit trivial and ungrateful sometimes.



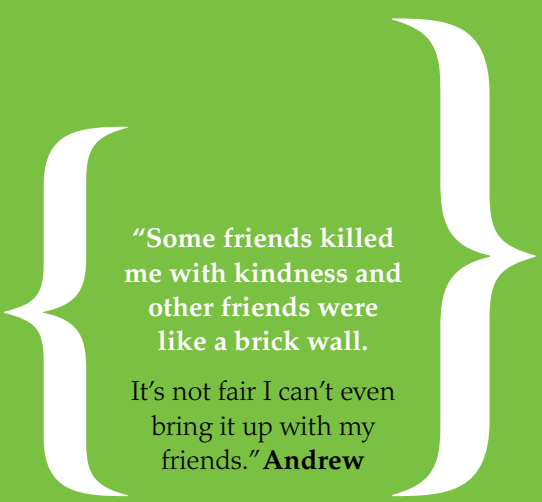
"My school friends just p*ssed me off.

They'd be like, 'Oh my mum made me such a crap sandwich today'." **Steph**

But if your friends are staying away, it doesn't necessarily mean they don't care. They might be trying to avoid upsetting you.

Here are some things to think about...

- Friends might be worried about saying the wrong thing, so they say nothing.
- They don't know if it's OK to mention cancer or your parent. You might have to start the ball rolling.
- They are worried about imposing on your family time so are shy to call or visit.
- They think their lives are boring and unimportant compared to yours and don't know if they should talk about normal things.
- This is new territory for your friends. Before you had this experience you might have acted the same way.
- They won't say things that deliberately upset you. Sometimes they might say things that annoy you or make you angry. But try not to be offended, they just don't understand.
- Friends may change. You might find that you lose some friendship along the way as you and your friends start to have different perspectives on life. But this may have happened anyway, cancer or no cancer.



“Some friends killed me with kindness and other friends were like a brick wall.

It's not fair I can't even bring it up with my friends.” **Andrew**

Staying in touch

Try to stay in touch with your friends. Let them know that even if you can't always go out, you still like to be invited to things. It's important to have some fun and take your mind off things sometimes.

Be as open as you can with your friends. If you don't feel like telling the same story a hundred times, you could just keep everyone updated on what's going on with your Mum or Dad through Facebook or MySpace or group emails or texts.

Knowing there was someone else there who's lost their Dad helped me get through the worst of the days.

Andrew

Making new friends

So many other people say that the best kind of support comes from meeting and talking to other young people who have 'been there and done that' and really know what it's like.

There are support groups out there – like CanTeen – that bring together people your age who also have a parent with cancer, or who has died from cancer.

It can really help to connect with people who are going through the same thing and having similar feelings to yours. You can compare battle scars and give each other tips, or just hang out and have a break from it all. It can be a big relief to realise you are not the only young person who has a parent with cancer – and to hear how other people deal. CanTeen organises free camps and day activities that you can go on to get support and just have fun.

You can also read real-life stories from other young people, share your own, or chat to 'experts' on websites like www.nowwhat.org.au or www.youngcarers.net.au.

“ I had become a bit isolated, so coming into CanTeen was a good help, having the opportunity to get away from things and talk about it.

To see other young people whose parents had died and see how normal they still seemed. **Lizzie**

”

Tips for friends

Your friends probably really want to help you but don't know how. Maybe you could give them some suggestions, like....

- Just give me a hug.
- Just listen and be there for me.
- Let me cry. You can cry with me.
- Let me rant and vent.
- Talk about my parent. Use their name. They exist and they are important to me.
- Don't focus on cancer, but don't ignore it either.
- We can still laugh and have fun. I need to be distracted sometimes.
- Invite me over or to the movies. If I say no, ask me again another time.
- Treat me like normal. I'm still the same person.
- Ask me how I'm doing, not just how my parent is doing.
- Write me a card. Not just a generic one, but one that says what you really want to say.
- Check up with me regularly. Don't smother me, but just be there.
- I know it's hard to talk about, but don't abandon me just cos it's easier.
- You can help me by

.....

The most helpful things people said was not, "Call me if you need me". It was nice, but I didn't want to inconvenience anyone who had family and jobs of their own.

The best thing was people offering specific things at specific times; "Shall I come over this Saturday and help clean up a little?" or "Do you want me to cook dinner for you this Wednesday?" Lizzie

DUMB things people say



When you have a parent who is really sick or dying, you might find people say the most unhelpful things.

Some people feel the need to say something, even if they don't have the right words to express themselves. Some of the old clichés might hurt, some of them might make you angry.

Here are some of our favourites (not!) and the answers that you probably wish you could shout.

"I know how you feel"

No, you don't! You haven't been through this – and you're not me!

"They can do amazing things these days, he'll be fine"

You don't know that.

"I'm so sorry"

But you didn't do anything!

"I understand, my dog died last year."

It's so not the same!

"Stay positive. My neighbour was given a week to live and she was still here fifty years later."

Good for them, I only care about my mum/dad right now!

"Life goes on"

Yes, life may go on, but for me losing my mum/dad is not something I'm going to get over!

“It could be worse. Think of the children in Third World countries that have to go out and work 15 hours a day.”

But my mum is dying here! I deserve to complain and feel bad sometimes.

“You are so inspiring.”

I’m barely coping. Do you expect me to be able to save the world now or something?

“It’s God’s will.”

How do you know I believe in God? And why would God want them to die, anyway?

“Everyone dies. Get over it.”

So you’d be over it by now if it was your parent? Yeah right!

“It will be over soon and you can start a new chapter.”

So I should just forget my parent and move on?

“You’re lucky you had them for this long at least.”

I would trade anything to have more years. Is that supposed to make me feel better?

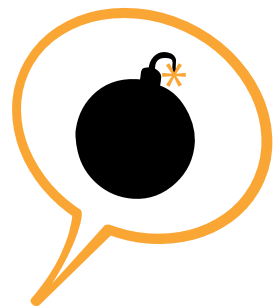
“You’ll see them again in a special place.”

You’re assuming I believe in heaven.

You probably don’t want people to look at you with puppy dog eyes and say, “It’s going to be OK”. But you don’t want people to tip-toe around and ignore it’s happening either.

What can you do?

- You could ignore it.
- Say, “Hey, my mum/dad has cancer. How would you feel if it was your mum/dad?”
- Try to remember they probably mean well and are just trying to help. But no one teaches this stuff. Most people don’t have much experience talking about cancer or dying. Their words might not quite come out right, but they don’t mean to cause offence.
- If people are being mean on purpose, tell someone about it. A teacher or counsellor could help you if you are being bullied.
- Give them the “Just one thing” card at the back of this book to give them an idea about how to help you.



The sad truth is, there is really nothing anyone can say that will make this better, no magic words that will take away the pain.

TALKING about it

“If you’re upset, you can tell someone.

You don’t have to be strong. It’s not your job to hold the family together.” **Eloise**

It can be really hard to let people know you are struggling. You might not be able to find the right words, or feel embarrassed or scared of looking like a whinger or getting upset.

But heaps of young people say that talking things out can be a big relief. It can help to put things into perspective and sort things out in your head. It can also help you feel less alone.

Your first step in getting support is admitting that you need it. The second step is finding the right person.

The right support person will be easy to talk to. They will listen and not judge or make you feel ashamed for anything you are feeling.

So where do you find someone like that? It can feel like there are people all around you, but no one who really gets it.

Family

Everyone in your family is going through this too. If you don’t feel you can talk to your sick parent, you may be able to turn to your other parent or your brothers or sisters. Your aunts, uncles, grandparents and cousins can also offer great support. They are probably sharing many of your fears and you can make decisions together.

Other people

You might be lucky and have some great friends who know how to provide you the support you need. But if they’re not great at being there for you, you might be able to turn to a teacher at school and let them know what’s bothering you. Community and religious leaders, like priests, pastors, rabbis, imams or elders are also experienced in supporting people and offering advice.

“ Even if you are feeling alone, there is always someone there. You just have to find that special person that you feel *comfortable* sharing with. It may take time to find them but if you are patient it will be worthwhile. Melissa ”

Your local doctor

Doctors don't only treat physical problems, but can also help in offering you support. They might have also known your family for a while and understand what's happening for you. If you are over 14, you don't need your parent's permission to see a doctor.

Palliative care team

If your parent is receiving palliative care, the team is there to provide emotional and practical support for the family and carers, too. Don't be afraid to talk to them about anything that is bothering you. They will be very happy to answer any questions you have about all kinds of stuff, not just medical questions.

Counsellor or social worker

These are professionals who have been trained to give emotional and practical support to people who are going through tough times. They can help you find solutions to problems and find ways to cope with the different parts of your life. They can also help your family to make decisions together if you are not so great at communicating right now.

The Australian organisation, CanTeen runs a free counselling service especially for young people aged 12-24 who have a parent who has cancer, or has died from cancer. Email support@canteen.org.au or call 1800 CANTEEN for more information.

You can ask them about anything that you are worried or wondering about and they will keep it confidential. Lots of counsellors and social workers have particular experience working with families living through cancer, so they will really understand what you're going through. If you prefer, you can often talk to counsellors on the phone or by email, too.

Other places you can find a counsellor

- There may be a counsellor at school or uni you can go to.
- Ask your local doctor to organise one for you.
- Your parent's hospital might offer counselling services to family members. Ask the nurses or palliative care team about this.
- Look up "Community Health Services" or "Family Counselling" in the Yellow Pages to find a service near you.
- The Cancer Council Helpline can also provide support and information. Call 13 11 20.

Usually you need to make an appointment to see a counsellor. If you need to talk to someone right now, you can call Kids Helpline on 1800 55 1800 or Lifeline on 13 11 14.

It might take you a couple of tries to find the right counsellor for you. If you don't feel comfortable with your counsellor, or if you feel that they are not listening to you, try a different one. You will eventually find someone that you click with.

“About counsellors; go to a couple, try before you buy, shop around and find one that suits you. Andrew”

“It helps to talk. You don’t have to keep it all inside.

People care, they want to listen. If you don’t have anyone like that, there are people out there, like CanTeen.” **Eloise**

Support groups

There are organisations that bring together people with similar experiences so you can talk about things with people who really, truly understand – or just take some time to chill out and have fun.

Sometimes you talk about cancer in these groups and share stories and tips for coping with each other and with professionals. Other times you just hang out and make new friends with people who get what you’re going through.

CanTeen is one organisation that offers support to people who have a parent living with cancer, or who has died from cancer. There are other organisations listed in the back of this book.

Your church or local community might have other youth groups that you can join.

Online support

There are lots of on-line forums, blogs and support groups that can bring together people in similar situations. It can be really helpful to read other people’s real-life stories and realise that you are not alone in what you are feeling. It can also make things easier to open up when you can be anonymous.

The website www.nowwhat.org.au brings together young people in Australia who have a family member with cancer, or have cancer themselves. You can read heaps of real stories, join forums and access information written specifically for people like you.

“

Showing *emotion* is not necessarily a weakness.

You can think of it as a *strength*. **Eloise**

”

how your parent feels



Being told that they are not going to recover from their cancer is probably the hardest and most scary thing your parent will ever hear. Like you, it's likely they are feeling all kinds of things that can change from day to day.

They might be feeling lonely, angry or desperately sad. They may be shocked or in disbelief and very afraid. They may be worried about being a burden or about what will happen to your family after they die.

Your mum or dad might not be sure how to talk to you or be trying to protect you from upsetting information. You might also have lots of questions but don't think you can bring them up. It's OK to figure this out together, and to be upset together. Just like you, your parent probably never expected this could happen to them and won't always know the right things to say or do. They may not get it right all the time, but they are doing their best in a really difficult situation.

Try to be as open and honest as you can with your parent. This may not be easy, particularly if you have never gotten on that well and are not used to talking about your personal feelings. But it's never too late to try and tell them how you feel - and you will probably be glad you did in the future.

"When Dad was so sick, I was scared to upset him. I didn't want to go up and hold his hand cos I knew I'd cry and I didn't want to make him cry..."

Even though it's scary and hard, after that person dies you can't go back... I do try and tell myself that he knew that I loved him and how important he was to me. I'm sure he'd have known it, but I'm sure he would have liked to hear it." **Eloise**



It was like there was an elephant in the room

but no one would talk about it! We all knew it was coming but what was there to say? **Melissa**



They are still them

It may be true that your parent's illness is going to shorten their life. But they do not stop living until the last breath. While they are still here, treat them as you always have. They are still your parent.

It's OK to still argue with them sometimes. Or to joke around and talk about normal things. It can really help them to feel included in what's going on and like they are still part of the world.

Talking about death

It can be really, really hard to talk about dying. You may have lots of questions, or you may not want to talk about it at all. Your parents might also find it difficult to talk about.

If you and your family can, it can be helpful to talk about things like where your parent would prefer to die, who they would like to be around them when it happens, funeral arrangements or things that might change after they die.

Talking about these things does not mean that you want your parent to die or that you have given up hope. Your palliative care team can talk with you as a family (or individually) about these things if you like.

Your parent might actually be relieved that you brought the topic up. They might even feel comforted to know that you know the end is coming.



"Accept every moment for what it is,

don't focus on "I wish I could do this" or "I wish this was different". **Eloise**



“Sometimes we’d just pop on a movie and all sit in silence. Just be together, you don’t have to say anything.” **Amrita**

Follow their lead

Your parent might not always feel like talking. In the later stages of their illness, they might be tired, or trying to put on a brave face, or overwhelmed by feelings of sadness. Their illness or medication may have caused changes in their thinking or behaviour. Everyone deals with stuff in different ways and your parent might cope by withdrawing from family activities, or becoming argumentative or demanding. Try not to take this personally.

Just being with them and giving a hug or holding hands is enough, they will know how you feel.

If they feel like talking, listen. If they want to talk about dying, don’t correct them and say things like, “No, you’re not. Don’t talk like that”. It can be painfully hard to talk about, but it’s OK to be upset and afraid together. You could try, instead to say something like, “I know this hard. But it would help me to talk about this”.

“ **I wish I’d known before that I should spend as much time as possible with Dad.**

Every second with him was better than being anywhere else, even when he was sleeping. **Sarah** ”

There will be good days and bad days

There will be some days when your parent is too tired or sick to talk. They may become impatient or testy or seem withdrawn or distant. This might make you feel hurt, disappointed or worried.

If your parent is feeling too ill to spend time with you, this doesn’t mean that he or she doesn’t want to. There may be other ways you can show that you care – like writing notes or bringing them small gifts, or just sitting there.

If your parent is in hospital, it’s OK to visit. It might be less scary if you ask a nurse or someone in your family beforehand how they are going and what you should expect. Most young people find that even though it is really hard to see your mum or dad when they are weak and sick, you will value all the time you have spent with them later.

“ **He wasn’t conscious for the last few days. It was about just being there and talking to him even though he didn’t respond.** **Peta** ”



saying

goodbye



How do you possibly think about saying goodbye to your mum or dad?? The truth is, you will never be ready for a life without them.

“ 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 ”

How do you know when it's time to say goodbye?

No one can tell you exactly when your parent is going to die. So, how do you prepare to say goodbye?

It might seem a bit embarrassing to have big deep and meaningful conversations and tell your mum or dad all your deepest secrets, when they might still be around for months or years. Or you might be worried that they will think you have lost hope if you start talking about life without them.

But would it really be so bad for your parent to know now how much you love them?

It often helps us feel more ready if we find ways to say lots of little goodbyes, bit by bit, in a lot of different ways.



“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**



In the words of other young people who have been through this:

Don't let things go unsaid.

“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 ”

Not every family finds it easy to talk openly with each other. This doesn't necessarily change when someone is dying.

Here are some thoughts 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.
- I know that this is really hard for you too.
- I will be OK. I will get through this somehow.
- Do you have any advice for me in the future?
- What are your hopes and dreams for me?

“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

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

Don't worry if you didn't say it all

It is daunting and scary to try and remember everything you think you have ever wanted to tell them before they die. Don't be scared to forget things, or fail to remember a specific memory you wanted to share one last time. The truth is, they know how you feel, how much you love them, how much you will always love them.

You might find it hard to be around your parent as they approach the end of their life. You are not just a visitor in this experience. It can be really draining to be around them when they are really sick and you might feel like you need a bit more space. You don't need to feel bad about that. That's normal too.



"The last month was the best –

it had already sunk in and we saw a lot of our family. We had a "Daddy Day" each week and got a day off school. There were some good times in the end stages." Erin



Just hang out together

If you can, make the most of the time you have with your parent, you will probably really cherish this time. Try to think of things you can still do together. You might be able to play a board game, watch DVDs, read the paper or a book to them, or get them to help you with your homework.

Make some one-on-one time

There might be lots of people around helping and wanting to spend time with your parent. But it's alright to demand a bit of alone time with your mum or dad. You will value this time in the future.



memories **and** *stories*

“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**

Look back over their life...

Often when a person is dying, they like to reflect on their past and think of their achievements so that they can see that their life has been important.

If your mum or dad feels up to it, you could sit down and talk about their favourite memories and look back over their life. Even if they don't, you might be able to get answers and stories from other people in your family or community.

Don't worry that you'll say the wrong thing or that you'll both get emotional. Ask them about anything and everything you want to know. No question is too simple.

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

...and look forward over yours

A lot of young people say that trying to imagine life without your mum or dad is by far the hardest part of this experience. It will be heartbreaking to think of all the things they will miss out on and you wish they could be there for – your graduation, your wedding, having kids.

At moments like this in the future, you may wonder what your parent would think about this and what they would say about that. You will not be able to predict all of the conversations you might ever want to have with them, but many young people like to spend this time now hearing 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

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

Ideas to get the ball rolling...

- 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 my Mum/Dad?
- Who was your first boyfriend/girlfriend?
- Tell me about when I was a baby.
- What is your favourite memory?
- What did you think I’d be when I grew up?
- What do you hope for the future?
- 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**”

Collecting memories

When your parent dies, the memories you have of them will probably become really precious. Even the smallest knick knacks and silliest stories can take on huge sentimental value and become special keepsakes that you will treasure forever.

If you have the opportunity now, you might be able to start collecting things that will help to remind you of them in the future. This might be something you can do together.

Here are some ideas:

- Create a photo album or slide show. You could write a paragraph next to each one about what your parent remembers about that photo.
- Make a CD of songs that your parent likes or that remind you of them.
- Make a scrapbook.

“ My sister and I both made scrapbooks of sayings (from Dads 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 ”

- Make a memory box. You could put things in there that are special to your parent or remind you of them - like photos, tickets, cards, clothes, toys or jewellery.
- Write a journal. You could write down all the things you are feeling now. It might help you to maintain a connection in the future.

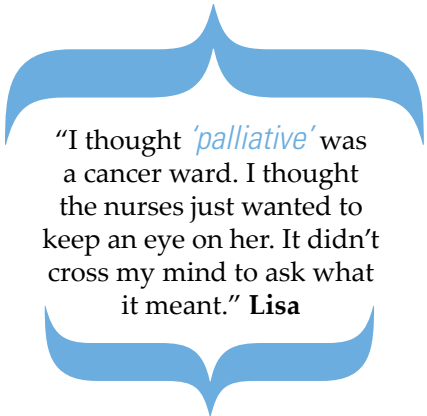
- Take photos. You can never have enough. You may not want to take photos of your parent if they are looking really sick. You could take photos of what the house looks like now, how your parent decorates the house at Christmas, what their room was like. There might be big changes in your home and one day you might really want to remember.
- Create a video or voice recording. You could ask them to tell stories about their life, or retell memories you have together.
- Make a physical record. Draw around their hand, make a handprint in plaster, record how tall they are, cut off a lock of hair.

“ 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 ”

- Write a song or poem about your parent, or how you are feeling.
- Create a family tree. Record what they know about your family history.
- Collect their smell. The sense of smell can be really powerful in bringing 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 preparing things like this with you before they die. It doesn't mean they don't care. You can still prepare memories on your own later, if you like. If you don't want to that's OK too. There will be lots of ways to remember your mum or dad.

intro to *palliative* care



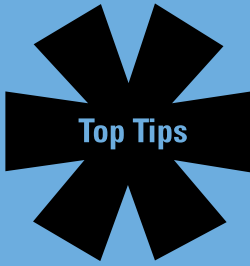
“I thought *‘palliative’* was a cancer ward. I thought the nurses just wanted to keep an eye on her. It didn’t cross my mind to ask what it meant.” **Lisa**

When it no longer seems likely that your parent will get better, the focus of their treatment shifts from trying to get rid of the disease, to managing symptoms and pain and helping them to feel as comfortable as possible. This type of care is called “palliative care”.

The main aim of palliative care is to improve the quality of life for your parent by looking after all of their physical and emotional needs. It is a focus on giving your parent the best life possible while they deal with advanced cancer.

“Palliative” does not mean “dying”. It is not just for people who are about to die, although end-of-life care is part of palliative care.

Palliative care does not aim to make your parent’s life shorter or longer. It aims to make what life they have left as dignified and peaceful as possible.



Palliative care aims to make your parent comfortable so they can focus on living.

What kind of support does palliative care provide?

A palliative care team recognises that your parent has many different physical, emotional, practical and spiritual needs and that the best kind of approach is one that works together to look after all of these needs. It also offers support to you and your family to help you care for them and cope with the situation.

Each palliative care team provides its own set of services to a patient and their family. They tailor it to your unique needs as a family. This may include:

- Nursing and medical care – in a hospital or hospice or at home
- Counselling and social worker services
- Dietary advice
- Loan of equipment
- Physiotherapy and occupational therapy
- Therapists skilled in music, massage, aromatherapy, or colour
- Spiritual support and pastoral care from a range of cultural and religious backgrounds
- Volunteers to help you care for your parent

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.

There are services available in most areas of Australia.

How do we know if it's time to consider palliative services?

Accessing palliative services as early as possible can make things easier for your parent and your family. A lot of people avoid palliative care as long as they can because they are afraid that it means they have given up hope and are going to die soon.

Your parent's health care team will probably recommend if it is time to consider palliative care. Your parent can even refer themselves by contacting a local service.

You can start palliative care from the first time you are diagnosed with a terminal illness. It's not a one-way door. If your parent's illness stabilises or improves, palliative services can be stopped.

If my parent is referred to palliative care does that mean they are about to die?

Palliative care is for people whose illness has not responded to treatment and it's likely it cannot be cured. The focus of palliative care is comfort and quality of life. But no one can tell you exactly when they will die. Palliative care will help your parent to live in comfort for the rest of their life. This could be weeks, months or years.

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 about helping to give your parent the most comfortable and pain-free life.

Will we have to pay?

Palliative care is usually free. It is often funded by the government or charitable organisations. However, some hospitals and hospices might charge fees for in-patient services (these can often be covered by Medicare or private health insurance).

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

In almost all cases, pain can be overcome or made bearable. There is a wide variety of drugs used to treat pain and various ways that it can be given such as orally, into the vein or patches on the skin.

A family of drugs commonly used to treat pain are called "opioids". Morphine is one of the best known and commonly used. Morphine can be used for long periods of time and although the dose may need to be adjusted as your parent's body develops a tolerance to it, this does not mean that their condition is getting worse or that they are getting addicted.

There are also other ways to relieve pain, such as massage, meditation, using hot and cold packs, aromatherapy, acupuncture or hypnotherapy.

Who can I ask if I have questions?

Your parent's palliative care team are there to help you too. There is no question too small or silly to ask.

Remember:

Your parent has a right to make decisions about their treatment and care right up until the end of their life.

Things to discuss - End of life decision making

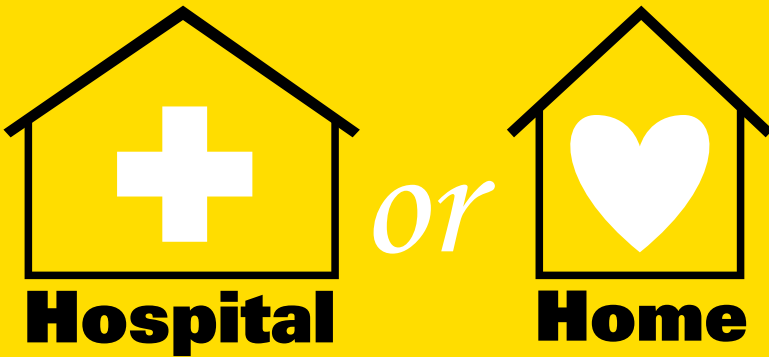
We all know that sooner or later we are all going to die. But who wants to think about that before you really have to?

Your family might avoid talking about your parent's death, thinking that if you accept it is going to happen somehow you will make it happen sooner. But sometimes when we avoid having a conversation about death with the person who is dying while they still can, we miss out on the opportunity to hear their wishes for what will happen at the end of their life.

Your parent has a right to make decisions about their treatment and care right up until the end of their life. They may be less able to think clearly as death approaches, so it's a good idea to start talking about these things sooner rather than later. It's important to write these wishes down and to tell the medical team about them, to make sure they get followed when the time comes.

These include things like:

- Making an "advance care directive" to tell doctors what kind of treatments are or are not wanted, no matter how ill they become. This includes things like whether they want to go on life support.
- Deciding who will be their "Medical Power of Attorney". This is a person who will make decisions for your parent if they can't speak for themselves.
- Where would they like to die if they have a choice?
- Would they like to donate organs if they can?
- Would they like their body to be buried or cremated?
- Do they have any ideas for their funeral?
- Do they have a Will? This is a legal document that states what a person wants to happen to their money and property after they die.
- Who will look after you (if you are under 18) and your brothers and sisters after they die?



where will they be *at the end?*

Depending on your parent's illness and other factors, your family might decide that your parent will be cared for at home, in a hospital, or in a special palliative care unit or facility, sometimes called a hospice. Your parent might move between these places as their need for care and support changes.

There will be lots of things to consider when your family decides where your parent will be, such as their care needs, the area you live in, the support available and what your family feels comfortable with. There is no right or wrong place for them to be. And you can change your mind at any time.

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.

Caring at home

Many people would prefer to be at home in the final stages of their illness. If your family decides that your parent will be cared for at home, the palliative care team can provide all sorts of support to make them comfortable and help your family to cope.

It can be really rewarding having your parent at home in their final stages. They may be happy to be in their own bed, surrounded by family and friends. You may appreciate having the time to spend with them and come together as a family.

But looking after someone at home can be physically and emotionally tough. Your family may not have much experience caring for someone who is dying and it's important you don't take on more than you can handle. While it's OK for you to help out, you should not be in charge of their care. If you have any concerns about your dying parent being cared for at home, speak to your family or the palliative care team. The palliative care team will be able to support you.

“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”

You may want to talk with your family about what you do and don't feel comfortable doing for your parent. There are lots of ways to support them if you don't want to help with their physical care. Bringing them some fresh flowers or reading the paper to them can make a big difference to their quality of life.

“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”

“Dad came home from hospital;

we set up a hospital bed in the lounge room. It was good to have that time.”

Amrita

There may be changes in your parent's mood, behaviour and appearance when they are approaching the end of life. You might find it really distressing to see them become weaker and have less energy.

“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”

It's really important that you plan time to get out of the house and take a break from the situation sometimes. Also try to get as much sleep as you can and to eat regular and nutritious meals. You need to take care of yourself too, so you have more energy to enjoy the time you have with your parent.

Remember that there is also a lot of support available to help your family care for your parent. Your GP should be available to call on if you need. There may also be district nurses who can come and help with nursing care such as giving drugs, changing dressings and helping with washing and toilet needs.

Hospital or hospice

Your family may also feel more comfortable if your parent is cared for in a hospital or hospice where trained staff can look after them and relieve pain and other symptoms as necessary.

A hospice or palliative care unit in a hospital is a place that provides all sorts of care for people with an illness that is unlikely to be cured.

If your parent goes into hospital or a hospice, you might feel worried that they might not be able to come home again. But it's usual for someone to go into a hospital or hospice for a short time to have their symptoms monitored and brought under control and then, if they wish, go home again. Your parent might be able to go into a hospice for a little while to give your family a rest from looking after them.

Many hospices are often smaller and quieter than hospitals, or might be a dedicated area within in hospital.

You may be able to stay over with your parent in a hospital or hospice – but make sure you get away sometimes, 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



the *final* stages

Dying and death are very frightening words that we all struggle with. You might be having horrible, unbearable thoughts and feel quite scared and confused about what is going to happen when your parent dies.

The pain and stress that knowing that someone you love is going to die cannot be taken away. But if you know a little bit about what to expect when it actually happens you might be a bit less freaked when it does.


You may be really worried that death will be painful for your parent. But the time before death is usually peaceful. The body slowly winds down as it starts to 'let go' of life.

There are some signs that death is near, although it is impossible to know the exact moment that death will occur. Sometimes these changes start weeks before death, sometimes days, sometimes hours. Each person's experience is unique.



It was surreal.

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



Signs of approaching death

- **Weak and lacking energy.** Your parent may spend a lot of time sleeping and be hard to wake up. It's best to let them sleep and talk to them when they seem most alert.
- **Less appetite and thirst.** As your Mum or Dad gets weaker, they may have trouble swallowing or digesting food. Small sips of water or ice to suck might help.
- **Temperature changes.** 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 nurses will advise you how to help.
- **Breathing changes.** Their breathing may be noisy as fluid collects in their breathing passages. This can sound like gurgling or rattling sounds. They may also breathe really fast one minute and really slowly the next and they may stop breathing for a few seconds. These breathing changes are usually not distressing for the patient, although you may find it frightening. It can help to raise the head of the bed with pillows.
- **Hearing.** Even if your Mum or Dad doesn't respond when you are talking, they can probably hear you. They may find it really comforting to know you are there.

- **Changes in mood and behaviour.** As your parent nears the end of life, they may experience a lot of different emotions that may change very quickly. They might seem to become withdrawn, talking less and losing interest in things around them. Sometimes it might seem like they don't recognise you. This can be really upsetting, but it's a natural process of gradually withdrawing from the world. Sometimes they might be angry or irritable. You may not have done anything wrong and just being there and listening can be supportive.

Check with the medical and nursing staff if you are unsure or worried about any changes you notice in your parent.

Whether your parent is at home or in hospital or a hospice at this time, there will be huge changes to your life. It may feel like real life is suspended and you are living in a completely different world.

“ 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 ”

Try to talk with your family about whether you want to be woken up or taken out of school when death is approaching. If you do want to be there, make an agreement with your family that they will let you know what is happening as soon as they know. It's OK if you don't want to be there, there will be plenty of ways you can still say goodbye.

Notes

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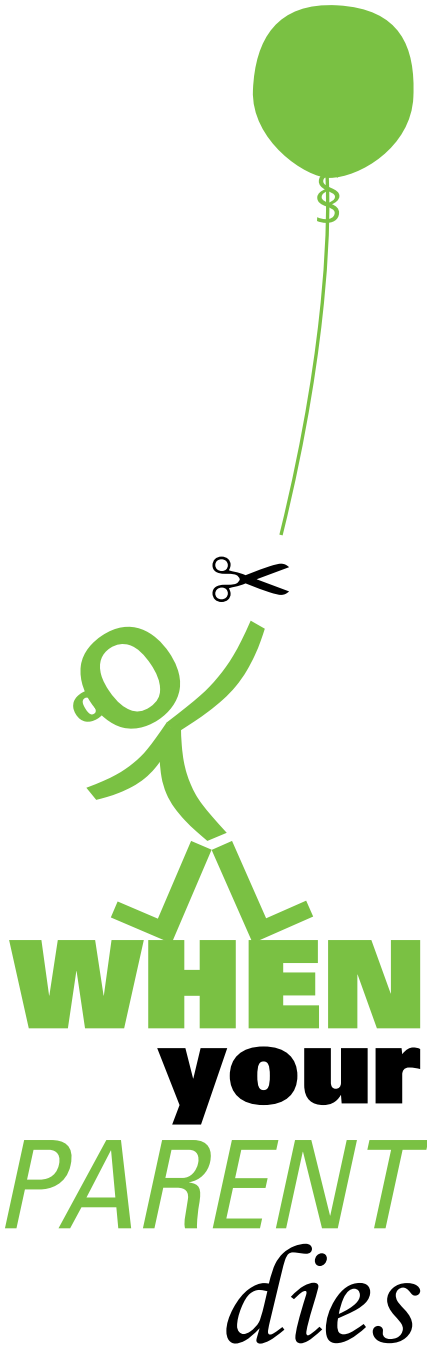
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You might be scared about what your parent will look like after they die. Being aware of what might happen can help you feel more prepared.

These are some signs that death has occurred:

- 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
- Control of bowels or bladder is lost as the muscles relax

What do we have to do?

Wherever your parent dies, there is nothing that needs to be done in a hurry. This is a personal time to be with them and say goodbye. Take as long as you need.

Some families have chosen to spend this time doing things like sleeping next to their parent one last time, washing them and brushing their hair, cutting a lock of hair to keep, holding their hand and talking to them. It's perfectly OK to touch and hold your parent after they have died.

“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**

The decision to see your parent after they die is up to you. Remember that even with the best planning things can change when the actual moment arrives, so be gentle with yourself and understand how you are feeling.

If things don’t go exactly as you would have liked, there are lots of things you can do to say goodbye in different ways.

If your parent dies at home

Your parent’s palliative care team will tell you what you need to do and who you should call if your parent dies at home.

Usually, you will have to call your parent’s doctor and a funeral director and they will lead you through the next steps. If your parent dies in the night, it’s OK to wait until morning before you call the appropriate people if you want to.

The doctor will come and check your parent and sign a death certificate and give this to your family or your funeral director.

If they die in a hospital or hospice

It is fine to sit with your mum or dad for a while after they die. There is no rush to call anyone or get anything done right 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 for you to take to the funeral director. You may be able to take your parent home for one last visit. The funeral director might also come to collect your parent’s body from the hospital or hospice.

It can be really hard to leave without your parent. The staff will support you and let your family know what you should do next.



“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



What happens now?

No matter how long you have known this was going to happen, how much you have thought about it and how ready you think you are, nothing can ever fully prepare you for how you will feel when your parent dies.

Your reality has changed forever and it can be impossibly hard to think about facing your life without them in it.

There is no guidebook for how to get through this. There is no ‘right thing to do’ or ‘best advice we can give’. Each person deals with grief in their own personal way.

The first few days

The first few days or weeks after it happens might feel very strange and life at home might seem really flat. It is impossible to predict how you might feel, or what this time will be like. Here are some things other young people have described:

Numb. Your body might be going through the motions, but you don’t feel sad or anything at all. You might feel disconnected from the world and like nothing feels real. You might think you should be crying but the tears just aren’t there. This is your body’s normal reaction to shock.

“ The day he died I went to dancing so I could get my mind off it. I wasn’t sad the day he died. I needed a distraction. Erin ”

“ I think the next few days we just stayed with each other and didn’t really do much. We didn’t really get into a normal routine, making food and doing chores for a few weeks. Sarah ”

Lost. It might feel eerily quiet and calm just after your parent dies, particularly if you have been living with their illness for a while. When you don’t have to care for your parent anymore, what are you supposed to do now? It can take a really long time to get used to the massive changes in your life and for things to settle back into a new kind of “normal”.

“ I was used to saying “no” to friends’ invites as I had to look after Dad, so I lost a lot of friends as it seemed like I wasn’t interested in going out with them. Having to create a *new life* for myself and become more self-confident to get by was a challenge, but I am achieving that. Melissa ”

Get up, go to hospital, go home.

You get into a routine and then it’s over.

Andrew


Distracted. It might also be really busy, there might be people everywhere and things to do and you don’t get a lot of time to yourself to take in what has happened.

“ The week after Dad passed away to the day of the funeral all seem like a blur. I threw myself into preparing a slideshow and booklet for the funeral and that’s about all I remember doing. Our Grandma came to stay and looked after meals, etc. Melissa ”

Denial. You might find it really hard to accept that your mum or dad has gone and that your life will not go back to the way it was before. It might feel like they will just walk back in the door any minute.



You might need to sort through your parents things after they die. This can be very upsetting as it feels so final. It's fine if you don't want to do it for a while. Some families like to leave their loved ones things just the way they left them until they feel ready to pack them away.

Remember, everyone in your family will deal with this in different ways. You have to do what is right for you. You may worry that you can't talk about your parent in case it upsets people. But make sure you do find someone you can talk to. You might have a friend or relative. You could also call a counsellor or support line.




“For a long time I denied that Dad was gone and thought I could ignore it.

Although there was a big hole inside me that nothing could fill. Deep down I was devastated and didn't want to continue my life without Dad. I sheltered myself away from the world and didn't want to deal with anything or anyone.” **Melissa**



“I felt the lifting of a burden and I felt guilty for that.

I was just glad there was room for me in this world again.” **Lizzie**



Relief. It's perfectly natural to be glad that this is all finally over.

“ I'd reached a point where I couldn't handle anymore. I couldn't handle seeing my parent so dependent on others to feed them, clothe them and shower them. Because it had become so evident that they were not going to be able to recover, I felt that the quicker they died, then the quicker life could begin to get back to 'normal'. **Chris** **”**

A decorative graphic in the top right corner of the page. It features a trail of four hearts (two white, two black) and four birds in flight, all arranged in a diagonal path from the bottom left towards the top right.

Funerals

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

A funeral is a very personal occasion. There is no 'right' way to do it. Your family's cultural and religious traditions might play a part in how it goes. Your parent may also have given you some ideas about what they would like before they died.

Your family will probably start to plan a funeral within a couple of days after your parent dies. But there's no rush, it doesn't have to happen straight away.

Most families choose to use a funeral director to help them organise the day.

They can help you decide things like:

- 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?
- Will there be a viewing?
- What sort of casket or coffin? Who will carry it?
- What personal touches – like music, flowers, photos or booklets - can you add that show your parent's personality?
- Will there be a "wake" after the service? This is a gathering that could be anything from a cup of a tea and a biscuit to a raging party.

There are contacts to help you find a funeral director in "Where to get help" on page 79.

If you want to be involved in the funeral, make sure you tell your family. You might like to do a special reading, write a letter or poem or just talk about your mum or dad and share your memories. You could also help to choose the music or put together some photos.

“ 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 ”

Many young people find that it helps them to go to their parent's funeral and share their sadness with their family and friends and celebrate their parent's life.

“ 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 ”

But if you don't want to go to the funeral, there are other ways you can say goodbye. You could plant a tree, tie a message to a balloon and let it go, or visit a special place you used to go to with your parent.

This is one of the biggest and hardest things that will ever happen to you, so don't feel like you have to be a certain way, or say particular things. Let your feelings come when they come.

“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 about how much Dad meant to me and I missed it.” **Melissa**



Bereavement

As the initial shock wears off and you gradually acknowledge that your parent has died, you might start to feel pain more strongly.

“ The hardest part is realising Dad’s not here for the special occasions. And not having him ring at night to say goodnight. Amy ”

When someone you love dies, you are “bereaved”. The mixture of thoughts and feelings you have as you deal with your parent’s death is called “grief”. The way you display your grief is called “mourning”. This will be different according to your culture, religion, family traditions, as well as your personality.

“I was sad that Dad wouldn’t be there to see me become the woman I was meant to be, to see me achieve my goals, to possibly see grandkids one day.” **Lizzie**

Whatever you feel when someone dies is normal

Grief shows itself in different people in different ways. This can include things like:

- Crying (or not crying – it doesn’t mean you don’t care if you don’t cry)
- Wanting to be alone
- Sleeping a lot, or not much at all
- Finding it hard to concentrate, being forgetful
- Your body hurts – your head, stomach, your throat all ache
- Lack of interest in usual activities
- Wanting to party or keep really busy
- Wanting to move away from where you live
- Talking to the person who died
- Doing activities that remind you of them
- Throwing things out
- Avoiding talking about what’s happened

There are lots of other grief reactions you might have. Whatever reactions you experience, they are normal for you. Everyone experiences grief differently. There is no right or wrong way to grieve.

Grief has a mind of its own

It doesn't follow a pattern and you can't predict how long it will take.

It might feel like it comes and goes in waves. You will have some good days, then you might be knocked over by a wave of feeling so strong you don't know which way is up. This can happen at times like birthdays or anniversaries. Or when you least expect it, like when you hear a song on the radio, or are reminded of the last movie you watched with your mum or dad, or someone rings up and asks to speak to them on the phone.

Be kind to yourself and others

You will need to have a lot of patience for yourself and the people around you – particularly if you show your grief in different ways.

It's OK to deal with it at your own pace. Don't listen to people who tell you to "move on" or "get over it". You will always feel connected to your parent, even when they are not there.

When things get really crazy, you may be tempted to vent your feelings in ways that can harm yourself or other people. Beware of signs that you are not coping with your grief, such as using drugs and alcohol or taking it out on others with violence.

As much as you can, it helps to maintain a routine. It also helps if you keep your body as healthy as possible with good food, drinking enough water and getting enough sleep and exercise.

Tips to help you get through grief:

- Take one day at a time. Don't worry about tomorrow.
- Remember that everyone will act differently – there's no right or wrong way.
- Find someone you can trust and share your feelings.
- Try to be active and exercise.
- Listen to music that suits your mood. Sad music won't necessarily make you feel worse, it can actually make you feel less alone. It can be comforting to know that other people have felt as sad as you before.
- Hold onto hope. You might find hope and comfort from people who have experienced a similar loss. Learning about some of the things that helped them and realising that with time, things do get easier can help to give you hope.
- It can be really helpful to talk to a bereavement counsellor because they are used to being around people who are grieving like you and they really understand what you are going through. You may be able to find one through your parent's palliative care team.



Some thoughts to carry with you

You will always have memories.

Do not be afraid that you will forget your parent. It will not be possible to forget them, even if you wanted to. They will always be a part of your life. You don't need to feel guilty if you go for 20 minutes without thinking about them, or if you catch yourself laughing or having fun with your friends.

“ One thing I found helpful were the kind words people expressed about Dad. Knowing that he had impacted so many lives, not just mine, made me proud of everything I had done for him. Mark ”

The pain will get less with time

At first you may wonder if you will ever feel happy again. Time has a way of healing. As much as it feels the world is going to end, you will get through this.



You will never forget your parent.



“I have learnt that I can get through just about anything.

As much as I thought I wasn't going to make it after Dad died, I found an emotional strength I didn't know I had inside of me!”

Melissa



It's OK to make mistakes

No one is perfect in these situations. There is no point dwelling on the things you wished you could have done differently or punishing yourself for not handling things better.

“ I learned that making mistakes is so important to growth and learning and that you can learn from failures. It isn't really failing anyway, it's just valuable life experience. Lizzie ”

“

I think if you don't laugh it's even harder. It's a way of coping. *Even though it's not funny.* **Peta**

”

Your parent would want you to be happy

Stay open to new experiences. It's OK to make some changes in your life and spend time with new people.

Your life won't be the same as it was before, but it will be rich and full.

You cannot change what will happen/has happened, accepting it and living your life to the fullest is all you can do. Life is too short!

It's OK to take some positives away from this

This experience will change your life. Some young people like to look at the meaning and impact it has had on their life.

You may realise more about what your family means to you or be proud of the strength you showed in getting through this. You may feel motivated to achieve certain goals, or to appreciate life more.

But there's no need to search for deeper meaning or think about what lessons you have learned if you don't want to.

It's perfectly OK to think the whole thing sucks. It's also OK to come out the other end of this being the same, faults and all.

{

*"I didn't learn anything per se, but definitely feel much more strongly about appreciation and *living life to the fullest* – an overused term but I feel the meaning has always been underrated."* **Megan**

}

Glossary

Advanced cancer Cancer that is unlikely to be cured. It might be the original cancer or cancer that has spread or come back.

Bereavement The period after the death of a loved one during which grief is experienced and mourning occurs. "Grief" is your personal experience of loss and includes physical and emotional responses. "Mourning" is the way you display your grief. The time spent in a period of bereavement is different for each person.

Cancer A general term for a large group of diseases that have uncontrolled growth and spread of abnormal cells.

Carer A carer is generally a family member or close friend who looks after the patient and makes sure they have everything they need. A young person (read: you) might be your parent's carer.

Chemotherapy The use of drugs to treat cancer by killing cancer cells or slowing their growth. It is also used in palliative care to control pain or other symptoms of cancer.

Chronic illness A medical condition that is permanent or long-lasting.

Complementary therapy Treatments (such as yoga, relaxation or nutrition) that may be used as well as medicine to make your parent feel more comfortable.

Coroner A government officer who investigates any death that is not obviously from natural causes. There does not have to be anything suspicious about the death for a coroner to be involved.

Diagnosis The process of identifying a disease by its signs or symptoms.

End-of-life care The end stage of palliative care where the patient is very close to death.

Euthanasia The assisted death of someone who would rather die than suffer from the effects of their illness. It is illegal in Australia.

Funeral Director A professional person who can organise the practical and legal requirements of a funeral.

Holistic care Care that incorporates different types of therapies and services to make sure that all your physical, emotional, spiritual and practical needs are met.

Hospice A place that provides care for people with a life-limiting illness in a home-like environment. Patients might go in for a short time to bring their symptoms under control or to give their carers a break, and then go home again. They may also choose to die there.

Life-limiting illness An illness that is unlikely to be cured and will cause the person to die at some stage. A person may live with a life-limiting illness for weeks, months or years.

Malignant cancer A malignant tumour is likely to spread to other parts of the body if untreated.

Metastasis Also known as secondary cancer. A cancer that has spread from another part of the body.

Morphine A strong and effective painkiller, which is commonly used to treat people with cancer who have pain.

Oncology The study and treatment of cancer.

Palliative care The care of people who have an illness that cannot be cured. The main aim is to improve the quality of life of the patient by looking after all of their needs – including physical, emotional, spiritual, social and practical. It is not just for people who are about to die, although end-of-life care is part of palliative care.

Palliative care team A multidisciplinary team which may include nurses, doctors, social workers, volunteers, chaplains, psychologists, physiotherapists and other kinds of complementary therapists.

Pastoral care Care provided by a person trained in giving spiritual and emotional support for a patient and their family, often just by talking to them and if requested, offering prayers and religious rituals. It is usually provided by counsellors, chaplains and other religious ministers or elders.

Post-mortem A medical examination to determine the exact cause of death.

Primary cancer The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

Primary carer A person who takes the most responsibility for looking after the patient. The primary carer of your Mum or Dad might be your other parent, another relative or even you. There are many support services available to help the carer.

Prognosis The likely outcome of a person's disease. When people are receiving palliative care, their prognosis is usually that the illness cannot be cured and is life-limiting. Doctors make their judgement based on their knowledge and experience with patients with similar medical conditions.

Quality of life The patient's level of comfort and satisfaction, based on how well all of their physical and emotional needs are met.

glossary

Radiotherapy A cancer treatment involving high energy X-Rays to kill cancer cells, stop them growing or to reduce the pain from cancer.

Red blood cells Cells that contain 'haemoglobin', that carries oxygen around the body.

Relapse The return of the disease after a period of improvement.

Remission When there are no signs or symptoms of active disease.

Respite care A service which provides temporary care for the patient, to give the carer and the patient a short break from their usual situation. Respite can be in a hospital, hospice or at home.

Resuscitation A medical action that aims to return someone to life when their heart or breathing has stopped. Resuscitation may or may not be successful.

Survival Rate The percentage of people who are still alive after a particular time with a certain disease.

Symptoms Signs of an illness. This includes things such as pain, fever, nausea, fatigue and breathing difficulties.

Terminal When a person who has an incurable disease is showing signs and symptoms that suggest their death is about to happen.

Tumour A growth or lump, which may or may not be cancer.

White blood cells Cells in the blood that help to fight infection.

who DOES what?

Oncologist	A doctor who specialises in the treatment of cancer.
Oncology Nurse Specialist	A registered nurse with additional education and training in cancer.
Registered Nurse	A nurse who provides regular care in the hospital or outpatient clinic.
Cancer Care Coordinator	A nurse who is the main point of contact and helps patients and families communicate and deal with the different members of their treatment team.
Palliative Care Nurse	A nurse with special training in caring for people with a life-limiting illness. They provide care, advice and support for patients and their families - in hospital, in hospices or at home.
Palliative Care Specialist	A doctor who has special training to be able to assess the needs of a person with a life-limiting illness. They prescribe medical treatment for pain and other symptoms, advise the other members of the palliative care team and support the patient and their family and carers.
Physiotherapist	A professional who helps with recovering physical movement and muscle strength.
Clinical Psychologist	A professionally-trained therapist who helps with emotional and mental well-being.
Social Worker	A trained professional who helps patients and their families cope with life with cancer. They help with things like support services, financial assistance and other practical issues.
Dietician	A professional who provides information to patients and their families about nutritional needs related to cancer and treatment.
Pharmacist	A professional who is knowledgeable about drugs and medication.
Pastoral Care Worker	A person trained to provide spiritual and emotional care as a part of treatment. They include counsellors, chaplains and other religious ministers or elders.



Cancer info, stories and support groups

www.nowwhat.org.au

This is a website for all young people who have cancer in their lives. There are lots of real-life stories, blogs, forums and heaps of information. You can also order free copies of the other "Now What...?" books from this site.

www.canteen.org.au

CanTeen is an organisation that supports young people aged 12-24 who have a parent who has, or has died from, cancer (it also supports young cancer patients and their siblings). They run a range of camps and programs to bring together young people in a similar situation, share their experiences and get away from it all for a while. Call 1800 226 833.

www.cancer.org.au

The Cancer Council Australia website has lots of good, clear information on cancer and can direct you to Cancer Council support services in your state. These include counselling, support groups and practical or financial assistance. Call 13 11 20.

Counselling and emotional support services

www.canteen.org.au

CanTeen runs a FREE counselling service especially for young people who have a parent who has, or has died from, cancer. You may be able to talk to a counsellor in person, in a group, on the phone or online. Call 1800 CANTEEN or email support@canteen.org.au to find out more.

www.kidshelp.com.au

Not just for kids, but for teens and young adults too, this website has a free and confidential counselling service for people going through tough times. You can talk about anything that's bothering you. You can talk to a counsellor on the phone, on web chat or by email – any time of the day. Call 1800 55 1800.

www.lifeline.org.au

Lifeline is an organisation that has useful information on counselling, health, accommodation and many other services to help you. Call 13 11 14.

www.youthbeyondblue.com

Youth Beyond Blue supports young people dealing with depression, anxiety and other mental health problems. They provide tips on how to talk about depression and get help.

Tips for dealing with grief and loss

www.grief.org.au

The Australian Centre for Grief and Bereavement is an organisation that provides information about grief – and how to get through it! It also has links to other resources and information that offer support when someone is dying.

www.skylight.org.nz

This is a great website with lots of tips and helpful articles to help young people who are experiencing grief and stress.

www.reachout.com.au

A site for young people who are going through tough times. Find stuff out, understand more about mental health and wellbeing, get help and connect with other young people.

www.myparentscancer.com.au

This site you can read simple information about cancer, some suggestions for coping and the personal stories of other young people. It is mainly about young people who have a mother with breast cancer, but lots of the information is relevant for any cancer.

www.winstonswish.org.uk

This is a UK website that provides services to bereaved young people and some great tips about talking about death and dying and living with someone who is seriously ill.

www.macmillan.org.uk

This UK website gives information and advice on how to deal with the practical and emotional and effects of living with and after cancer.



Palliative care and help for carers

www.pallcare.org.au

Palliative Care Australia includes information about palliative care services. You can access the palliative care organisations in your state from this site. The state sites have directories of palliative care services in your area, plus information for families and carers.

www.homehospice.com.au

Home Hospice offers free support for people who are caring for a loved one living with a terminal illness at home. They can send a trained Community Mentor to offer your family guidance, information and support so that your ill parent can continue to live at home until they die.

www.caresearch.com.au

This website brings together resources and information about palliative care and how to find services in your area. It gives really good suggestions about how to care for someone who is ill, and how to yourself as a carer.

www.youngcarers.net.au

This organisation supports young people who are caring for a parent who is physically or mentally ill. They run support programs and provide information and links to other services. You can access the Young Carers Association in your state from this site.

Practical assistance

www.centrelink.com.au

If you need financial assistance, you may be able to receive payments through Centrelink if you are a carer, a student, unemployed, in a remote area or bereaved.

www.australia.gov.au/life-events/death-and-bereavement

This is Centrelink's bereavement support page. It gives information about payments and services you may be able to receive after your parent dies. Plus information about who you need to tell and other legal requirements.

www.lawstuff.org.au

This site for under 18's can answer any questions you may have about the law.

www.afda.org.au

The Australian Funeral Directors Association provides information on what to do when someone dies and a directory to help you find a funeral director.



HELPFUL phone numbers

CanTeen

1800 226 833

Kids Help Line

1800 55 1800

Lifeline

13 11 14

Cancer Council Helpline

13 11 20

Young Carers

1800 242 636



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Recommended Books and Videos

Now What...? Living with the death of your parent or brother or sister from cancer (2010) – CanTeen Australia

This book looks at the issues of bereavement and grief, how it feels and what is normal.

It's Like This...How young people and their parents deal with cancer (DVD) (2010)

This DVD is produced for parents of young people to give an understanding of the experience of living with cancer as an adolescent and young adult. It was produced as a joint project between CanTeen and RedKite.

Cancer Council Booklets

The Cancer Council has a fantastic series of booklets covering lots of topics, including types of cancer, palliative care and tips for coping with your emotions. Check them out at www.cancerCouncil.com.au.

Sometimes Life Sucks: When someone you love dies (2010) – Molly Carlile

Stories, tips and advice to help teens get through their personal experience of grief.

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Now What? When your parent's cancer can't be cured.

Free copies of this book are available by calling CanTeen on 1800 226 833 or by going to www.canteen.org.au

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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.

