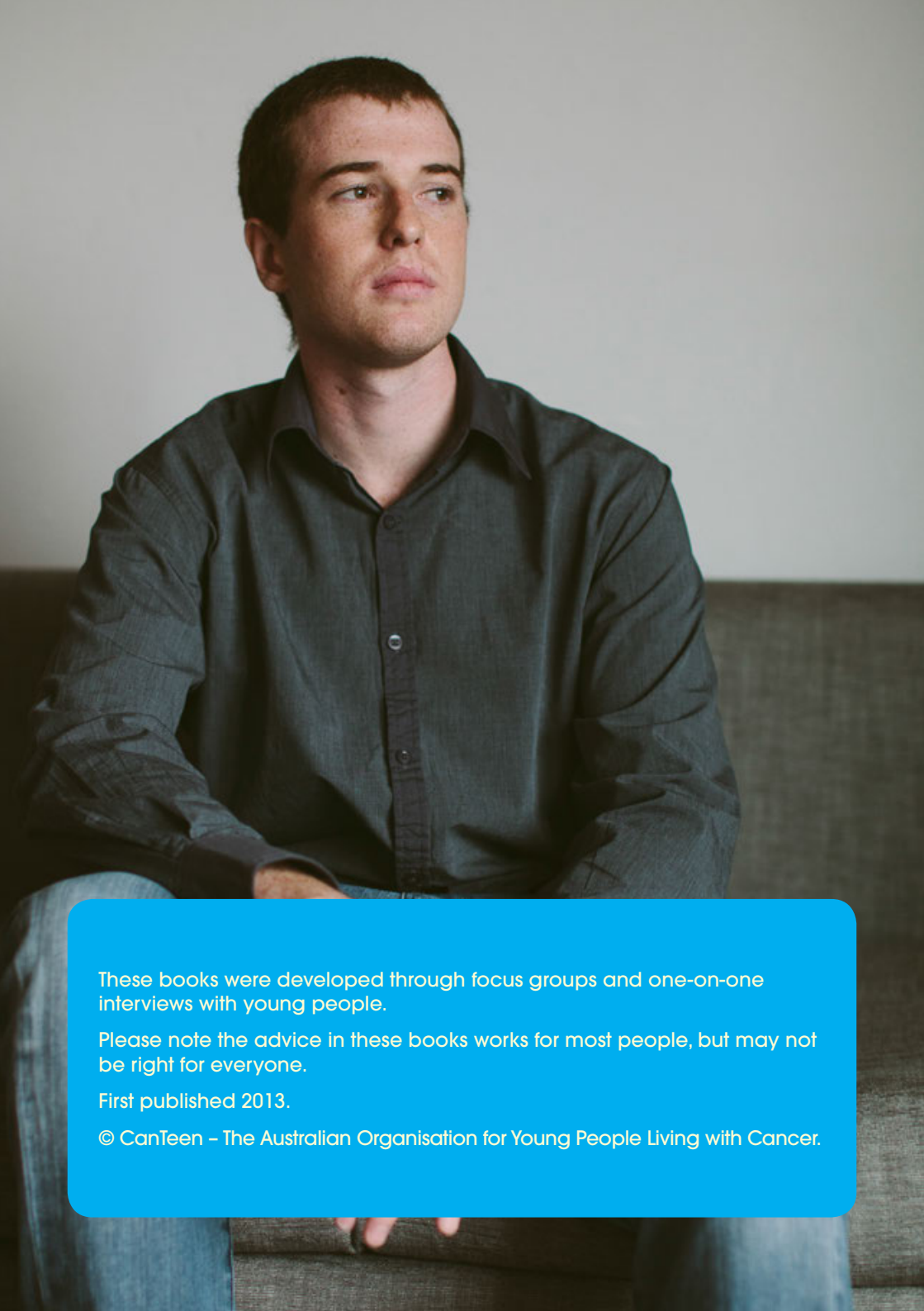


# Wait... did you say “cancer”?

A guide to supporting your partner when they have cancer





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

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

First published 2013.

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# Your reaction

Everything is ticking along as normal and then BOOM! Your world is tipped upside down. The person you love has cancer.

- You might be wondering, now what?
- What am I supposed to do, say, what does this mean for me, for our relationship?
- How am I supposed to deal with this?
- Do I even want to deal with it? (And that thought is OK too)

Being the partner of someone who has cancer is not easy (Oh really??). It can be scary, confusing and throw you way out of your comfort zone. This isn't exactly what you may have signed up for. By now you may have already realised that your partner is going to experience a truckload of changes and is facing a whole lot of really big challenges. But so will you.

You might be really surprised at your reaction to having a partner diagnosed with cancer. You might be shocked, puzzled, totally freaked out or you may feel nothing at all. It can be very difficult to watch the person you love struggle through treatment or go through pain. You are not expected to make everything better. It's OK to be lost for words, not know what to do and be freaked out by the whole thing.

Finding out the person you love has cancer can be very stressful and you may experience worrying thoughts and difficulty concentrating, as well as physical reactions such as fatigue, nausea and headaches. It can also bring up some

huge scary questions about health, life and death that you may not have thought much about before. It can take some time to process what this all means for you, your partner and your relationship.

There will be a lot of focus on your partner who has cancer. You may want to yell – hey what about me? Well this booklet is for you.

If your partner hasn't already got a copy of [Now What...? A young person's guide to dealing with cancer](#), it's a good idea to get hold of one. It has heaps of information and facts about cancer, causes, treatments, what it's like to be a young person diagnosed with cancer, practical stuff like money and legal information.

You'll probably find the [Now What...? A young person's guide to dealing with cancer](#) book useful too – it can help you to understand what your partner might be thinking, which in turn can help you understand how to be the best support you can be.

You may both be surprised that you share a whole lot of similar feelings. What is important is finding a way to communicate with each other. It's really important for you to take care of yourself, find ways together to deal with this and to manage it all the best way you can.

### Telling people.

There is nobody that you have to tell, but letting people know can make things a little easier for you. Who you tell is up to you but you also need to be aware of what your partner wants and thinks is OK in terms of sharing the news.

Sometimes this can cause a bit of conflict if you have different ideas and feelings about telling people. You need to respect your partner's wishes but also find ways to get support for yourself from family and friends. Letting friends know can be really tough – sometimes you have to worry more about how they are reacting than how it is for you. There is a good section in *Now What...? A young person's guide to dealing with cancer* that has tips on telling people (pages 95-96).

"To those who are just learning their partner is sick: I know it feels like this time will never pass and that you are stuck in a awful circle of bad news and hospitals and more bad news but this time will pass. And no matter how bad it seems it's still possible for both you and your partner to smile and have a good time, the willingness and attitude to believe that good things can happen even at the worst points is what I think is most important."

(Luke, 22 years whose partner has cancer)

"Loss of reality, feeling as if everything had come to a standstill e.g. time, work normal thought processing, confusion, sickness in stomach."

(Luke, 22 years whose partner has cancer)

# Life turned upside down

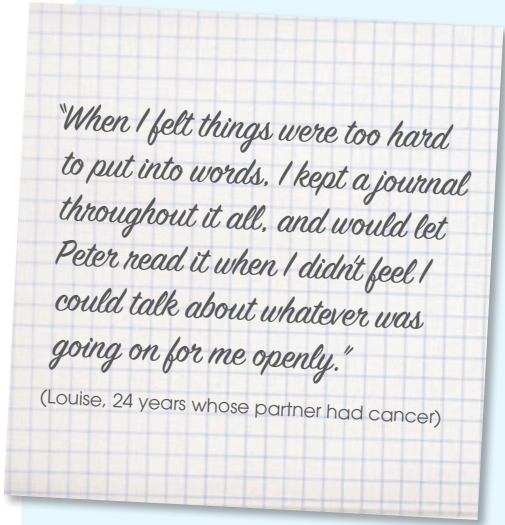
Supporting someone through a cancer experience can be incredibly tough and it's likely that it will have a big impact on your life, including your relationship, your wellbeing, your study or work and how you spend your time.

## Your relationship.

Some couples find that going through something like this together strengthens their relationship and reinforces their closeness and commitment to each other.

But living with cancer places an enormous amount of pressure on everyone and problems can arise even between the most loving couples. You may want to make things better for your partner and feel helpless and frustrated when you can't make it all go away. With all the stress of what's happening, you might not be communicating as well as you used to. Sometimes when you are close to someone you expect him or her to be able to read your mind and know what you want.

Your partner might get upset or angry with you if you don't know the best way to handle things. And you may get upset or angry with your partner because they don't seem to understand what you are going through. There are all sorts of changes that might happen to your relationship. Don't take things personally – realise that often people may disagree and argue because they're just not coping.



*"When I felt things were too hard to put into words, I kept a journal throughout it all, and would let Peter read it when I didn't feel I could talk about whatever was going on for me openly."*

(Louise, 24 years whose partner had cancer)

**REMEMBER:**  
Everyone responds to stress in a personal and sometimes unpredictable way.

### Things that might happen:

- You might struggle with how to respond and start to get a little distant and avoid talking about their cancer. You may even try to block it all out. This can really hurt.
- You may go into overdrive and try and protect your partner and not let them do anything for themselves. This can make them feel frustrated and helpless.
- You may feel like you can't handle the situation and that you can't give them what they need right now. This may make you feel sad and guilty.
- You may find that your partner's attitude towards things and their outlook on life changes because of their cancer experience, and this can impact on your relationship. Your outlook on life may also change.
- You might start to worry that you and your partner's feelings and attitudes about their cancer are not in sync. One of you might be feeling hopeful while the other might be more pessimistic. This can sometimes make it hard to make decisions about treatment or plans for the future together.
- You may worry that your partner thinks that you are just sticking around because you feel sorry for them and bailing now would be a really slack thing to do. Your partner may not feel that they have the right to dump this on you so may also start to distance themselves and shut you out, thinking that they are protecting you. Find ways to let them know that it's your choice to stick around.

Hiding emotions creates distance between partners. It's normal that you and your partner won't always feel the same way (but that was probably true before they had cancer). Talk about differences and respect each other's feelings without criticism or blame.

Both of you may be a bit scared about how treatment, side effects, surgery and scars will impact on your sexual relationship. Your partner may be scared that you won't find them attractive anymore and you may also be scared that you will find it difficult to deal with the physical changes that result from their cancer treatment. You may be scared that you will hurt them in some way.

Being really tired, being in pain and some medications can make your partner lose interest in sex. Their physical ability to have sex may also be affected. You may find that the stress and strain of caring for your partner also impacts on your interest in having sex. That's the bad news.



# Let's talk about sex

The good news is that unless the doctor tells you otherwise, there is no reason why you can't have sex while your partner is undergoing treatment.

(Although if they are bald, vomiting, stuck in hospital and generally feeling unwell, sex may be the last thing on their mind).

The other thing to remember is that there are other ways to show that you care about each other and to have an intimate relationship.

## Some suggestions are:

- Stay physically connected; holding hands, massaging, hugging, and kissing.
- You may be embarrassed talking about things to do with sex, but it's really important to find a way to discuss it with each other.
- Just spending time together – going out for breakfast or lunch, the movies or just cuddling on the couch.
- The most important thing is to let your partner know that you still find them attractive.

*"I often wondered if regularly asking how she was feeling was more of a nuisance than a help particularly in the early stages of treatment. I did however continue to ask and began to notice patterns in how her body reacted and could then limit the questions."*

*(Luke, 22 years whose partner had cancer)*

## Things that can help:

- Try to talk about everyday things – it doesn't always have to be about cancer.
- Do something special for each other; it can be something really simple.
- Plan time together that doesn't revolve around cancer, hospitals or Drs' visits.
- Being able to laugh and cry together is what it's all about.





"Taking things slowly and asking her how different things cause her pain/discomfort."

(Luke, 22 years whose partner had cancer)

"I think it's very important to talk to your partner about their stresses and pressures as well as yours. Topics we found hard basically included anything negative e.g. side effects of treatment/ illness and the possibility of treatments not working. The best advice I could give is not to focus on these things until they happen (much easier said than done I know)."

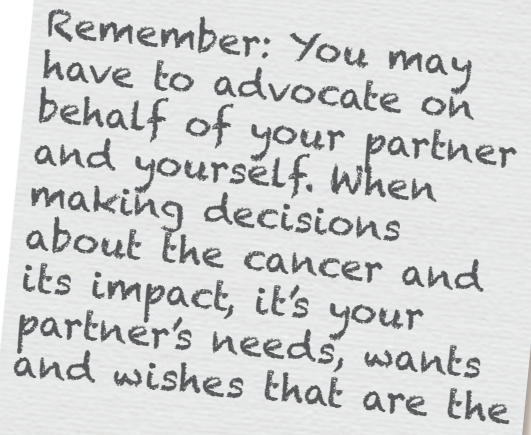
(Luke, 22 years whose partner had cancer)

# Relationships with your partner's family

Just as it's hard for you to see the person you love sick and in pain, your partner's parents and siblings will also be having a tough time. It's the role of parents to protect their kids (no matter how old they are) and when they get sick, this protective streak can sometimes go into overdrive.

If the two of you have been used to doing your own thing, taking care of yourselves and making your own decisions – having all of this challenged might take some negotiating. A lot will depend on the status of your relationship, your living arrangements and also the relationship that both of you have with your partner's family.

If you are not living together, understanding your role might take some time to figure out. You may be relieved that you don't have to be the main support, or you may feel a little sidelined.



Remember: You may have to advocate on behalf of your partner and yourself. When making decisions about the cancer and its impact, it's your partner's needs, wants and wishes that are the

# Making decisions about the future

**A cancer diagnosis can fast track the need to make decisions about certain issues that both you and your partner may not even have thought about before.**

## **Fertility.**

Some cancer treatments can cause infertility (a person's inability to have a child) for males and females. Before your partner begins treatment they may need to make some decisions about taking steps to preserve their fertility.

While you may not want to think about it, your partner might have to.

Even if you are part of these discussions it doesn't mean that it ties you into the relationship for the long haul, but these are really important decisions for your partner to make in order to give them choices in the future – whether that is with or without you.

## **Maybe Later Baby – a guide to fertility for young people with cancer.**

(Available from CanTeen) is a book that has heaps of information that can help you and your partner discuss the issues and make decisions (see the 'Where to get more information and help' section on page 28).

## **Breaking Up.**

Being faced with something as big and as serious as cancer can be very scary. It can put all sorts of stresses and strains on you and your relationship. You may question whether you are prepared to hang in there and be part of your partner's cancer experience.

You might feel very pressured to stay if you don't think you can or want to. Staying with someone just because you feel sorry for them (or out of guilt) is not a good basis for a relationship – not for you or your partner.

It's OK to decide that this isn't what you signed up for and that you can't be the support that your partner needs right now. But many people feel that it's important to try and make an effort to make things work and support your partner through this.

# Supporting your partner

Your partner will need a lot of support (practical and emotional) throughout their cancer journey.

The role you take on in terms of supporting your partner will depend on what the status of your relationship is. If you are living together then you may take on a much bigger role in caring for your partner, whereas if they live with their parents, or move back home, you may be less involved in the day-to-day caring role.

Whatever role you take on it will bring some big changes for you and it may take time to adjust. It can be pretty tough trying to balance it with everything else going on in your life like work, study and other commitments.

## Remember:

### You don't have to do this all on your own.

A carer is the term used to describe someone who helps and supports someone through a disease like cancer. You may not see yourself as a carer but simply someone taking care of the person you love.

Every situation is different and what you do will depend very much on your situation and what your partner needs and wants from you. However, if you are a full time carer, then it is important to find ways to share the load with other family members and friends. There are lots of roles that you might take on as part of supporting your partner.

Some of the roles you might take on include:

### Dealing with doctors and other members of the health team.

This can be quite a scary thing especially if you haven't had much to do with doctors, nurses and treatment centres before. It may feel like they are all speaking another language and that there are a whole lot of new "customs" and "rituals" from another planet.

But getting a handle on what is happening is really important. You have a right to be included as part of your partner's care team. Don't be afraid to ask questions, let healthcare professionals know when you don't understand something, and ask for more information if you think it will help.

You may feel excluded from important conversations because health professionals or family members may not recognise your role. If you are feeling excluded it's OK to let your partner know how you are feeling and talk about ways for you to be included.

It's always a good idea to keep checking in with your partner to make sure that you know what their needs or wants are. While it's easier said than done – keeping open and honest communication going will help to make this a lot less stressful for everyone.

### Note Taker.

Often when you are stressed, you don't remember everything that is said to you – especially when it involves medical stuff. You may be surprised to find that both you and your partner hear different things when you go to Dr's appointments – or that you both miss stuff.

A great way to support your partner is to take notes during the appointment, or even record it on a smart phone or other device, so that you can refer back to it at another time.

### Paper organiser.

You will be amazed by how much paperwork gets generated by a cancer diagnosis – bills, receipts, referral letters, scripts, scans, X-rays, blood test results. It's a good idea to keep them in one place. You might end up being the person who looks after these so you can find them when you need to. If you need some help, this is one area where parents or friends can come in handy – they might have had some experience in organising paperwork.

### Drug Manager.

Your partner may be taking prescription and non-prescription medications. You can help them by being informed about what they are taking and when they need to take them. A 7-day pillbox is a great idea (you can get these from a chemist) – you just put in all the meds they need to take each day of the week. There are also some great apps that you can get to remind you when and what they have to take, or you can download it for them.

### Physical Carer.

When your partner returns home they might also require help with their personal care (washing, dressing etc.) or with physical tasks (such as getting in and out of bed).

### Communicator.

It's likely that your partner will need to take time out from work or study and they might need your help to communicate with their employer or educational institution about their progress.

### Best friend.

Your partner is going to be on an emotional rollercoaster and might need support from you in terms of giving them a shoulder to cry on, someone to laugh with to lighten the mood or someone to vent to about how unfair everything is at the moment.



*When he was ready to joke and laugh about certain things, I could too. When he was ready to share, so would I.*

(Louise, 24 years whose partner had cancer)



## REMEMBER:

Sometimes your partner may feel like people are taking over and they want to feel more independent.

Other times they may feel like a burden and they may not want to ask for help.

Always check in with your partner to see how you can help.

### Other support.

There are many ways to help other than the more traditional ones that people think of like cooking, cleaning, and taking them to Dr's appointments.

Other support can include:

- Keeping friends in the loop
  - updating Facebook, tweeting or posting on instagram (check with your partner first as to what they are happy to share).
- Answering questions so that your partner doesn't have to keep repeating the same stuff.
- Coordinating visits.
- Being their social organiser.

These things can be incredibly important in helping them to have an outlet and focus, other than being the "cancer patient".

Sometimes it can be helpful to get your partner to let you know what would help to support them. Ask them to tick any of the things opposite that they want you to do including things you already do.



# Checklist -

- Discuss important decisions about my treatment with me.
- Listen to me talk about my feelings.
- Ask me how I am feeling (even if I am not feeling so good).
- Tell me that you love me just the way I am.
- Don't avoid talking to me about tough stuff.
- Don't try to solve my problems.
- Tell me how YOU are feeling.
- Encourage me to exercise or exercise with me.
- Just sit with me.
- Give me some time alone.
- Take messages, return phone calls or send texts for me.
- Talk to me about things other than cancer.
- Take me out.
- Make me laugh (well try to).
- Hug me.
- Rub my back, feet, shoulders or hands.
- Please accept there are some decisions I need to make on my own.

This checklist has been amended and reproduced with kind permission from the Cancer Council Queensland 'Partners guide to coping with cancer'.



# Finding support for you

All of this may seem really overwhelming and you might be worried that you can't organise it all. A good idea is to write down the things that you already do and then work out what could be done by someone else. It's important to involve your partner in this as there may be things that they only want you to do (showering, getting dressed, going to Dr's appointments). It's also OK to pick the things that you like to do - cooking and shopping, taking them out and then delegate the things you don't like - cleaning, washing, ironing.

Certain things might freak you out like seeing your partner receive chemotherapy or going through other medical procedures. Sometimes finding out more information about what to expect and what your partner is going through can help. You might need to call on family or friends to help you out by being there to support your partner if you can't.



The support has come from going to appointments, chemotherapy and still trying to do fun things that she enjoyed that had NOTHING to do with hospitals, cancer, tests etc. to keep preoccupied in her quiet time when she felt well.

(Luke, 22 years whose partner has cancer)



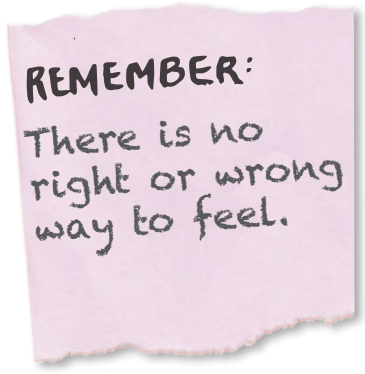
Remember: Asking for help can be difficult but not asking can make an already hard situation harder.

# Impact on your everyday life

Being the partner of someone who is living with cancer can mess with many parts of your life. There will be both big and small changes that you may have to deal with.

## Your wellbeing.

It's likely that you will go through some major ups and downs. You might swing from one emotion to another (it's actually possible to be happy and miserable at the same time). Some days your feelings may be so intense and out of control that you feel completely overwhelmed.



At different times you might feel:

ANNOYED  
Scared  
JEALOUS  
uncertain  
CONFUSED  
numb  
shocked  
sad  
EMBARRASSED  
nothing at all  
relieved  
ANGRY  
FRUSTRATED  
LEFT-out  
lonely  
OVER IT

### Living arrangements.

Your partner may choose or need to move back in with their parents so that they can get looked after. This might be a relief for you or you may feel that your role has been taken over. It may also mean that they move to a different town or city. If you have been living together this will be a major change for both of you.

Working out what roles all of you play in supporting your partner will take some negotiating.

Depending on where they live, your partner may have to move so they can receive their treatment. Being separated from each other can put a whole lot of extra strain on your relationship. You might feel guilty for not being able to be closer but you might also feel relieved that you don't have to be involved in the day-to-day care. Both reactions are OK. You could also feel excluded from some of the decision-making and also feel like you are the last one to know about treatment and care.

There are lots of ways to stay in touch and feel connected and involved in your partner's care. Thank goodness for smart phones, iPads, Skype, snap chat, instagram and every other device and app that keeps you connected. It may just take a bit more planning.

### Money matters.

On top of everything else on your mind, you may be worried about how much all this cancer treatment is going to cost and how you are both going to manage financially. Having a partner with cancer can put financial pressure on you; they may not be able to work which will

mean they can't contribute to the rent and other household expenses, you may have to reduce your working hours to care for them. There could be increased expenses like medications, equipment and transport costs. If you are used to being independent, asking for financial assistance can be really hard.

### Financial assistance.

There are government agencies, charities and other organisations that exist to help people through tough times. There are government payments that you may be entitled to such as:

- Carer payment – if you live together and you provide most of the care. It's income and means tested (depends on how much you both earn and how much money you have in the bank).
- Carer allowance – if you provide a significant amount of assistance either in your own home or where your partner is living. This isn't means tested so you may be able to get it even if you are working or getting another government benefit.

There is no shame in applying for assistance. It's there for all people in your situation no matter what your finances are like.

There is a lot more information on this in the [Now What...? A young person's guide to dealing with cancer](#) book and there are links and contact details in the 'Where to get more information and help' section at the back of this booklet.



You and your partner might be eligible to receive:

- Rent assistance
- Carer's assistance
- Unemployment assistance
- Pharmaceutical allowance
- Student assistance
- Concession cards
- Parking vouchers at the hospital
- Accommodation close to the hospital during treatment
- Transport costs to and from the hospital

# Study and work

It's likely that whilst you are supporting your partner you'll also be trying to juggle study and/or work.

## Work.

If you are working full time you may be able to speak to your manager about flexible hours so that you can be around to care for your partner. You may need to take annual leave or personal leave.

Speak with the Human Resources (HR) Department at your workplace to find out what your entitlements are. If there isn't an Human Resources Department then you will need to speak to your manager.

A lot of workplaces also have what's called an Employee Assistance Program (EAP). This is a free and confidential counselling service that employees can access. Check if your workplace has a program.

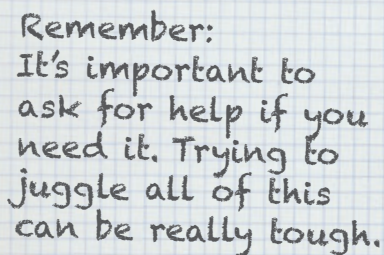
There is no obligation to tell your manager anything about your personal situation, but you might find it's helpful especially if you are finding it all a bit tough and need some time off. The same goes with your work colleagues. Who you tell is up to you (but you might need to respect your partner's wishes about who they want to know).

For more information on your rights at work check out [fairwork.gov.au](http://fairwork.gov.au)

## Study.

How much your studies are affected may depend on what your caring role involves. However, don't be surprised if you find concentrating on study difficult regardless of whether you are a full-time carer or not.

If you are finding it all a bit much then speak to your tutors and lecturers to let them know what is happening. There may be ways to reduce your workload, get extensions or special considerations for exams and assessments. Most campuses also have a Student Services Centre that provides support services such as counselling and financial assistance.



Remember:  
It's important to  
ask for help if you  
need it. Trying to  
juggle all of this  
can be really tough.

## Looking after yourself

You will probably expect that your partner with cancer will be the main focus for family, friends and even well meaning strangers. The first question will usually be about how they are doing. But after a while you might start to feel like the invisible bystander; like your feelings and wellbeing are not an issue for anyone.

When you are looking after someone you love who has cancer it can be very easy to forget about yourself. It's likely that you will feel that their needs at this time are far more important than yours and living with cancer trumps everything else.

You might think 'How can you complain about being tired or having a bit of a headache when your partner has a mouth full of ulcers and can hardly drag themselves out of bed to have a shower?'

This isn't a competition, but if you don't look after yourself then you won't be able to look after them. Taking care of yourself is not selfish – it's good for both of you.

## Things that can help

- Try to keep doing things that you enjoy – going to the gym, playing sport, hanging out with friends or whatever other activities you are involved with.
- Find ways to be a partner, not just a carer.
- Don't skip meals or rely on takeaway food. Eating healthily is important. If cooking isn't your thing then this may be a good way to get support from friends and family.
- Go easy on the alcohol (and any other substances). Without the lecture, while they might feel like they're helpful in the short term they aren't good for your body or your mind in the long run.
- Take some time out to reflect on what you're going through and what you're feeling. Talking about how you're feeling or writing it down can often help you make sense of your feelings and put them into perspective.
- If it all starts to feel a bit overwhelming, finding someone to talk to can really help. You may already have a great support network but sometimes this might not be enough. Seeing a counsellor or psychologist can be very helpful. Seeing a psychologist, or a social worker or occupational therapist with mental health training, can be very helpful. If you are diagnosed with a mental disorder (e.g. depression, anxiety) then a GP can organise a mental health treatment plan for you and refer you to one of these clinicians. Medicare will cover some of the cost of these sessions.



# Things that can help (continued)

- You may feel like you are the only one dealing with this, so talking to someone else going through a similar experience can help. The support services (or health professionals) listed on page 27-29 may be able to link you in with others going through a similar experience to you.
- If there aren't any support services in your area, you can look online for chat-rooms and forums for young people dealing with similar stuff. Sharing your experiences may help others too!
- While you may be used to partying, staying out late and not getting enough sleep – with the added emotional stress of caring for your partner – lack of sleep can make it all a whole lot harder.
- Going to the doctor may not be something that you have ever done regularly (most young people don't). But it's important to get things checked out if they are worrying you. You may find that you are more aware of aches and pains and that you are scared that they could be serious. This is not an uncommon response.
- Ask other family members and friends to help out so that you can get regular breaks.
- Protecting yourself from colds, coughs and the flu is important for yourself and your partner. Their immune system can be comprised by their treatment, which means they'll be more at risk of getting infections. (You will also be able to better manage the extra stress of being a carer if you are feeling well).
- Take time everyday to do something for yourself – even if it's just 10-15 minutes.

**REMEMBER:**  
No matter what happens, you are not alone.



# Beyond cancer

**When you and your partner are stuck in the middle of treatment you might not have the energy to think about what will happen when it's all finished.**

While the end of treatment is a cause for celebration, it can also bring fear, anxiety and confusion about what the future holds.

Life has changed for both of you. Once treatment has finished, your partner will move into a stage often called survivorship. Figuring out what to do after cancer treatment is one of the hardest things for a cancer survivor to do.

Your partner will need time and space to adjust. Cancer treatment can leave the body and mind pretty battered.

This may also be a tough time for you. You might expect them just to "get back to normal" and get on with it. You may feel frustrated that they can't seem to get back to the way they were before. You may also feel like you have had to put your life on hold as well and that now treatment is over you just want to go back to the way it was before cancer gatecrashed your world.

Sometimes it's only after treatment has finished that you take a breath and realise just what an emotional rollercoaster both of you have been on. You may have tried to be the "strong" one and hold it together for your partner, but once their treatment is over you might feel all sorts of things. It's normal for you to have these thoughts and feelings. You are not a bad or selfish person.

## Long term effects.

Cancer treatment, as you have probably already worked out, can be pretty brutal. It can result in long-term effects (both physical and emotional).

## Physical changes:

### Fatigue.

Fatigue is a feeling of tiredness or not having enough energy despite how much sleep you get. Many cancer survivors experience ongoing fatigue after their active treatment has finished. This can have a negative impact on their quality of life and also affect you.

For your partner, feeling like you are a young person trapped in an old person's body can be very frustrating and feeling like you are living with an old person can be frustrating for you. You both may have to make adjustments to the way you do things to manage this.



*It took me a long time to learn how to be a girlfriend again and stop stepping into his "carer" mode so quickly.*

(Louise, 24 years whose partner had cancer)



### Your partner's body.

Your partner may have to deal with permanent physical changes from surgery, chemotherapy and radiotherapy. Some of them may be very obvious like a loss of a limb, breast, testicle or scars from surgery. These changes can impact on your partner's self esteem, their confidence and adjustment to life after cancer.

### Cognitive changes.

Some cancers and treatments can result in cognitive changes, which means changes to the way people think, learn, process or remember information. People sometimes refer to this as "chemo fog" but other types of treatment can also have an impact. Changes in these abilities can be upsetting because they may affect many aspects of your partner's life such as the ability to work or even to do everyday tasks that used to be routine.

This can also mean changes for you – having to take on extra tasks that you didn't have to do before the cancer or feeling like they are not the same person you were used to. Your partner may also get frustrated because they can't do things that they used to be able to do. Finding ways to manage these new challenges will take patience and open communication.

### Emotional changes.

It's common for people who have survived cancer to experience long-term emotional effects related to their cancer experience. You may find that your partner experiences ongoing worries about the cancer returning and has other symptoms such as anxiety and depression. It's important to encourage them to access appropriate support to help them deal with these thoughts and feelings. CanTeen offers a free counselling service (visit [canteen.org.au](http://canteen.org.au) for more information).

It's likely that you will continue to experience some of these fears and anxieties too and accessing support for yourself is also important.

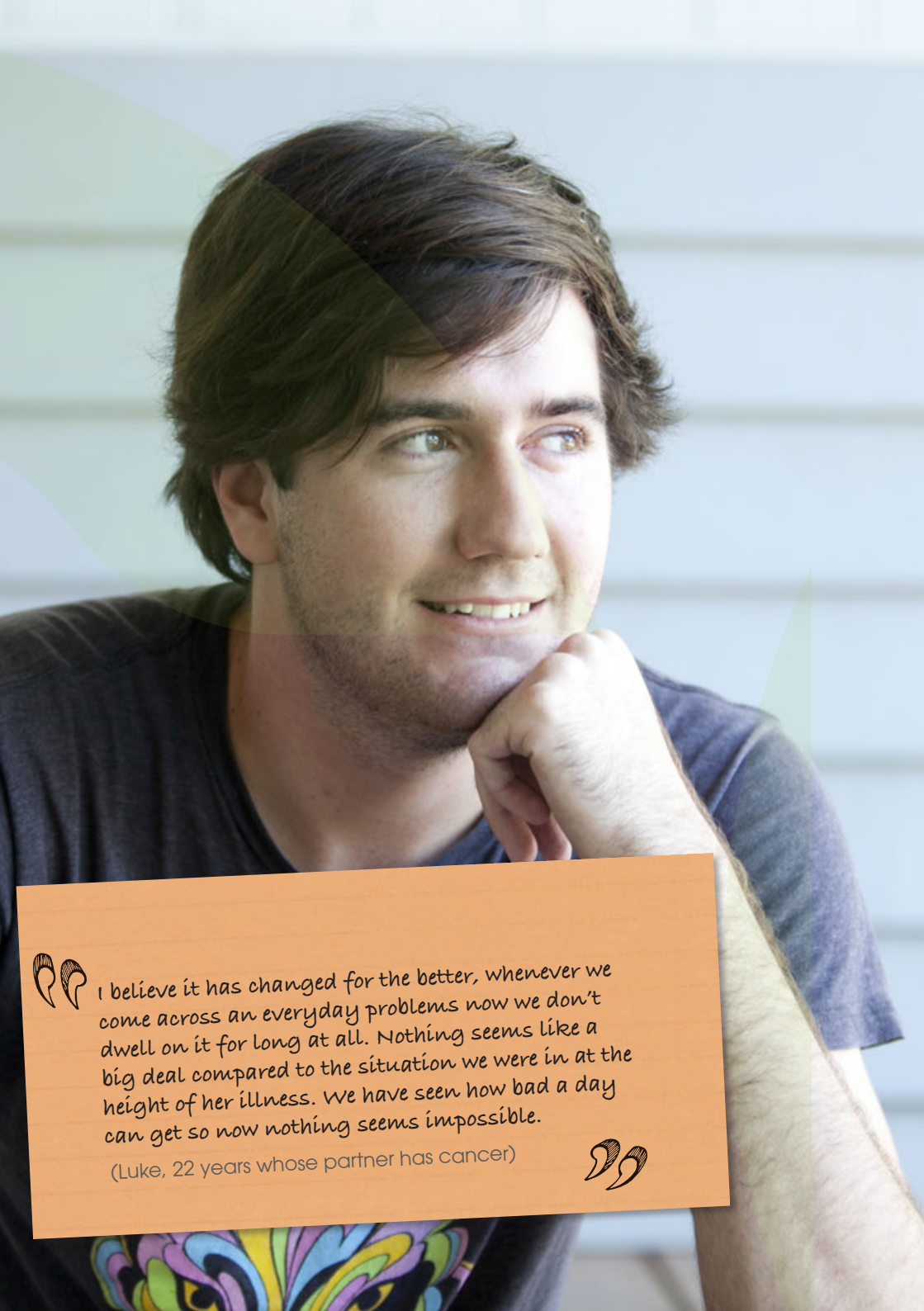
The cancer experience doesn't finish when treatment does. These long term effects can continue to impact on both of you. As with so many aspects of this whole experience, having realistic expectations, open communication, the right information and good support is important for you, your partner and your relationship.



*After we were thrust back into normal life, with David's encouragement, I decided it was time to take active steps toward my own goals and dreams. David did the same with his own goals. Having an individual outside focus really helped us get back to being a normal couple.*

(Louise, 24 years whose partner had cancer)





I believe it has changed for the better, whenever we come across an everyday problems now we don't dwell on it for long at all. Nothing seems like a big deal compared to the situation we were in at the height of her illness. We have seen how bad a day can get so now nothing seems impossible.

(Luke, 22 years whose partner has cancer)



# If cancer returns

While doctors will have tried to give your partner the very best treatment, there is a chance that the cancer will come back. This may feel like you have both been dealt a seriously rough deal and it can seem like it's the end of the world. You might wonder how the two of you are going to get through it again and if you have the strength to support your partner through this a second time.

The emotions you feel can be very powerful and overwhelming and you may wonder if everything you have been through before was for nothing. What sort of treatment your partner is offered will depend on what treatment they have had before as well as what type of cancer they have relapsed with and where. You can read more about this in the [Now What...? A young person's guide to dealing with cancer](#) book.

Having done it all before might make it easier or it might be a whole lot harder because you know what you are in for. There will be decisions your partner will have to make about their treatment. You might both have different ideas on how to deal with this and it can be hard if you feel like you have no control.

While your feelings and reactions are valid, the reality is that it's your partner's right to make the decisions that are best for them.

**REMEMBER:**

Be kind to yourself  
and don't be afraid to get help.

# If treatment doesn't work

**Most young people will survive their cancer treatment. Unfortunately, however, for some young people their cancer can't be cured, despite the best treatment. Finding out that your partner's cancer can't be cured is one of the hardest things that you will ever have to deal with. You may want to yell and scream about how unfair it is or you may just want to hide away and shut everything out – whichever way you react is OK.**

It's important to remember that nothing you did, didn't do, thought, felt or said had anything to do with the situation you are now facing. It's just the brutal reality of a cancer diagnosis. And yes, it sucks big time.

Learning to live with the knowledge that your partner can't be cured is never going to be easy. As with any shock it will take time for you to process what this means and how you are going to deal with it – and at the risk of repeating it once too often there is no right or wrong way to feel about this.

You may both try and protect each other by denying and pretending that it's still all OK even though you know it isn't. Trying to be honest and open can help you support each other through the anger, fear, sadness, anxiety and uncertainty.

It's important to try and keep your relationship as normal as possible. Trying to make big changes now can just put extra strain on you. You may find that your relationship gets even stronger as you face this new reality together. But don't be surprised if there are times when you both get angry with each other and need some time alone.

Dealing with other family members and friends will also take some negotiating. Everyone will be doing it tough and trying to make sense of it all. If there were strains in relationships before don't expect them to just disappear – in fact they may get a whole lot worse. You may feel stuck in the middle or feel that your feelings and needs are being ignored.

Getting the right information and support will help you in supporting your partner in making decisions that are right for them and also help you to manage your own fears and uncertainties.

Self-care through this stage is also important. Remember that you are under a lot of emotional stress and you need to take care of yourself. Dying is really scary stuff. Find people you trust and who will be honest with you about what is happening.



# Where to get more information and help

## Cancer information and support services for young people living with cancer:

### [canteen.org.au](http://canteen.org.au)

CanTeen supports young people when cancer turns their world upside down and helps them cope with the physical, emotional and practical impact of living with cancer. We provide specialist hospital care, counselling and individual assistance as well as information and peer support programs for 12-24 year-olds affected by cancer.

### [youthcancer.com.au](http://youthcancer.com.au)

This website is a service directory where young people diagnosed with cancer and their families can find information about services available to them. This includes youth cancer hospital wards, support organisations, financial services and information services. You can search based on your location and even the type of cancer your partner has.

### [cancer.org.au](http://cancer.org.au)

Cancer Council's website has some really good, clear information on lots of things to do with cancer including different types of cancers, treatments and side effects. From this site you can access Cancer Council in your state.

### [cancerconnections.com.au](http://cancerconnections.com.au)

Cancer Connections is an online peer support community. People can read blogs, posts and participate in conversations with others in a similar situation. There are groups for family and friends and for young adults.

### [redkite.org.au](http://redkite.org.au)

Redkite provides a range of services to support children and young people

(aged 0-24 years) with cancer, as well as their families. They provide emotional, financial and educational assistance.

### [youngcarers.net.au](http://youngcarers.net.au)

This site is for young people who are caring for someone in their family who has an illness like cancer. There are support groups, advice on financial issues and tips on how to take care of your own wellbeing.

### [thewarwickfoundation.org.au](http://thewarwickfoundation.org.au)

The Warwick Cancer Foundation aims to support young adults 18-40 who are living with cancer. They provide programs such as Mates in My Shoes, a peer support program, Wellness Programs and also offer the opportunity to be "pampered".

## Dealing with grief and loss and other tough stuff:

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

This is a national organisation that has useful information on counselling, health, accommodation and a whole lot of other services. They can help you deal with things like stress, depression and loneliness.

### [youthbeyondblue.com](http://youthbeyondblue.com)

Beyondblue's website for young people - information on depression, anxiety and how to help a friend. They also provide links to organisations and doctors who have experience dealing with depression.

### [headspace.org.au](http://headspace.org.au)

Headspace is an Australian site that supports young people with mental health issues.

### [kidshelp.com.au](http://kidshelp.com.au)

This has a free and confidential online counselling service as well as other helpful information on dealing with tough things.

### **Drugs, alcohol, sex and other tricky topics:**

### [somazone.com.au](http://somazone.com.au)

Somazone offers free confidential advice and information for young people about drugs, sex, mental health, body image and relationships.

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

A site specifically designed for young people going through tough times. Reach Out has info on issues like depression, drugs and alcohol, relationships, sex and grief.

### **Information about fertility:**

### [fertilehope.org](http://fertilehope.org)

Fertile Hope is a non-profit organisation dedicated to providing reproductive information, support and hope to cancer patients and survivors.

### [thewomens.org.au/fertilityandinfertility](http://thewomens.org.au/fertilityandinfertility)

This is the website of the Royal Women's Hospital reproductive health service that has information related to fertility and cancer treatment for both women and men.

### **Financial assistance:**

### [centrelink.gov.au](http://centrelink.gov.au)

Centrelink is a government agency that offers financial assistance to people in need, including people who are sick, disabled or caring for others. You can also call 13 27 17.

### [cancer.org.au](http://cancer.org.au)

Cancer Council can provide details of many local financial assistance services for patients and carers.

### **Legal stuff:**

### [lawstuff.org.au](http://lawstuff.org.au)

This website provides lots of information and advice for children and young people about legal matters.

### [youthlaw.asn.au](http://youthlaw.asn.au)

Young People's Legal Rights Centre provides free and confidential advice to people up to the age of 25.

### **Regional and remote patient services:**

### [ama.com.au/node/4099](http://ama.com.au/node/4099)

The website of the Australian Medical Association provides information on Patient Assisted Travel Schemes available in each state. They help with the cost of travel and accommodation for cancer treatment.

### [vise.org.au](http://vise.org.au)

Volunteers for Isolated Students Education provide educational assistance to students in rural Australia and domestic and personal support in the case of illness.



### [angelflight.org.au](http://angelflight.org.au)

Angel Flight is a charity that coordinates free non-emergency flights to medical facilities for people in need.

### **Palliative care and end-of-life support:**

#### [pallcare.org.au](http://pallcare.org.au)

Palliative Care Australia provides help and information on accessing palliative care.

#### [homehospice.com.au](http://homehospice.com.au)

Home Hospice provides information and support for people preparing for dying at home.

#### [makeawish.org.au](http://makeawish.org.au)

Make a Wish Australia grants wishes for children under the age of 18 who have life-threatening medical conditions.

### **Talk to someone:**

#### **Kids Helpline**

1800 55 1800

#### **LifeLine**

13 11 14

#### **Cancer Council Helpline**

13 11 20

### **Other resources:**

#### **Now What...? A young person's guide to dealing with cancer.**

This book provides support and information to help young people who have or had cancer deal with practical and emotional challenges and regain a sense of control. It is divided into six sections:

- Finding Out – dealing with the diagnosis, getting the right information.
- Med Stuff – cancer facts, treatments and side effects, hospitals.
- Heart Stuff – coping with feelings, changing body image, getting support.
- Life Stuff – relationships, tips for talking, managing study and work.
- Beyond Cancer – finding a new kind of 'normal' after treatment.
- Handy Stuff – where to get help, tear off cards to give to family and friends.

#### **Maybe Later Baby: A guide to fertility for young people with cancer**

This book provides honest, clear and accurate information so that young people can be informed of their fertility options both before and after treatment, allowing them to make decisions about their fertility at the time that is right for them.

You can order these books online at [canteen.org.au](http://canteen.org.au) or by calling 1800 226 833.

# References

## The following were useful in putting this booklet together:

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Cancer Council New South Wales (2011). Caring for Someone with Cancer. Available at [cancerCouncil.com.au](http://cancerCouncil.com.au)

American Cancer Society (2012). What It Takes to Be a Caregiver. Available at [cancer.org](http://cancer.org)

American Cancer Society (2012). What You Need to Know as a Cancer Caregiver. Available at [cancer.org](http://cancer.org)

Free copies of this booklet are available to order or download at the website [canteen.org.au](http://canteen.org.au) or by calling 1800 226 833.



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