

Partners guide to coping with cancer

A guide for partners of someone with cancer



First published 2012. This edition February 2020

Partners Guide to Coping with Cancer is reviewed approximately every three years. Check the publication date above to ensure this copy is up to date.

Acknowledgements

This edition has been developed by Cancer Council Queensland.

We thank the reviewers of this booklet: Christine Cotter, Senior Social Worker, Royal Brisbane and Women's Hospital; Dr Carly Fay, Psychologist, Cancer Council Queensland; Patricia Husband, Prostate Cancer Specialist Nurse, Townsville Hospital; Kerry Caldwell, consumer; Margaret Nugent, Coordinator Cancer Support, Cancer Council Queensland.

We would like to thank the health professionals, consumers and editorial teams who have worked on previous versions of this title.

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Cancer Council Queensland

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If you would like to know more about the information and support services provided by Cancer Council Queensland, call **13 11 20** Monday to Friday, 9am to 5pm, excluding public holidays or visit cancerqld.org.au

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Introduction

Being diagnosed with cancer is one of the most distressing and demanding experiences a person can face. The focus naturally falls on the person with cancer. But partners, and other family members, often suffer as much or even more distress. Fears for your partner, emotional turmoil, and increased demands can continue for some time and leave you vulnerable to the effects of stress. And just at a time when you are needed more than ever. If you are the partner of someone with cancer, this booklet is designed to help you with these challenges.

Being a partner involves being in a relationship, and there are issues that involve you both. This book is designed to share together; to help understand each other's feelings and reactions, and to work together to protect and strengthen your relationship.

Not every topic in this booklet will relate to everyone. There may be too much information to take in all at once. It may not contain all the information you need but can point you in the direction of other resources. It can be reassuring that many other people have faced similar feelings and issues. Their experiences can give you ideas to help you find your way through change and new demands. What worked for them may help you to support your partner, look after yourself, and work together to maintain your relationship.



The impact of diagnosis – a partner’s perspective

Your emotional reactions

As a partner, you also face the shock of diagnosis, concerns about surgery and other treatments, and fears for your loved one’s wellbeing. You may be facing more demands. You might need to take on extra household tasks and find ways to support your partner. You could be dealing with pressure on your relationship. And the impact of the diagnosis on other family members.

The thought of cancer is frightening in many ways. In the time after diagnosis you may experience a range of different feelings. Some people have described feeling like they were in shock or numb when they heard the news. Other common reactions include feeling anxious and scared, upset or emotional. You can feel confused, particularly when trying to understand complex medical information. Or when helping your partner decide about medical treatments.

Feelings of helplessness and frustration are common, especially when you are watching your partner undergo many medical tests and procedures. Sometimes you may feel angry. You may feel it is unfair your loved one got cancer or wish the cancer had been found earlier.

With so much happening for your partner, you can feel that your own feelings and needs don't deserve attention. And you may push them into the background. But it is common for partners of cancer patients to experience high levels of emotional or psychological distress. You might find you are thinking less clearly, with difficulties such as:

- Poor concentration
- Memory problems
- Worrying thoughts
- Confusion

You may also experience physical responses to the shock of the cancer diagnosis including:

- Fatigue
- Disturbed sleep
- Nausea
- Nightmares
- Restlessness
- Headaches

You may have never felt this way before and it can be overwhelming. But feeling like this does not mean you are 'going crazy' or that you are 'weak'. These are all normal reactions as you try to take in complex and distressing information, make some sense out of it, and put it into perspective. With time, people usually begin to adjust to the changes brought about by cancer and begin to feel more like their usual selves.

Sometimes people continue to feel very worried, upset, or depressed in ways that interfere with their lives. If you find your distress is very high and stops you from functioning, or you don't feel any better over time, talk to your doctor or health professional about support options and ways to help you manage.

'When the specialist said the results showed that my partner had cancer I felt like I had been kicked in the guts. She is the best person I know and doesn't deserve it.'

'I kept getting these visions of me with the kids on my own. I thought that we were going to lose her and that there was no way we would cope without her.'

'John and I just sat there stunned. It probably looked like we were taking it on board but neither of us could remember a thing about that doctor's visit.'

Shifting roles

When your loved one is diagnosed with cancer, there may be changes in family roles and routines. The adjustments will vary depending on your situation. Your partner may not be able to manage all their usual roles and tasks, such as household chores, work, home maintenance, childcare, financial affairs, and/or family relationships. They may now be more dependent on you, and you might have to take on roles that don't come easily or that you find hard to manage. While it can be a relief for your partner to get practical support, it is also important that your help doesn't stop them doing the things they want to, or can, do.

At first, a shift in roles can be difficult for you both. It is important to talk together about how you are both coping with these changes. You may also need to adjust your expectations about the way tasks are done (or even not done!). You might relax housekeeping standards, simplify tasks where possible or accept offers of help from friends or family.

Adjusting to change

A diagnosis of cancer marks the beginning of a journey. Cancer is not just one stressful event to deal with and move past – it is a series of changing situations and demands. This means that you and your partner might need to regularly review how you are managing things. While this requires effort, it will help you to use your time and energy effectively. Working together as a team to figure out new ways to adjust to the changes in your lives will help to ensure you understand each other's efforts to cope and choose ways that work well for you both.

Cancer can raise concerns about plans you already had in place, both short and long term. Changes to your day-to-day lives are to be expected during cancer treatments. These changes can involve loss – for example income, your sense of safety or control, future plans, or roles changing in the family. Such losses can have an impact on the way you are both feeling and coping. It is essential to; acknowledge your disappointments (rather than dismissing them); take time out when you need to; have realistic expectations; and allow yourself time to adjust.

Understanding your reactions and respecting differences

Your partner might respond to stress in a completely different way to you and this can be hard to understand. One partner may express their emotions more openly than the other (such as crying or talking about their feelings).

This doesn't mean the less expressive partner doesn't experience emotion. They may just deal with it in different ways. Some people focus on trying to find ways to solve the problem (which can be productive if the problem can be solved). Others focus on trying to manage their emotional reactions to the problem (which is helpful when the problem is beyond their control).

You may have recognised these differences in the past, but a stressful event like cancer might make them more obvious. Although it can be difficult to accept these different reactions, it is important to understand this may be the only way a person can cope at the time. Reactions are not necessarily right or wrong. But they can be more or less helpful depending on the situation.

Ways of reacting to stress that are common, but often cause misunderstandings and hurt feelings, include:

Withdrawal

This can include avoiding talking about cancer-related issues. Or becoming occupied with distracting activities, such as work. Withdrawal can seem like a lack of caring or coldness, but it is often a response to strong emotions that are difficult to handle, such as fear and anxiety. Avoiding opportunities to talk is also a way to protect yourself or others from overwhelming, unpleasant emotions. If you sense this is happening, it is best to approach your partner gently and talk about the situation with understanding.

Over-protection

Sometimes partners or family members do more for the person with cancer than is necessary. They might not want/allow the person with cancer to do their usual household tasks or other activities. Or they might continually tell the person with cancer what to do to take care of themselves. They may also stop them from expressing any negative thoughts or feelings and/or avoid telling the person about their own fears or feelings.



Tip

If you want to help the person with cancer, it is important to ask them what they would and would not find helpful.

Partners and family members often believe doing these things will help the person with cancer. Unfortunately, these behaviours may take away activities that give the person satisfaction or a sense of purpose. Trying to protect your partner from negative thoughts and feelings can often have the effect of making them feel dismissed and isolated. Or even that you don't trust them to be able to deal with these very natural feelings. Not talking honestly takes away the chance to understand one another, to feel better through sharing, and to work together as a team.

Anger

Frustration that things are not happening the way you would like or feeling out of control, may result in anger in you or your partner. Anger can be difficult to understand because often another emotion – such as fear, hurt, sadness, or grief – lies underneath. When people feel angry, they can behave in unhelpful ways, including yelling, criticising, or withdrawing. If you or your partner are behaving like this, it is important to remember that neither of you have caused or are to blame for the cancer.

Feeling angry is a normal response to a diagnosis of cancer and the feeling will not last forever. But it is not a normal part of adjustment if anger becomes excessive, ongoing, violent or abusive. If this occurs, it is important to get help and support as soon as possible.

Frequent discussions

You might want to talk about the cancer or your feelings. This can be a useful way of sorting out thoughts, releasing emotions, and gaining understanding. But frequent or recurring discussions may become exhausting or distressing for one partner. It can be useful for the other partner to find support outside the relationship to meet their need to talk.

These reactions can be confusing and cause misunderstandings. Remember they are rarely deliberate and usually reflect difficulty coping with emotions or knowing what to do. Using good communication and handling conflict well can make a difference. We will look at this in more detail further on.

‘Terry’s way of coping was to get on with things, where I wanted to talk things over and over. At times it was frustrating, but I knew that he was doing what he needed to do to manage his thoughts and feelings.’

Supporting your loved one

During this stressful and demanding time, you are likely to be putting a lot of effort into supporting your loved one. But sometimes, despite our best intentions, our efforts do not seem to be as effective as we would hope. Often this can be due to a mismatch between what we think would be helpful and what is actually needed. We may also feel uncomfortable raising difficult topics, or concerned about upsetting each other if we are open about our feelings and needs. Talking openly and non-defensively together about how to support each other is the best way to improve understanding. Being creative about ways to support each other can lead to other ideas and make it more likely that your efforts are where they are most needed and appreciated.



Ideas for supporting your partner

Ask your partner to tick any of the items below that would help to support them (including those things you already do that they would like you to keep doing).

- Discuss important decisions about my treatment with me
- Listen to me talk about my feelings
- Ask me how I'm feeling
- Express an understanding of my mood and feelings
- Tell me that you love me just the way I am
- Give me words of encouragement
- Don't avoid talking to me about the tough things
- Don't try and solve my problems
- Tell me how YOU are feeling
- Help me with the shopping
- Help out with the kids
- Make me a cup of tea
-
-
-
- Exercise with me or encourage me to exercise
- Keep me company
- Take care of me if I feel unwell
- Give me some time alone
- Take messages or return phone calls for me
- Help me to think of and talk about other things besides cancer
- Speak positively about the future
- Cheer me up with your sense of humour
- Rub my feet/shoulders or back
- Take me on an outing
- Give me hugs
- Accept there are some decisions I need to make on my own



Maintaining your wellbeing

It can be easy to forget to take good care of yourself during everything you are doing to support your partner. As well as your normal roles and responsibilities you can find you have increased demands on you. You may need to provide more emotional support to your partner and other family members. You may have to deal with financial stress. You might find there are more demands on your time and energy. When stressed it can be hard to find the opportunity or motivation to relax or re-energise through leisure activities.

At times it can seem that the best approach to a crisis is to throw everything you have at the problem. And that once it is over you will be able to stop, catch up, and recover. This may be fine for a short-term crisis – like a sprint where you put everything you have into the race because you only have to last a short distance. But dealing with cancer may be less like a sprint and more like a marathon. Not looking after yourself may lead to high levels of stress and burnout. And you may not be able to last the distance and support your partner effectively.

It is okay to put your own needs on hold for short periods of time, but continuing to do so for longer may affect your own health, relationships, and quality of life. If you make sure you take good care of yourself and have enough support, you are more likely to be able to continue to support your partner long term - with you, and your relationship, still in good shape.

Looking after yourself

It may be helpful to think about your wellbeing as a bank account. Your account stays in credit if you look after yourself well. That is, you make 'deposits' into your account to offset what you take out to meet life's demands. The demands of cancer treatment and supporting your partner can mean that you are taking more out of your account than usual. If you are not looking after yourself – that means, you are putting less than usual into your account – your wellbeing account will soon be emptied and in deficit.

Ways to look after yourself and maintain your wellbeing include:

Stay connected

Although a lot of your attention will be focused on dealing with your partner's cancer, it is draining to do this all the time. Staying connected with the world around you can help. It can help you see a life outside and beyond cancer. This can also give you time out from your worries. You might continue to work, spend quality time with your partner, do a hobby, or spend time with family or friends.

Invest in your physical health

Make sure you are eating well to give your body the best chance to cope with stress. Alcohol and caffeine (found in coffee, tea, soft drinks, and chocolate) can put a strain on your body so try not to drink too much.

Try to exercise regularly

Making time for exercise can be hard but regular physical activity can improve your mood, lower blood pressure, improve sleep, and reduce stress. Also, physical activity is an important way to manage fatigue. It helps you feel more energetic and less tired. But make sure you match your physical activity to your current level of fitness. Seek advice if you plan to increase the amount or intensity of your exercise regime.

Do things you enjoy

It is important to create spaces for relaxation and enjoyment every day even though you may be extra busy and feel you don't have time. Think about things you do (or have done in the past) that help you unwind and feel good. It might be half an hour spent reading the newspaper, being in the garden, having a bath, or listening to calming music. These activities are not luxuries. They are important ways to prevent the build-up of stress and stay in touch with life's pleasures, despite the difficulties you may be facing.

Accept and deal with difficult feelings

Feelings (such as fear, anxiety, irritability, anger, guilt) are a natural response to the difficulties you are facing. Accepting these feelings as they arise can help you to move forward.

Some people believe that showing their feelings is a sign of weakness or will make them feel even worse. But pushing away difficult thoughts and feelings is tiring and can create more pressure. You might find that you are keeping busier to avoid the thoughts and feelings.

Sleep may be affected. Distressing thoughts and feelings will tend to surface when you aren't able to distract yourself with other activities. Some people find themselves withdrawing from loved ones. Or using drugs or alcohol to avoid facing their emotional distress. Trying to keep on a brave face all the time is exhausting. Rather than avoiding difficult thoughts or feelings, it is usually more effective to spend some time processing them. Talking about difficult feelings, or even writing them down, can help make sense of your feelings and lighten your load. Sometimes it can also help you put things in perspective.

Be kind to yourself:

It is normal and understandable to feel a little frayed at the edges with the extra concerns and demands of a loved one's cancer treatment. Make sure your expectations of yourself are reasonable. Consider whether you can set aside other demands in your life or hand them over to someone else to manage. It can also be useful to regularly stop and ask yourself what is really important to you. Then you can use your energy for these things and allow the less important tasks be put off for a while. Taking your loved one to their appointments and just listening if they need to talk may be more important than keeping up to date with routine tasks. Focusing on what you value most and letting go of some of the less important things can help you focus your energy and resources where they are needed.

Sometimes when dealing with difficulty, it can be helpful to imagine a loved one in your situation and consider what support you would offer them and how you might say it. It is easy to be self-critical when we are overwhelmed.

'For me it was so important to talk to one of my good friends for support every couple of days. Just telling someone about what was happening seemed to help me to put things into perspective.'

'It's a good idea to reflect regularly with your partner about what stage you are at, emotionally and physically, on this journey – you may not necessarily be at the same stage as each other at the same time.'



Tip

Sprint (crisis) or Marathon (long-haul)? In intense but short races, sprinters can afford to temporarily use up all their energy. In marathons, runners need to use different strategies to make sure they pace themselves – conserving enough energy and making use of resources in order to last the distance.

Stress management: Effective coping strategies

Increased stress is to be expected when dealing with your loved one's cancer. Stress is your body's natural response to threat or change. This is sometimes called the 'fight or flight' response. It immediately prepares your body to either confront the situation (fight) or run away from it (flight). To be ready for action, your body releases chemicals (such as adrenaline). These chemicals increase your breathing and heart rate. They increase your blood pressure. You sweat, your muscles tense, and it makes your stomach churn. These are normal responses and can be very useful when dealing with an emergency. But they are not very helpful in dealing with ongoing stress. If stress continues for a long time these responses can lead to exhaustion and burnout.

To manage stress, it is important to identify your own warning signs that stress levels are increasing. You will then be able to take action early before things build up.

Physical signs of stress may include headaches, physical tension, teeth grinding/jaw clenching, upset stomach, shallow breathing, chest pain or tightness. Emotional signs of stress may include being teary. Or feeling anxious, overwhelmed, tired, unwell, or overly sensitive. You might have difficulty sleeping or withdraw from loved ones. You may over-eat or lose your appetite or increase your use of alcohol/ drugs or cigarettes. For most people, feelings of stress will reduce as they adjust to their changed circumstances. In the meantime, there are things you can do to help you manage your response to stress and feel calmer during this unsettling time.

You and your partner might respond to and deal with stress in very different ways. For some people, being alone or engaging in a solitary activity is an opportunity to unwind and re-focus their attention and energies. For others, talking and being with others is essential to help them cope with stress. If you and your partner cope with stress in different ways, it may be helpful for each of you to find some relaxing activities that you can do alone. If you are both less stressed as a result, your relationship will also benefit.



Some strategies for coping with stress include:

Be active

Exercise maintains physical health and wellbeing and is an effective way to ‘burn off’ the effects of stress. If you have health problems, check with your GP that the exercise program you are considering is appropriate for you. If you haven’t exercised in a while, start slowly and be kind to yourself – gradually build up your endurance. Even small amounts of physical activity can be helpful in managing the effects of stress.

Relax

Your changed circumstances can make it difficult to do the things you normally do to relax. This might be formal relaxation practice (like meditation) or some other enjoyable activity (like listening to music or doing a hobby). Even if you are doing these things, you may still be experiencing ongoing stress and physical tension in your body. Regular practice of relaxation exercises can help you let go of tension and give your body a break from the effects of stress. Try to make some time each day to consciously relax.

If you would like more information, see our *A Guide to Relaxation* booklet, or listen to our *Learning to Relax* audio files, which can be found on our website <https://cancerqld.org.au/cancer-information/find-resources/podcasts-audio-files/>. Some brief relaxation exercises are provided on the following pages.

Identify problems and solve if possible

Some stress management strategies are useful in helping to change a stressful situation. Or sometimes get rid of it altogether. These might include problem-solving or learning to say “no” to other people’s requests. Although the cancer diagnosis cannot be changed or removed, many stressors related to it, or adding to it, may be able to be changed. You might be able to reduce work duties, get help with transport/childcare/home duties, and renegotiate bank or bill payments.

Under normal circumstances, it is often quite straightforward to work out what the problem is and take action to solve it. Yet when we are stressed, it often becomes much more difficult to do this. This is where taking a step-by-step problem-solving approach can help. You can use the strategies discussed in the section Solving Problems Together as a guide to solving many different types of problems.

Deal with unhelpful thoughts

The way we think about a situation directly affects how we feel. Your thoughts can 'coach' you through the situation, helping you to cope and feel better. Or they can undermine your efforts, increasing your distress and preventing you from coping effectively. Taking a step back and looking at the problem in a different way can help you keep your reactions in check and cope better.

There are a few key questions you can ask yourself to check whether your thoughts are helping you or not:

- *Is thinking this way helping me to cope?*
- *What is the evidence for the way I'm thinking? What are the facts of the situation?*
- *Are these thoughts realistic/rational/based on facts?*

If your thoughts do not pass these tests see if you can come up with some alternative, more helpful ways of thinking about the situation. Replacing your unhelpful thoughts with 'coping self-talk' can help you to feel calmer and cope better.

Some examples include:

- *I don't like what has happened, but I can cope without making it worse for myself.*
- *I can meet this challenge. It may even help me become a stronger person.*
- *Sitting and worrying about it isn't going to help. What can I do to help myself cope with this situation?*
- *I won't get overwhelmed; I'll just take it one step at a time.*
- *Let me focus on the good things about my situation/myself, rather than the negative things.*
- *I handled that situation really well. That proves I can cope.*
- *I'm going well. I'll just keep going slowly and doing the things I can do.*
- *Let me focus on the facts (what I know right now) rather than imagine and worry about what might happen in the future.*

If you feel you need extra help, our Cancer Council Queensland Counselling Service is there to support you.

'Stopping and just noticing how I was feeling in my mind and in my body helped to ground me in the present moment, helping me to step outside of the chaos in my mind, even if it was just for a short time.'



Relaxation exercises

There are many different relaxation techniques. Most of these involve one or more of the following components: slow breathing, muscle relaxation or mental relaxation. These can be done by themselves, or one after the other, as shown below.

Slow Breathing

Take a long, slow breath in and then let the air out slowly and gently → feel your whole body relax.

Take another long slow breath in and allow the air to travel deep into your lungs → filling from the base → feeling your abdomen and lower ribs expanding. As you breathe out, listen to the sound of your breath.

Continue to breathe with a slow steady rhythm, drawing the breath deep into your lungs, expanding the ribs and abdomen → and then letting it out slowly, hearing the sound of your breath.

Feel your body relaxing further with each breath, breathing in energy → and breathing out tension → and, with each exhalation say the word 'relax' silently to yourself, as you become more and more calm. If ending your relaxation at this point: In your own time → start to become aware of your surroundings.

Muscle Relaxation

Take a long, slow breath in and then let the air out slowly and gently → feel your whole body relax.

Starting at the top of your head, imagine a warm gentle wave of relaxation begin to travel down over you. As this wave passes down, feel the tension in your muscles easing away. This wave is moving slowly down your face, neck and then to your shoulders → feel them relax as you slowly breathe in → and out → The wave of relaxation continues down your back → chest → arms → hands → tummy → upper legs → lower legs → and feet → You feel your whole body relaxing and letting go. Every muscle in your body feels free of tension.

If ending your relaxation at this point: In your own time → start to become aware of your surroundings.

Mental Relaxation (Visualisation)

Take a long, slow breath in and then let the air out slowly and gently → feel your whole body relax.

Close your eyes, and picture yourself in a favourite place → It might be on a beach, by a river or in a forest → Notice the sights around you, see the scene in vivid colour, and imagine the sounds you would hear → Notice the smells → The image is clear and alive. Imagine how it would feel to be there → Let yourself relax → Now enjoy this place for a few moments → Breathe in slowly and deeply.

If ending your relaxation at this point: In your own time → start to become aware of your surroundings.

Recruiting help

When you are facing the extra demands of cancer, help from family and friends can make a big difference.

People often find it very hard to ask for and accept offers of help. You may worry about burdening others. But often family and friends want to help and may feel helpless or shut out if you don't ask for or accept their help. Ask yourself the question "If someone I loved or cared about had a problem, would I want to help out?"

Not everyone in your circle of friends and supports will be able to help in the same way. Some people are comfortable talking and providing emotional support. Others may be able to help in practical ways, like helping with meals or transport or around the home. At times when your focus is on your family, you may not realise how much support you have available. It may be helpful to complete the 'Support Map' on page 22 to see if your support network can be strengthened or extended.

It is important to let people know the things you would find helpful. Then they can choose ways to help that match their abilities. It can be useful having a list of things that it would be nice to get help with. When people ask if there is anything they can do, they can choose from the list something they would be comfortable doing. Or you could get support from a trusted and capable friend willing to coordinate offers of help. You and your partner let this coordinator know what type of help you would like. Then when someone offers their help, you can ask them to talk to your coordinator. The coordinator can then give them an appropriate task. Your list could include different types of help.

Some ideas for practical help could be:

- Grocery shopping
- Help with transport
- Help with children
- Keeping others informed, such as setting up a 'phone tree' (where news is passed on from one person to another), group email, or Facebook page
- Helping you to have fun and take a break.

'My next-door neighbour started mowing our lawn, and you know what, he said that it helped him to feel like he was doing something useful.'

Using a list makes it more likely that your supporters will feel useful and satisfied with the help they are providing. You will also get your real needs met and well-meaning general offers of help (e.g., "let me know if I can help") will become actual support.

Support Map

The diagram on the next page can be used to help identify the important people in your family's life. When completed, it clearly shows how much support you have at present and how much further support might be available that you are not currently accessing. The circles indicate how close people are to your family, while the different quarters of the circle identify that person's role.

To use the diagram:

- Put the names of your closest family members in the white circle in the middle.
- Put the names of other people who are currently supporting your family in the yellow circle – people who know you or your family well and are willing to help in various ways (e.g., emotional support, practical aid, communicating with others).
- Put the names of people who are potential supports in the outer blue circle: that is, people who have a relationship with your family and could be willing to help but have not yet made an offer to help/provide support.
- On the outside of the circle, put the names of other people or organisations who could possibly be a new source of support if you made/renewed contact with them.

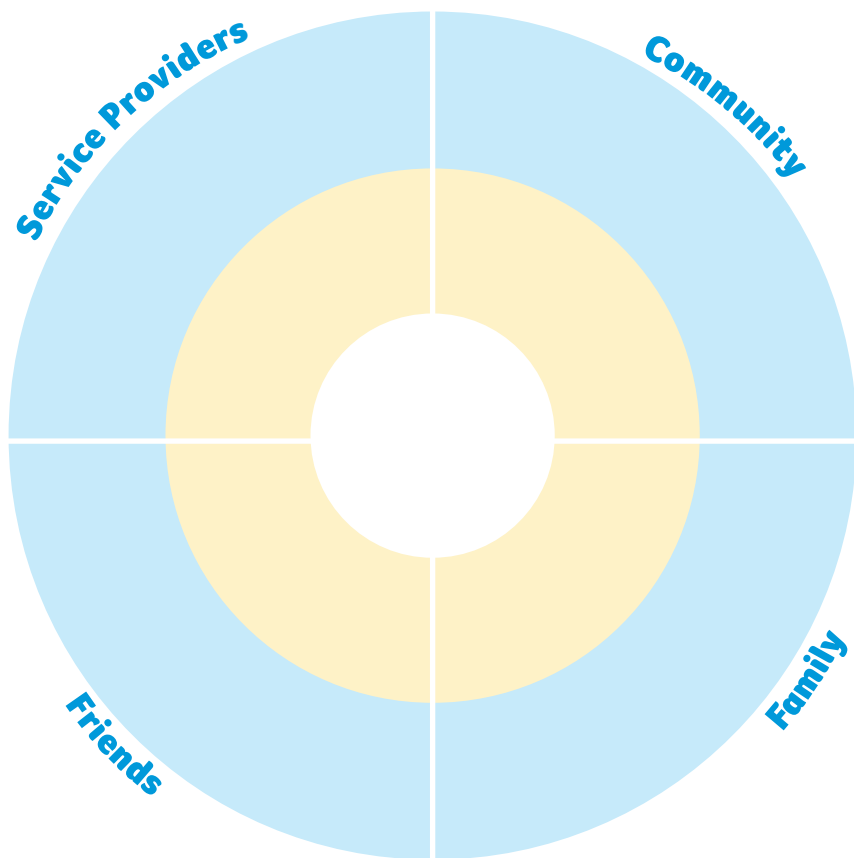
Think about how you could use the information on your map.

For example, you may decide to:

- List the ways in which each person on your map provides support for you and your family.
- Think about how you could strengthen existing relationships with those on your map. Consider asking them to support you.
- Consider whether you would like to build up your support network and link your family with new (or out-of-touch) supports. How could you go about doing this?

**'What do we live for, if it is not to make life less
difficult for each other.'**

George Eliot



Based on *Make a Difference, A Guidebook for Person-Centred Direct Support*.
John O'Brien and Beth Mount. Inclusion Press 2007



Tip

Remember that, as a couple, coping with cancer is tough and is best managed with support. Accepting help doesn't mean you're not coping; it is a way to help yourself and those around you.



Strengthening your relationship

Facing cancer is often a new experience for couples and it can cause unexpected thoughts and feelings. It is not surprising that in the busy time of diagnosis and treatment, couples can find they lose touch with each other. This can lead to couples feeling frustrated and disconnected – even though they might be spending more time together. It is normal for a couple to feel vulnerable when faced with a cancer diagnosis and treatment side effects. You or your partner may need extra reassurance to feel less afraid and/or to know that you love each other as much as ever.

‘What I struggled with the most in the beginning was knowing how to support Alan. It sometimes seemed that the more I tried to reach out to him the more he withdrew. Although I know now that I was on the right track, for a long time it felt like I was groping around in the dark.’

Ways to show you care

Showing that you care is more than just providing support. It means reaching out to each other and showing how you feel. This is particularly important if the ways you use to show care and affection have changed or reduced during or after treatment. We all have different ideas of how we show we care. Some people might show care with hugs and affection. Others may prefer to help in practical ways and ask, "What can I do to help?" Feeling helpless about how to let your partner know you care can lead to an increase in frustration and stress. Even for couples who feel a new appreciation for each other, it is not easy to know how to show you care.

Think about the things you can do for one another to show you care. These don't need to be big gestures like planning a holiday or a major purchase, they can be small, everyday things. It can be useful for each of you to take some time to think about things you might like your partner to do that would mean something to you or help you. Then discuss and plan together ways of caring for one another over the next week. Even writing down one caring activity each day that you will do for your partner. Try to be creative (you can use the list below for some ideas). Try to vary your activities (a kiss and a compliment every day could get a little boring). Don't make them too difficult – use many, small caring acts that only take a minute or two, and a few that need more effort. You can make your plans alone, or you can use this list to talk about the ways you would like the other to show they care.

Ideas to show you care

- Say "I love you"
- Give a tender kiss, not just a peck on the cheek
- Take a walk together
- Reach out to hold hands
- Put a love note in your partner's lunch box/ wallet/on their pillow
- Do something your partner asked for
- Give your partner a cuddle
- Bring home some flowers
- Call during the day to let your partner know you are thinking of them or to say something romantic
- Tell your partner how much you appreciate the things they do
- Spend time with your partner's friends
- Make a cup of tea or coffee and take it to your partner
- Plan an activity that your partner likes, even if it is not your favourite and enjoy it!
- Give your partner a back or foot massage
- Rent a movie and watch it together or go to the movies together
- Wear something special just to please your partner
- Write down your thoughts and feelings about your partner in a letter or card
- Make love in a way you know they will like
- Make a nice dinner
- Have a shower together

Improving communication

After a diagnosis of cancer, there are various reasons couples may not connect as well as before. One partner may feel that if they talk about their real feelings this may upset the other partner. The idea that you always must ‘think positively’ could mean you don’t share your natural concerns, leaving you alone with your worries. Good communication during the challenges of cancer can bring a deep sense of connection. It can help you to better understand and support each other. Think about times in the past when you felt you were connecting with your partner. You were probably communicating well and sharing with each other.

Sometimes it can be hard to know where to start, so it can help to take some time to think about what you want to say. Instead of talking about complex issues straight away, it can be better to start with small, less difficult topics. This can be the start of deeper conversations. You may find that talking about how you think and feel will encourage your partner to talk as well. You can let your partner know that you are open to discussing difficult topics and suggest a time to talk. Make a time that will suit you both – don’t wait for the ‘right’ time, it may never come. It can be as simple as saying, “There’s something I want to talk to you about. It’s important. I know things have been busy but let’s make a time when we can talk.”

During the conversation it is important to limit distractions. Turn off the television, radio and phone and focus on each other. Try to talk openly about what is happening and how it affects you and your relationship. Be honest about your thoughts and feelings even if it is upsetting. If you do not speak honestly with each other, both of you are forced to try and read each other’s minds – and probably neither of you will get it right! Listen to each other. It can be difficult to listen well if you are thinking about your own response when your partner is talking. Try to put aside your own thoughts so you can listen to your partner and try to understand what your partner is saying and why. It’s useful to check with your partner that you have understood them. If you have, they’ll feel good that they were heard. If not, they have the chance to clarify the misunderstanding.

Good communication involves both speaking well and listening well. See if you can improve your skills as a speaker (i.e. getting the right message across), and as a listener (i.e. listening and showing you understand).

‘Sam is a different person now. He tells me that he loves me and he doesn’t take me for granted. I make sure that I remember to tell him all the things that he does that help me.’



You may find you automatically try to solve problems your partner raises. You may want to find a way to make your partner feel better. But solving the problem is not as important as listening and showing you understand. You can follow-up with problem-solving together (see the section on Solving Problems Together) after you have both heard and understood each other. Trying to solve problems too early can lead to frustration and conflict.

Be forgiving and patient. Remember, no one is perfect. We can let each other down for any number of reasons. We may be exhausted, or forgetful, not understanding, or not be aware. Maintain a gentle and forgiving attitude with one another and do not expect too much at first. It may take time for you both to feel confident and comfortable with this more open way of communicating.

Loving and supportive communication is not just about words. Being there, holding hands, smiling, sharing eye contact, being calm and patient, and showing affection are all important ways of showing respect, concern and support.

‘Grace made the point that she didn’t want me to solve her problems, she just wanted to know that I understood what she was going through. It was hard for me to step back and just listen but that was really what she was after.’

Tips for improving

When sharing how you feel or what you would like, use 'I-statements'. Using 'I' instead of 'you' is a useful skill, especially during conflict. For example, saying "I feel hurt when you keep things to yourself" is a less blaming way of expressing your feelings than "You make me so angry when you don't even trust me enough to tell me what's wrong".

Describe the situation, how you feel and what you would like. For example, 'I'll do my best to help out, but I need you to be more specific about what would be most useful.'

AS A SPEAKER

1 Choose a time to talk when you are not likely to be grumpy or tired. If you are grumpy or tired you are more likely to become angry or upset, switch off, or say things you might later regret.

2 Try to speak honestly about how you feel even if it is difficult. Most partners say they prefer to know things even if it makes them a little upset. More problems are caused by hiding things than by dealing with them directly.

3 Think about what you want to say and try to keep it simple and to the point. This makes it less likely you will be misunderstood.

4 There are always positive things you and your partner are doing. If you can let your partner know what they have done that you like, they will be less likely to switch off to what you are saying e.g., 'I'm really glad you let me know what was troubling you'.

5 Let your partner know what you dislike or what you would like to see change. State the negatives simply without blame or attack e.g. "I felt as though I hadn't done it well enough".

communication skills

Don't judge what your partner says. Hear your partner out and put your own reactions on hold until later. People who have known each other for many years may feel as if some discussions (even if important) are no longer worth having as they always seem to end in the same way. Responding differently to how you usually do can break old patterns and helps to reach new ground.

AS A LISTENER

- 1 Pay** attention to your partner when they talk. This includes making eye contact, facing your partner, and removing distractions (put down the newspaper and turn off the television!).

- 2 Be** encouraging. Say things like "Mmm hmm", "Go on", or "I see" so that your partner knows that you are interested and listening to what they are saying.

- 3 Notice** the feelings that you hear or see your partner trying to express. Often feelings aren't put into words but will be reflected in how your partner says things or how they look.

- 4 Ask** open-ended questions that encourage your partner to speak freely. Use questions beginning with why, what, when, where and how, e.g. "How are you feeling?", "Why is that worrying you?"

- 5 Summarise** in your own words what you think your partner has said. This helps your partner to feel understood and gives him/her the opportunity to correct you if you haven't got it quite right.

Solving problems together

A structured approach to solving problems can give you an extra tool to use to improve communication and your efforts to work together. This approach can be used to tackle difficulties that arise as you face the challenges of cancer, and also problems in your relationship.

This is a simple method. You can use it to make sure you have thought of all the possible ways to solve a particular problem, and the likely outcomes. Using this approach together as a couple can bring particular benefits:

Increased understanding

Discussing the problem together in more depth may reveal other underlying issues.

Less blame

It can be natural to think a problem could be solved if only our partner would change. Thinking about the problem as a difficulty you have as a couple can help take the blame off one another.

Better brainstorming

You will be able to come up with more solutions if you work together.

Consider all possible outcomes

You are less likely to overlook possible outcomes by working together. These could be good and bad, long term or short term.

Commit to the solution

Both you and your partner are more likely to commit to the agreed option if you are both involved in the discussions.

Feeling connected

Solving problems for your partner may be a good intention but may not be their preferred solution. Working together is more likely to encourage connection and closeness.

A structured approach may take a little more time and effort, but it can have positive outcomes. You may have better mutual understanding and closeness. This could then help your relationship generally.

Steps for successful problem solving

1. Make a list of all the challenges you are facing.
2. Put the problems in order. List those that need immediate attention first followed by those that can wait.



3. If a problem feels huge or overwhelming, break it down into smaller problems. For example, coping with treatment may involve **a)** sorting out transport, **b)** arranging childcare and meals, **c)** organising time off work, and **d)** managing financial difficulties.
4. Brainstorm. Take your most urgent problem, and list all the possible options to deal with it. Make sure you include every idea, no matter how silly it may seem. These ideas can lead to more flexible and creative thinking.
5. Weigh up the two or three best options. Consider what might happen if you follow it through. Will it help you reach your goal, who will it affect, how much time and effort will it take? It may help to use a problem-solving worksheet to weigh up the advantages and disadvantages of each idea (see below).
6. Decide on the option or strategy (or combination) that seems best and then try it out. If it doesn't work, then try your next idea!

Problem solving sample worksheet

Using a problem-solving worksheet with your partner may be a helpful aid in solving problems together. Take some time to relax, calm down and focus clearly on what the real problem is. Then work through the problem using the **ABCD** steps on page 32.

A **Attitude**

Take an optimistic attitude

Take a deep breath → stop and think → there is no catastrophe
→ think of this as a challenge → we can handle this problem.

Acknowledge the problem

State the problem and details e.g. Loss of partner's income → difficulty meeting commitments → worry/poor sleep/irritability

What is a reasonable goal? e.g. Find ways to balance your books.

Can I change the situation? e.g. Find other sources of income?

Do I need to change my attitude? e.g. Worry less about debt → review our needs and make realistic plans

B **Brainstorm**

Write down all your ideas

Find ways to reduce payments → talk to the bank and utility companies → tighten budget → borrow money → do extra work → check superannuation/long service/insurance(s) → sell house or downsize → sell other goods → see financial counsellor

C **Consequences**

Predict the likely outcomes of your ideas, for example:

1. Approach bank/utilities about temporary reduced payments

Pros: Reduce outgoings temporarily

Cons: Must be paid eventually

Will it reach my goal? Yes No

2. See financial counsellor

Pros: Objective, specialist advice about effectiveness of ideas and possible new ideas

Cons: None (use a free service e.g. Lifeline)

Will it reach my goal? Yes No

D **Decide**

Decide on your best idea, put it in action and rate outcome

Either:

You are satisfied with the outcome – congratulate and reward yourself

Or

You are not satisfied with the outcome – don't give up, try again

Example:

Best idea: See a financial counsellor before we make any decisions.

Outcome: We received advice about reducing mortgage payments, payment plans for electricity/gas, and spreading regular bill payments over the year. So, we can both worry less.



A ATTITUDE Acknowledge the problem:

State the problem and details:

.....

.....

What is a reasonable goal?

.....

Can I change the situation?

.....

Do I need to change my attitude?

.....

B BRAINSTORM Write down all your ideas:

.....

.....

.....

C CONSEQUENCES Predict the likely outcomes of your ideas:

1.

Pros:

Cons:

Will it reach my goal? Yes No

2.

Pros:

Cons:

Will it reach my goal? Yes No

D DECIDE on your best idea, put it in action and rate outcome:

Best idea:

.....

Outcome:

.....

.....

Maintaining intimacy

Treatments for cancer can affect how a person feels about their body. This can affect their ability or desire for lovemaking. This may be as a direct result of physical changes caused by surgery or radiation therapy. Treatments, such as chemotherapy or hormone therapy, may lower libido (desire), cause vaginal dryness (in women) or erectile dysfunction (in men). Fatigue, feeling unwell due to cancer or cancer treatments or stress can also reduce sexual desire.

The ability to function sexually is something that we may take for granted. It can be hard to imagine what life might be like if this changed. Sex can mean pleasure and excitement, a way to relax and reduce tension, and a way of feeling close to each other. It can also be an important part of how someone feels about themselves as a person. Sudden changes in your ability to perform or respond sexually can lead to a deep sense of loss.

Physical changes may affect how attractive or desirable a person feels. These may be because of the effects of surgery, scarring, hair loss, or weight gain/loss. Some people may worry their partner will find them less attractive or love them less if their appearance changes or they are not able to respond in the same way sexually. This is not likely to be true, especially for couples who have been together for many years and have a shared life together.

While it can be difficult to talk about, it is likely you are both worried about the impact of cancer on your physical and emotional intimacy. Talking with your partner about each other's concerns can help with your fears and prevent distance forming in the relationship. Remember, hugs, kisses, and general affection are ways to show love, create closeness, and reassure each other.

Some common factors that can increase sexual difficulties include:

Expectations

Expectations that are too high can lead to performance anxiety. This can make sex more difficult and less enjoyable.

Focusing on performance

Focusing on achieving sexual penetration and/or orgasm can be frustrating and unfulfilling. Instead, focus on mutually satisfying sexual closeness and/or intimacy.

Failing to communicate

It can be a difficult topic but not talking about sexual problems can create distance, resentment, and insecurity.

'I still struggle a bit when it comes to sex. It's getting better, but it is not the same, that's a loss. But my partner and I work at it, and in some ways, we are even closer now.'

'I felt hurt when we stopped having cuddles in bed. I started to think that maybe he no longer found me attractive, didn't feel the same way. It was a form of self-protection to start going to bed at different times, but it felt so lonely and put more distance between us.'

There are no simple solutions to sexual problems, but the following tips can help you improve your sexual relationship:

Talk to your partner about how you are feeling

It may help to have this discussion outside the bedroom when you are feeling less vulnerable. Discuss how the cancer or cancer treatments have affected desire for intimacy or ability to respond sexually. This will help to clear up misunderstandings and help you to better support each other and find ways to stay intimate.

Let your partner know how much you care

Tell them how much they mean to you, how important the relationship is to you, and how you want to work it out together.

Change your expectations

Sexual function may change as a result of cancer. Resisting these changes won't make them go away but will leave you disappointed and wishing things would go back to the way they were. Or you can accept that changes have occurred and adjust your expectations. This will help you make the most of your sexual relationship and find creative alternatives.

Focus on enjoying each other in ways that don't involve intercourse

Recognise that intimacy is more than sexual intercourse. This can be cuddling, massage, or more intimate contact. Being imaginative can help with self-consciousness or discomfort about physical changes such as scars. Use dim lighting, nice sheets, or sexy clothing.

Try looking at changes as challenges to solve together

Try not to let sexual difficulties be one person's problem or something that comes between you. Being creative in problem-solving can help you to find new ways of being intimate that you are both happy with.

Information is available to help you and your partner enjoy a satisfying, intimate relationship. Your doctor can advise you about using aids and medications. They can refer you and your partner to other health professionals who specialise in the management of sexual problems. Sex after treatment may be different. With the right advice, patience and effort, it is possible for couples to find ways to continue a satisfying sex life.

Managing conflict

Conflict can emerge in a relationship during times of stress. Unfortunately, this can be when everyone involved is most in need of support. Several factors may contribute to conflict, including increased stress and difficulty dealing with strong emotions. In the struggle to handle these, some people may 'close up' and withdraw from those close to them. Others may react by directing emotional anger at those around them. The person may care very much but be affected by difficult feelings. Conflict doesn't necessarily mean a lack of caring.

The misunderstandings that occur can make it hard to feel close to someone and to believe they care. Disagreements are not necessarily a problem. What matters most is how we handle them so they don't go on to damage our relationships. It is important to take time to work out what is happening and to agree on better ways to deal with it. Some ideas people find helpful include:

Take your time

Don't try to solve the problem too quickly. Take one step at a time. Focus only on the immediate issue at hand.

Take turns to listen and to speak

Hear your partner out and ask how they are feeling. Let them know how you feel about what they have said. Use good communication skills (see the Improving Communication section in this booklet).

Make a time to talk

Discuss with one another in private with no distractions at a time that suits you both.

Listen without interrupting

Allow each other the chance to be heard before trying to solve the issue.

Notice if things start to get heated and work together to keep things calm

Keep it balanced. Remember the positives not just the problems.

Listen and feed back what you think the other person is trying to say

They will feel heard and know you understand their point of view, even if you don't necessarily agree with it.

Seek solutions

Respect each other's differences.

Have realistic expectations

Have realistic expectations of your partner and their ability to meet your needs. Agree in advance to stop the discussion if it becomes destructive. If necessary make a time to try again after a cooling off period.

All couples experience differences and difficulties from time to time. Especially during times of stress. It can help to remind yourself that the reason you fought was not because your partner doesn't care. Hanging onto hurt will make it harder for both of you to move forward, so look for ways to rebuild trust and show you care. Let your partner know you love them and let them come around in their own time.



Coping with uncertainty **Into the future**

People often look forward to the day their partner's treatment finishes as the light at the end of a long tunnel. It can be a surprise to find that the journey continues even as your partner enters a phase of recovery and returns to a normal way of life. Even though treatment has finished, your partner may experience its ongoing effects. This can make recovery more difficult. People are often surprised and frustrated at the level of fatigue they feel in the weeks after treatment. Your partner's physical recovery may take some months. This could be as long as the treatment lasted. There may be other effects such as hormone changes from ongoing treatment, or body changes as a result of surgery or radiation. You may both find this period confusing, with feelings of frustration, anger and grief. These are natural in a situation where things have changed, and you need time to adjust to these changes.

Instead of the expected period of relief and normality, you may find that your partner still feels anxious. They may feel even more anxious than they did during treatment. Without the demands of treatment, your partner finally has time to think about what they have been through. It is not unusual for others (sometimes partners and often family or friends) to be ready to move on quicker than the person who has had cancer.

This can lead to your partner feeling misunderstood and isolated in their experience. It is common for patients and partners to miss the regular contact with the treatment team. And miss the reassurance that everything is being done to keep the cancer from coming back. Without a medical team around for support, it can feel like being ‘out on your own’. This feeling of coping on your own can intensify if you and your partner don’t feel as though you are in this together.

You and your partner may find that the people closest to you are less available for support. They may assume that everything is ‘over’ and ‘back to normal’. That you are both feeling on top of things, but without understanding the challenges you may still be facing. You may get less practical support, and also less emotional support, with advice to “be positive”. This is a well-meaning, but it may be out of sync with how you and/or your partner are feeling. It can stop you expressing feelings and working through natural fears and concerns.

Increased anxiety will be a feature of the weeks and months following the end of treatment. This can often be related to cancer reminders. Cancer reminders can include; follow-up medical visits, the anniversary of an important date (e.g., the date of diagnosis), new aches or physical symptoms, learning of someone else’s diagnosis with cancer, or media reports about cancer. You and your partner may respond to these reminders in a range of ways. You might experience mild discomfort, irritability, physical tension, anxiety/distress, and sleeplessness. At these times you may start to feel you are not coping or are moving backwards. Be reassured. These are normal responses to coming to terms with a very difficult life event.

The end of treatment can be a difficult and confusing time. It can give rise to many conflicting emotions. Knowing that the transition can be difficult can help you have more realistic expectations. It can also allow you time to make a plan to get through this period.

‘We focused hard on reaching the end of treatment, but when it came, nothing was as we’d expected. We thought we should be able to just pick up where we’d left off before, but this was totally unrealistic. My partner was still dealing with the impact of having cancer and how to move forward. It’s taken time and understanding – from myself and others – to adjust and feel comfortable with the changes.’

A time of transition

It is helpful to think of this period as a time of transition for you and your partner. You are moving from one stage (pre-cancer and cancer treatment) to another (after cancer). Making this transition takes time. The more difficult the cancer experience was for you both, the longer the transition may take. It is a time of coming to terms with the changes brought about by cancer for you, your partner, and your relationship. It may have affected your future plans and goals and require learning to live with greater uncertainty.

Use this transition time to look after yourself and recover your physical and mental stamina. Allow time and space for 'reflection'. Times when you can let your thoughts and feelings come and go without feeling like you have to do anything to change them. Now may not be the best time to make any life-changing decisions. If possible, wait until you both have had more time to adjust to the changes brought by cancer. In the meantime, you may want to plan for some short or medium-term goals now that cancer treatment has finished. Like taking a holiday or returning to activities you had stopped.

In time, most people find they are less preoccupied with worrying thoughts. In the meantime, remind yourself that it is a normal part of moving forward to experience fear and uncertainty at times.

Some ideas to help you manage living with uncertainty include:

Seek medical reassurance

If your partner is worried by any signs or symptoms, is very distressed, or has continuing medical difficulties, see your GP.

Acceptance

The future is always uncertain – when we make plans, we don't usually think about this. A cancer experience makes this more confronting. Learning to tolerate uncertainty, and living fully despite it, can help you move forward.

Finding direction

Focusing on what is most important to you may help to guide you forward (see the section on Finding Direction).

Balanced thinking

Instead of using energy to constantly push away frightening thoughts, set aside time to deal with them. Acknowledge that they are there and that they are just thoughts. This will help you feel less overwhelmed. Focus on this moment. When something triggers fear or anxiety, bring your attention back to the present. Use slow breathing or relaxation strategies to stay calm and cope with difficult feelings.



Talk it over

Discussing your feelings with someone else can help restore your perspective. It can also help them to understand how you're feeling.

Pace yourself

This transition stage is still part of the journey and it will take time to work out the way forward. Give yourself (and your partner) permission to take each day, week and month at a time.

Remember that there are many people who have had a similar experience and understand how you are feeling. Your doctor, Cancer Council Queensland website or Cancer Council 13 11 20 can help you find information and support that is available to you.

‘Getting through cancer was the hardest thing we’ve faced together. Even several years down the track, there are still times when my partner feels worried. But overall, I think our life is great, we appreciate our family and friends and enjoy life. I do think that after cancer the goal posts change, and you get more focussed on the things that really matter.’

Finding direction

Accepting that you are in a time of transition gives you time to review your direction, the goals you had set, and whether these are still important or need to be revised. Focusing on what gives your life meaning and what is most important to you now may lead you to experience life in a new, more satisfying way.

Coping with cancer often leads to disruption of a family's normal activities and routines. This may mean that some activities or hobbies had to be postponed. Starting to do the things you value as soon as is practical can be good for your long-term health and wellbeing. You may want to reconsider aspects of your lifestyle. It is easy for the demands of work, family, and children to take up most of our available time, attention and energy. In time, this may mean that other important parts of our lives and relationship are neglected.

Some beneficial activities and the reasons that they are often neglected include:

Exercise

Finding the time and motivation to do regular physical activity is often challenging.

Diet

Limited time and motivation to shop, prepare and eat healthy food can lead to less nutritious choices.

Time out

Demands on our time can mean less opportunities for relaxation or personal space. This can increase tension.

Communication

Less time and opportunity to communicate, especially about difficult topics, can lead to misunderstandings, hurt feelings, and loss of closeness.

Shared couple/family activities

Extra demands on time and energy, can limit shared activities and opportunities for respite, fun, and closeness.

Social support

Fewer opportunities or less energy to see friends may mean less chance for respite/ fun, emotional release, communication, and/or extra help.

Spirituality

A cancer diagnosis and treatment may cause you to question your beliefs. You may not make time for prayer, meditation or contemplation.

Neglecting these important activities can cause us to become stuck in a cycle of stress and reduced wellbeing. We can be left feeling overstretched, dissatisfied and frustrated. Extra demands and/or changes become ever more difficult. You are at risk of becoming physically and emotionally drained.

It may be useful for you and your partner to work out a plan together based on:

- What is most important in your lives?
- Your agreed priorities and goals.
- Your commitment to protect these priorities even in times of high stress and demands.

Deciding what matters

It can be helpful to spend some time thinking about what is important to both you and your partner. What you as a couple value most in life. These 'values' provide a direction. An important point is that a value is not a goal to be accomplished, even though there will still be many goals along the way (see below). A value is something that helps you set a direction. A value could be supporting each other through difficult times. Or your approach to family/parenting. Or being available to your children and being the best parents you can be.

By identifying what is important you can clarify what gives purpose and meaning to your life. It can also show the impact cancer is having on things that are important to you. Maybe you have stopped doing things you value.

Neglecting or getting side-tracked from your values can make you feel stressed, frustrated or lost. Once you know what matters to you most, it is easier to identify your priorities. You can then set goals as a couple that will enable you to include meaningful activities in your life despite the obstacles cancer might put in the way. You might identify that doing enjoyable things together is an important value. That it gives your life meaning, helps you feel connected, helps you cope with stress. But that cancer/treatment has reduced your enjoyable time together. You can then decide if you can do anything to change this. Such as taking 10 minutes every day for a cup of tea together, no matter what else is happening.

**'You won't realise the distance you've walked until you
take a look around and realise how far you've been.'**

Unknown

Setting realistic goals

It is useful to put your values, and the activities they involve, in order of priority. This will highlight the things that are most important so you can focus your time and energy on them. It may be that your current circumstances don't allow you to manage your life as before. If a value is important enough, you may need to work out new ways of meeting that value.

Work together as a couple to agree on priorities and find new and manageable ways of meeting them. To give yourself the best chance of success, make sure the goals you set are realistic. Doing even small amounts of the things you value helps and can sustain your ability to cope long term.

'Values guide us on our journey, and goals keep us moving.'

McKay et al (2010)

Committing to action

Staying focused on your values strengthens your commitment to the goals you set yourself. To stay motivated, remind yourself that your actions are in line with the values that maintain the quality of your life. This can also help you stay on track when the going gets tough (the right road is not always the easy one).

When you are working out your new goals, it is useful to consider what practical, family, or other issues may interfere with them. If you identify possible obstacles in advance, and work out ways of overcoming them, you are more likely to be successful in reaching your goals. The section on Solving Problems Together can provide some helpful strategies.

As your circumstances are likely to change over time, you will need to be flexible about revising your plans as necessary. Your values can be a guide to finding new ways to stay on track despite any difficulties you encounter along the way.

Life usually does change after cancer. It may be different, but it can be good again, sometimes even better than before.

Identifying guiding values

It can be helpful to consider your values, both as an individual and as a couple, in various areas of your life. Remember, what gives meaning to you and your partner's life is likely to be different from your family, friends or neighbours. Examples of various values that couples may hold are listed on following page.



Tick those that are most important to you as a couple

Us

- | | |
|--|--|
| <input type="checkbox"/> Having a healthy lifestyle | <input type="checkbox"/> Sharing retirement |
| <input type="checkbox"/> Doing our best for our children | <input type="checkbox"/> Focusing on what we have |
| <input type="checkbox"/> Being the best partner I can be | <input type="checkbox"/> Finding meaning and purpose in life |
-

Our relationship

- | | |
|--|---|
| <input type="checkbox"/> Having a loving relationship | <input type="checkbox"/> Making time for fun together |
| <input type="checkbox"/> Maintaining our individuality | <input type="checkbox"/> Being companions |
| <input type="checkbox"/> Respecting each other | <input type="checkbox"/> Solving problems together |
-

Our activities

- | | |
|--|--|
| <input type="checkbox"/> Sharing activities | <input type="checkbox"/> Individual time for my own things |
| <input type="checkbox"/> Making time for friends | <input type="checkbox"/> Being adventurous |
| <input type="checkbox"/> Enjoying music, art, drama | <input type="checkbox"/> Being part of a community |
| <input type="checkbox"/> Running a business together | <input type="checkbox"/> Building a secure future |

The following questions can help pinpoint what you truly value:

- What is important to us? What matters most?
- What sort of partner/couple do I/we want to be?
- What sort of relationship do we want to have?
- What qualities do I want to develop as a person?
- How do I/we want to be thought of by others?
- How do I want to live my life? How do we want to live our life together?

Values versus goals

When you're thinking about what is important to you, it can be easy to confuse goals/feelings for values. Goals and feelings are by-products of living according to the value they represent. For example:

Feeling/Goal	Possible Value (why is the goal or feeling important)
Being happy; going on holiday	Involvement in meaningful activities
Being rich; having a big house	Maintaining financial security/ having an enjoyable lifestyle
Being thin; losing weight	Taking care of my appearance
Being fit; joining a gym	Having a healthy/active lifestyle
Being loved; getting married	Building caring relationships

Cancer is challenging and may alter your lives in the short-term and possibly long-term. Knowing what your values are helps to focus on what gives your life meaning and what is important to you, despite the challenges you face. Once you are clear on the things that matter most to you, you can find ways to bring them into your daily life and adapt to the changes brought about by cancer.

Remember

A value is constant – it sets your direction. When life is difficult or has been altered by cancer, it is helpful to be guided by the things that are most important to you.



Special issues

Helping children cope

It can be hard to know how much to tell your children about what is happening. It is natural to want to protect your children from worry and distress. With sensitivity and support, children can cope well with difficult times. In fact, trying to keep what is happening a secret can cause more problems. Even very young children can sense when something is wrong. Their imaginations may well create fears that are worse than the reality. They may hear upsetting or inaccurate information from other people. Trying to hide the facts can cause them to feel hurt and isolated. They may feel unable to talk about the subject at home. And cut off from one of their best sources of support, their parents.

Before talking to your children about the cancer, it can help for you and your partner to talk about how you will do this. What do you want your children to know? Do you want them to know what the treatment will involve? Or whether the family routines will change? Or what changes to expect?

For extra support it may also be useful to tell other significant people in your children's lives what is happening and/or enlist their help. This could include extended family, people in the school community such as teachers or other parents, sports coaches, neighbours, and so on.

It is best to ask these adults to manage this information sensitively. It is also important to ask each of your children who they would like to have on their support team. With you leading as parents your children can feel secure and involved.

Exactly how you talk to your children will depend on their ages and personalities. Some general guidelines include:

- Pick a time and place when you can get their attention and have time to talk.
- Use short, simple sentences to explain the basic facts. Find out what they already know about cancer. Don't overload them. Invite questions. Check for fears hidden behind the questions. It can also be important to tell young children that the cancer is not their fault.
- Be open and honest, hopeful but realistic.
- Reassure them about their welfare. Tell them about any changes to their normal routines. Involve them in how you intend to handle the situation, including who they may want to tell (or not to tell).
- Be available. Your children may need time to think about what you have told them. Things will change over time, so let them know they can come to you if anything worries or upsets them. Don't push them to talk about it more if they don't want to.
- Tune in and listen at other times (for example, bedtime, games, art, reading) to pick up on how they are feeling.
- Let them know it is okay for them to still have fun and to do their normal activities. This can help children feel safe, more optimistic and help them cope.
- Have confidence in your abilities – you know your children best.

More detailed information and advice can be found in the Cancer Council booklet *Talking to Kids about Cancer*.

There may be times when you feel you need professional advice. This could be from a school counsellor, psychologist, counsellor, social worker, or a member of your treatment team.

Cancer Council Queensland's Cancer Counselling Service is available to help people affected by a diagnosis of cancer. Call Cancer Council 13 11 20 for a referral.

Being a carer as well as a partner

The effects of cancer or the treatment can mean your partner requires a much higher level of care. You may find yourself in a very different role within the relationship. Not only a partner but also a carer.

A carer is someone who helps and supports a person through an illness or disability. They usually provide practical support. They could coordinate medical appointments, take over the running of the house, provide help with their daily activities such as bathing or dressing, prepare food, or deal with the medical system.

You may feel that becoming a carer for your partner is a natural extension of your relationship. Or, you may feel that being a carer is just something you have to do or 'should' do. Being a carer can be a very different role. It can take time for you both to adjust to the new dynamics in your relationship, particularly if your partner has been very independent. Adjusting to these new demands and changes can feel as if you are on an emotional rollercoaster ride. It is important to know that feeling afraid, angry, frustrated, lonely, guilty, tired, or stressed are all normal reactions.

Caring for someone with cancer is not always easy – it can be exhausting and daunting. Sometimes focusing on the value of caring can help you to cope with these new demands. You could learn new skills. You are able to demonstrate your love and commitment. You are, strengthening your relationship.

You may gain a sense of satisfaction from being able to help your partner when they need you most.

Carers sometimes need extra support to continue to provide care to their loved one over the long term. You can get support from other family members or friends. You may be able to access respite care. This allows you to have a break while your partner is cared for, either in your own home or in a care facility. Respite care can be provided for a few hours, overnight, or a few days. It provides the opportunity for you to have some time out to look after yourself.

You might need to catch up on sleep, attend a medical appointment of your own, or visit friends or family. Some carers feel uncomfortable and even guilty taking time out and leaving their partner in the care of someone else. But taking a break to protect your own health and wellbeing means you can continue to care effectively for your partner for as long as you need to.

Carers need to be aware that an ACAT (Aged Care Assessment Team) assessment is required for admission to respite. This may take some months to organise, so it is important to arrange the assessment ahead of time.

Please refer to the Cancer Council booklet *Caring for Someone with Cancer* for more information.

Fertility

Some treatments for cancer can cause permanent infertility. There may be uncertainty about the possibility of having children after treatment. If you have not started or completed your family, this can come as a shock. For some, not being able

to have children is devastating. It can involve loss of future hopes and plans. Infertility can cause some people to feel differently about themselves as a woman or man. Physical changes (such as early menopause, hormonal changes) can add to these feelings.

Early on, when you are still dealing with the shock of diagnosis and fears for your future, it can be hard to think about fertility. But if this is something that is important to you, discuss it with your doctors before cancer treatment starts. In some cases, there may be options to try to preserve fertility. They may include storing eggs, ovarian tissue, embryos, or sperm for future use. Even if this is not possible, knowing you have explored the possibilities can make a positive difference to how you feel later.

Chemotherapy and radiation therapy can reduce fertility. But conception may still be possible. If either partner is receiving treatment, it is important to seek medical advice about the possibility of pregnancy. Treatments can affect an unborn child and can also damage the patient's ova/sperm. You may be advised to wait for before trying to conceive. This could be from three months to two years depending on the cancer site and treatment. Talk to your doctor immediately if you/your partner become pregnant. If you need advice about fertility issues, talk to your GP or specialist. You could also ask about referral to a fertility specialist or counsellor. Call Cancer Council 13 11 20 for other information and support services.

‘When you’re in the middle of it, the possibility of not having children is the least of your worries – you just want your partner to survive. Later it hit me like a sledgehammer – everything we’d taken for granted about having a “normal” life. Today, I can accept that there is more than one ‘normal’ and that we have many opportunities to make life meaningful.’

When things in the relationship are difficult before cancer

There are times a couple may already be under significant relationship stress before a cancer diagnosis. You or your partner may have even considered separation before the diagnosis. When you have a cancer diagnosis it can be difficult to consider ending the relationship. This could be on both a practical and an emotional level. Caring for someone with cancer is demanding. When you experience a struggle in yourself to accept this role, feelings of anger, guilt, shame or resentment can grow. These feelings are natural responses to being in a very complicated situation. Many people say they feel trapped in a difficult relationship by the cancer diagnosis and the pressure of other's expectations of them.

A cancer diagnosis can also mean we start to think about what we want in our lives and from a partner. The decision to remain in the relationship or leave can seem to be more difficult.

Couples counselling can be difficult to consider, even when things are going well. But it can be helpful to look at all the options available to you. It might help to have a third party in the room to work out what is possible and sustainable for both of you in dealing with this. Or it can be useful to try some structured decision support. This is a process that helps you to work through your decision step by step. You consider all possibilities and figure out what is the most important for you both.

Cancer Council Queensland's Cancer Counselling Service is available to help support couples affected by a diagnosis of cancer and may be able to provide the independent mediation that could help in this situation. Call Cancer Council 13 11 20 for a referral.

When the outlook is poor

News that your partner has advanced cancer can be devastating and very frightening. Even though the cancer may not be curable, there may be treatments that can slow the disease and/or help to manage symptoms. You do not need to fear that you will have to cope alone. There are services available to support you and your partner now and during times to come.

Palliative care services provide active treatments to control symptoms and pain. As well as medical care, they may also provide practical, social and emotional support. These could include dietary advice, equipment loan, physiotherapy, occupational therapy, counselling, social work services, spiritual support, and bereavement support.

Palliative care can be provided either at home or in a health facility (such as a hospice). This depends on your partner's needs, preference, and the home environment.

The aim of palliative care is to help your partner experience a good quality of life for as long as possible. Early referral to palliative care can reduce you and your partner's concerns and boost your confidence. It can allow a relationship to develop that will provide appropriate support to you and your partner as you need it.

You are likely to have many concerns. Further information and support are available by calling Cancer Council 13 11 20.

Other Information

Useful Publications

Cancer Council have several publications that address some of the issues raised in this booklet in more detail. Visit our website cancerqld.org.au to download or call Cancer Council 13 11 20 to have a copy sent to you.

- *Caring for Someone with Cancer*
- *Talking to Kids about Cancer*
- *Emotions and Cancer*
- *Fertility and Cancer*
- *Sexuality, Intimacy and Cancer*
- *A Guide to Relaxation*
- *Understanding Palliative Care*
- *Understanding Grief*

Useful Websites

- [Cancer Council Queensland](#)
- [PalAssist](#)
- [Commonwealth Respite and Carelink Centres](#)
- [Carers Associations](#)

13 11 20
cancerqld.org.au

● Toowoomba

● Cairns

● Townsville

● Mackay

● Rockhampton

● Bundaberg

● Sunshine Coast

● Brisbane

● Gold Coast