



**Cancer
Council**
Queensland

A guide for partners of someone with cancer

Partners guide to coping with cancer

Cancer Council Helpline

13 11 20

www.cancerqld.org.au

Coping with
cancer

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This booklet was written by a team of psychologists in the Cancer Counselling Service, Cancer Council Queensland - with thanks to all whose experiences, knowledge, and skills contributed to the production of this booklet.

Cancer Council Queensland is a not-for-profit, non-government organisation that provides free information and support for people with cancer and their families and friends throughout Queensland. These services are made possible through the generous donations of Queenslanders and we thank them for their continued support.

If you would like to know more about the information and support services provided by Cancer Council Queensland, call our Helpline 13 11 20, Monday to Friday, 8am to 6pm.

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Introduction

Being diagnosed with cancer is one of the most distressing and demanding experiences a person can face. The focus of attention naturally falls on the person with cancer. However, other family members, and **partners** in particular, often suffer as much or even greater distress. Fears for your partner, emotional turmoil, and increased demands often continue over a lengthy period, and can leave you vulnerable to the effects of stress – and just at the time when you are needed more than ever. If you are the partner of someone with cancer, this booklet – *A Partner's Guide to Coping with Cancer* – is designed to address your particular challenges.

Being a partner obviously involves being in a partnership – with relationship issues that involve you both. Therefore, this book is one for sharing together – to aid understanding of each other's feelings and reactions, and to work together on ways to protect and strengthen your relationship at this time.

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

Note: Our other booklets *Coping with Cancer* and *Coping with a Diagnosis of Prostate Cancer* provide information and strategies to help guide patients and families through the challenges of diagnosis and treatment. This partner's booklet is designed to complement and to be read in addition to these booklets.

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The impact of diagnosis – a partner’s perspective

Your emotional reactions

As a partner, you too face the shock of diagnosis, concerns about surgery and/or other treatments, and fears for your loved one’s present and future wellbeing. You may be shouldering additional demands including taking on extra household tasks and finding ways to support your partner. At the same time, you may be dealing with pressure on your relationship and the impact of the situation on other family members.

The thought of cancer is frightening in many ways and 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 were told the news. Other common reactions include feeling anxious and scared, or perhaps upset or emotional. Often people feel confused, particularly when trying to understand complex medical information or when helping their partner to decide about medical treatments. Feelings of helplessness and frustration are also very common, often in response to seeing their partner undergo many medical tests and procedures. Sometimes people feel angry – they may feel that it is unfair that their loved one got cancer or wish that the cancer had been found earlier.

With so much going on for your partner, it can also be natural to feel that your own feelings and needs do not deserve attention and to push them into the background. However, 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. However, 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, 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 do continue to feel very worried, upset, or depressed in ways that interfere with their lives. If you find that your distress is very high, that it prevents you from functioning, or that you are not feeling any better over time, it is important to tell your doctor or health professional and discuss support options and ways to help you manage.

The Cancer Council Queensland's Cancer Counselling Service is available to assist people affected by a diagnosis of cancer. This service can be accessed in Queensland by calling the **Cancer Council Helpline on 13 11 20 (toll free).**

“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 she 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 particular situation, but your partner will probably 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 may have to take on roles which don't come easily or that you find hard to manage. However, while it may be a relief for your partner to receive practical support, it is also important that your efforts to help, protect, and care for them don't "take away" roles and involvement that they are still able and willing to handle.

At first, a shift in roles may be difficult for you both, so it is important to talk together about how you are both coping with these changes. You may also need to adjust your expectations in the way that tasks are done (or even not done!). This may include relaxing housekeeping standards, simplifying tasks where possible or accepting offers of assistance 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 be dealt with and moved past – it is a series of changing situations and demands. This means that you and your partner may 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.

A diagnosis of cancer often raises 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 and can also involve losses – for example, loss of income, losing your sense of safety or control, the loss of future plans, or loss or change of roles within the family. Such losses can have an impact on the way that you both are 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 may respond to stress in a completely different way to you and this can be hard to understand. A common difference is that 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. For example, some people tend to focus on trying to find ways to solve the problem (which can be productive if the problem is open to solution). Others may focus on trying to manage their emotional reactions to the problem (which is helpful when the problem is beyond their control).

You have probably recognised these differences within your relationship in the past, but a stressful event like cancer may make these differences more obvious. Even though it can be difficult to accept these different reactions, it is important to realise that this may be the only way a person can cope at this point in time. Reactions are not necessarily right or wrong – but they may 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 may include avoiding discussion of cancer-related issues or throwing oneself into distracting activities, such as work. Withdrawal can seem like a lack of caring or coldness, but it is often a response to strong emotions, such as fear and anxiety that are difficult to handle. In the same way, avoiding opportunities to talk is usually a way to protect oneself or others against overwhelming, unpleasant emotions. If you sense this is happening, it is best to approach your partner gently and discuss the situation with understanding.
- ▶ **Over-protection:** Sometimes partners or family members do more for the person with cancer than is actually 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 himself/herself. They may also stop the person with cancer from expressing any negative thoughts or feelings and/or avoid telling the person about their own fears or feelings. Partners and family members often believe that 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. As well, attempting to protect your partner from negative thoughts and feelings can often have the effect of making them feel dismissed, 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.

Tip

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

- ▶ **Anger:** Frustration that things are not happening the way that you would like, or feeling out of control in the face of the cancer, may result in anger in either yourself or your partner. Anger can be difficult to understand, often because another emotion – such as fear, hurt, sadness, or grief – underlies it. When people feel angry they often 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. However, it is not part of a normal adjustment to cancer for anger to become excessive, ongoing, violent or abusive. If this occurs, it is important to get assistance and support as soon as possible.
- ▶ **Frequent discussions:** Either partner may wish to talk about the cancer or their feelings, and this can be a useful way of processing thoughts, releasing emotions, and ensuring understanding. However, very frequent or recurring discussions may become exhausting or distressing for one partner. In such a situation, it may be useful for the other partner to find additional support outside the relationship to meet their need to talk.

These reactions can be confusing and cause misunderstandings. Remember that 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 (see later sections).

“It’s important to be on the same page and also check in with each other regularly. We also now respect that we are a bit different in the way we cope with things.”

“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.”

“If only one of you wants to talk, it’s good to know there are other avenues such as counsellors or people who have experienced similar situations.”

If you feel you need advice or support in coping with cancer, call the **Cancer Council Helpline on 13 11 20 (toll free)**.

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. However, 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. In addition, we may feel uncomfortable raising difficult topics, or may be 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 (see page 26 for communication tips). Being creative about possible ways of supporting each other can lead to additional ideas and, most importantly, make it more likely that your efforts will be focussed where they are most needed and appreciated.

Ideas for showing support are provided in Appendix 1.

Navigating the healthcare system

When your partner has been diagnosed with cancer, it is understandable that you will want them to receive the best possible care. Your partner's treatment will be managed by one or more medical specialists and it is important that your partner has confidence in his/her medical team. Your partner may also need to decide whether to have his/her treatment through a public or a private hospital.

Of course, what one person considers is best for them may be quite different from what will meet another person's needs. However, the following information may help to guide you and your partner to find the most appropriate care for his/her particular needs and circumstances.

Sources of information for finding a specialist that best suits you:

1. Initially, your GP will discuss referral options with you. These could include both public and private care. Factors to consider when discussing care options may include:
 - a. The skills and experience of the cancer team/specialist in dealing with your partner's particular cancer
 - b. The way in which the team/specialist provides information and answers questions/concerns
 - c. How the team/specialist provides patient support whilst under their care.
2. **Information about medical specialists:** Cancer Council Australia website has links to professional colleges:
<http://www.cancer.org.au/AboutCancer/FindaSpecialist.htm>

- 3. Recommendation of a family member or friend:** A family member or close personal friend may report a favourable experience with a specialist. You can use this as a guide, but remember that you may value certain characteristics (e.g. being a good communicator) while they may value others (e.g. being highly regarded in his/her field).
- 4. Seeking a second opinion:** Anyone, whether under public or private medical care, is entitled to ask their GP or specialist for a referral to another specialist for a second opinion.

Considerations when deciding to use private or public healthcare:

Is the same treatment available in both the public and private sector?

1. Can I access the same specialist in both the public and private sector?
2. What level of private health insurance and extras cover do I have?
3. If I do **not** have private health insurance but I want to use the private sector, what will be the cost? Can I easily afford this amount?
4. Is it likely that I will require allied health support that is normally available in the public sector (such as a social worker, psychologist, physiotherapist, dietician, or other)? If so, is it also readily available in the private sector and how do I access it? If I have to access it privately, how much will it cost?

Maintaining your wellbeing

It can be easy to forget to take good care of yourself in the midst of everything you are doing to support your partner. In addition to your normal roles and responsibilities, you may now need to provide more emotional support to your partner and possibly other family members, deal with financial stress, and absorb more demands on your time and energy. During stressful times, it is also harder to find the opportunity or motivation to relax or re-energise through leisure activities.

Often it seems that the best approach to a crisis is to throw everything you have at the problem in the belief that once it is all 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 can put everything you have into the race because you only have to last a short distance. However, dealing with cancer may be less like a sprint and more like a marathon. If you don't look after yourself along the way, you may not be able to stay the distance and support your partner effectively because of high levels of stress or burnout.

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

Looking after yourself

It may be helpful to think about your well-being 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, at the same time, you are not looking after yourself – that is, you are putting less than usual into your account – your wellbeing account will soon be emptied and in the red.

Ways to look after yourself and maintain your well-being 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 constantly. Staying connected with the world around you can help you see a life outside and beyond cancer and give you time out from your worries. This may mean maintaining some degree of work, arranging to spend quality time with your partner, engaging in hobbies or spending time with family or friends.
- ▶ **Invest in your physical health:** Make sure that you are eating healthily 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 keep them to a minimum. Try to exercise regularly. While making time for exercise is hard at the best of times, it is even more important now, as regular physical activity has been shown to lift mood, lower blood pressure, improve sleep, and reduce stress. Also (and perhaps unexpectedly), physical activity is also an important way

to manage fatigue – helping you to feel more energetic and less tired. However, do be sure to match your physical activity to your current level of fitness, and seek advice if you plan to significantly 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 as if you are pushed for 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:** Uncomfortable 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 lead them to feel even worse. However, constantly pushing away difficult thoughts and feelings can create more pressure and you may find that you are keeping more and more busy to avoid the thoughts and feelings. Sleep may also be affected because the distressing thoughts and feelings will tend to surface when you aren't able to distract yourself with other activities. Some people even find themselves withdrawing from loved ones or using drugs or alcohol to avoid facing their emotional distress. Trying to keep up a brave face all the time is exhausting. Rather than avoiding difficult thoughts or feelings, it is usually more effective in the long run 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 to 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 that 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 – so that you can use your energy for these things and allow the less important tasks to take a back seat for the time being. For example, taking your loved one to their appointments and just listening if they need to talk may be more important right now 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 most.

“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 utilising 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. It is sometimes called the 'fight or flight' response because 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) that increase your breathing and heart rate, increase blood pressure and sweating, tense your muscles, and make your stomach churn. These are normal responses and can be very useful when dealing with an emergency. However, they are not very helpful in dealing with ongoing stress, because if stress continues for a long time these responses can lead to exhaustion and burnout.

To effectively manage stress it is important to identify your own warning signs that your stress levels are increasing so that you can take *early* action 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 tearfulness, feeling anxious, overwhelmed, tired, unwell, or overly sensitive. Other reactions to stress can include difficulty sleeping, withdrawing from loved ones, over-eating or loss of appetite, or increased use of alcohol/drugs or cigarettes. For most people, feelings of stress will reduce over time as they adjust to their changed circumstances. In the meantime, there are things you can do to help you to manage your response to stress and feel calmer during this unsettling time.

You and your partner may 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 in company is essential in helping 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 independently – if you are both less stressed as a result, your relationship will also benefit.

“ I could tell I was exhausted because I totally lost my sense of humour and got snappy about the smallest things, even comments that I knew were well-meant. ”

Some strategies for coping with stress include:

- ▶ **Be active:** Exercise maintains physical health and well-being 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:** Sometimes your changed circumstances make it difficult to do the things you normally do to relax, whether that is formal relaxation practice or some other enjoyable activity (like listening to music or working on hobbies). Even if you are managing to do these things, you may still be experiencing ongoing stress and physical tension in your body. Regular practice of relaxation exercises can help you to 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 the Cancer Council Queensland’s relaxation CD and booklet. Some brief relaxation exercises are provided in Appendix 2.

You may already have a favourite relaxation exercise you like to practice. If not, try the Cancer Council Queensland’s relaxation CD, available by contacting 13 11 20 or order on website.

► **Identify problems and solve if possible:** Some stress management strategies (like problem-solving or learning to say “no” to other people’s requests) are useful in helping to change a stressful situation or sometimes get rid of it altogether. Although the cancer diagnosis cannot be changed or removed, many stressors related to it or adding to it may be able to be changed, for example, reducing work duties, getting help with transport/childcare/home duties, and renegotiating 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* on page 29 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 either ‘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 from a different viewpoint 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 (that is, there is no evidence for them, they are not realistic, or they are not helping you to feel better or cope better), 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’ will 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.

“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.”

Don’t waste your life in doubts and fears: spend yourself on the work before you, well assured that ... (this) will be the best preparation for the hours or ages that follow it.

Ralph Waldo Emerson

If you feel like your thoughts are causing difficulties for you, the *Coping with Cancer* booklet has a more detailed section on *Helpful thinking*. You may also like to get support from the Cancer Council Queensland’s *Cancer Counselling Service*.

Recruiting help

When you are facing the extra demands of cancer, help with everyday responsibilities from family and friends can make an enormous 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 are eager to find ways 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?" One idea for overcoming this barrier to getting support can be for a trusted and capable friend to take on the role of co-ordinating help. You and your partner need to let this co-ordinator know what type of help you would like (see over). Then when someone asks you whether there is anything they can do to help, you can direct them to your co-ordinator who will give them an appropriate task.

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, while others may feel more able to help out in practical ways, for example, helping with meals or transport or helping around the home. At times when your focus will be concentrated on your family, you may not realise how much support you do have available to draw on. It may be helpful to complete the 'Support Map' in Appendix 3 to see if your support network can be strengthened or extended.

It is important to let people know the things you would find helpful so 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 – then when people ask if there is anything they can do, they can choose from the list something they would be comfortable doing.

Your list could include different types of help – practical things like picking up groceries or help with transport or 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, or it could even include helping you to have fun and take a break. Using a list makes it more likely that your supporters will feel useful and satisfied with the help they are providing; more likely that you will get your real needs met; and more likely that well-meaning general offers of help (e.g., “let me know if I can help”) are converted into actual support.

A blue circular icon with the word "Tip" written in yellow text.

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; rather it is a way to help yourself and those around you.

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

“Having a close friend with us at medical appointments, helping to remember information, really helped take some of the pressure off us.”

What do we live for, if it is not to make life less difficult for each other? George Eliot

Strengthening your relationship

Because facing cancer is often a new experience for couples, it can bring up all sorts of unexpected thoughts and feelings. It is not surprising that in the busy time of diagnosis and treatment, couples can find that they lose touch with one another. This can sometimes lead to couples feeling frustrated and disconnected – even though they might actually 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 are loved just 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 old ways of showing caring and affection have changed or reduced during or after treatments. We all have different ideas of how to express caring. Some might show care with hugs and affection, while 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 always easy to know how to demonstrate that you care.

Think about the things that you can do for one another to show that you really care. These don't need to be big gestures like planning a holiday or a major purchase, just 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 really mean something to you or help you. Then together, discuss and plan ways of caring for one another over the next week – perhaps even writing down one caring activity each day that you will do for your partner. Try to be creative, and use the list in Appendix 4 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 separately, or you can use the list to talk about the ways you would each like the other to show they care.

Improving communication

After a diagnosis of cancer, there are various reasons that couples may not connect as well as before. For example, one partner may feel that if they talk about their real feelings this may upset the other partner. The idea that you always have to ‘think positively’ may also close the door on sharing natural concerns, leaving each of you alone with your worries. Good communication during the challenges of cancer can bring about a deep sense of connection. It can help you to better understand and support one another. Think about times in the past when you really felt that you were connecting with your partner – the chances are that you were 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 really want to say. Rather than diving into complex issues, it can be better to begin with small, less difficult topics as a way of opening the door to deeper conversations. You may find that talking about how you think and feel will encourage your partner to open up as well. You can also let your partner know that you are open to discussing difficult topics and suggest setting up a time to talk as a way to begin. Identify a time for the conversation that is likely to 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 properly.”*

During the conversation, it is important to limit distractions, so 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 one another, 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 really well if you are thinking about your own response while your partner is talking. Try to put aside your own thoughts so you can **really** listen to your partner – tune in to try to understand what your partner is saying and why. It's really useful to check with your partner that you have accurately understood them – if you have, they'll feel good to have been heard; if not, they have the chance to clarify the misunderstanding.

Good communication involves both speaking well and listening well. In addition to using the general tips outlined above, 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 understanding in the best way possible). Tips for ways to improve your skills as both a speaker and a listener are included in Appendix 6.

You may find yourself automatically trying to solve problems your partner raises. Even though you may want to find a way to make your partner feel better, solving the problem is not as important as listening and showing that you understand. You can follow-up with problem-solving together (see page 29) after you have both heard and understood each other. Trying to solve problems too early can lead to frustration and conflict.

Importantly, be forgiving and patient. Remember, no one is perfect and we can let each other down for any number of reasons from exhaustion to forgetfulness to not understanding or not being 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. Simply 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.

“ We always have a kiss and cuddle before we go to sleep. Sure I miss the sex but it is so much more important to have that physical contact. ”

“ We make a point of walking together in the evenings now. It is good physical therapy for John but we have also come to enjoy that time that we spend together after dinner. ”

“ 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. ”

“ We lose patience with each other pretty quickly during treatment week. The best way that we have found to deal with issues is to put them on ice and talk about them when we are not feeling quite as tired or distracted. And often we can't even remember what the problem was in the first place. ”

“ 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. ”

Solving problems together

A structured approach to solving problems can give you both 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.

Steps for successful problem-solving and a problem-solving worksheet can be found in Appendix 5. These explain how to use a simple method that helps to ensure you've thought about all the possible ways you could go about solving 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 issues underlying it.
- ▶ **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:** Thinking of as many solutions is more effective with two heads.
- ▶ **Considering all possible outcomes:** You are less likely to overlook possible outcomes – good and bad, long-term as well as short-term – by working together.
- ▶ **Committing to the solution:** Both you and your partner are more likely to commit to the agreed option if you have both been involved in the discussions (rather than feeling the decision has been imposed).
- ▶ **Feeling connected:** Solving problems **for** your partner may come from good intentions but may not be their preferred solution. Working **together** is more likely to encourage connection and closeness.

Although a structured approach may take a little more time and effort, it can bring positive returns such as better mutual understanding and closeness which, in turn, will help your relationship generally.

Maintaining intimacy

Treatments for cancer can affect how a person feels about their body and their ability or desire for lovemaking. This may come about as the direct result of physical changes caused by surgery or radiation therapy. Other treatments such as chemotherapy or hormone therapy may create sexual difficulties by lowering libido (desire) or causing vaginal dryness (in women). Fatigue or feeling unwell due to cancer or cancer treatments can also reduce sexual desire, as can the general stress of coping with cancer.

The ability to function sexually is something that we may take for granted, so 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 man or woman. Sudden changes in your ability to perform or respond sexually can therefore lead to a deep sense of loss.

Physical changes, such as the effects of surgery, scarring, hair loss, or weight gain/loss, may affect how attractive or desirable a person feels. Some people may fear that 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 with family, friends, and common interests. While this can be difficult to talk about, it is likely that 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. Also, remember that hugs, kisses, and general affection go a long way in showing love, creating closeness, and reassuring one another.

Some of the most common traps that couples fall into that can increase sexual difficulties include:

- ▶ Too high expectations leading to performance anxiety, making sex more difficult and less enjoyable.
- ▶ Focusing on performance – a focus on achieving sexual penetration and/or orgasm rather than focusing on mutually satisfying sexual closeness and/or intimacy can be frustrating and unfulfilling.
- ▶ Failing to communicate – although it can be a difficult topic, not talking about sexual problems is a recipe for creating distance, resentment, and insecurity.

While there are no simple solutions to sexual problems, the following tips can help you on your way to improving your sexual relationship:

- ▶ Talk to your partner openly 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 one another and work out ways to stay intimate.
- ▶ Let your partner know how much you care. Consider telling 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 wishing things would go back to the way they were, and being sadly disappointed. Alternatively 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 just sexual intercourse. This can involve cuddling, massage, or more intimate contact but without pressure to "perform". Being imaginative about the use of dim lighting, nice sheets, or sexy clothing can help with self-consciousness or discomfort about physical changes such as scars.
- ▶ Try looking at changes as challenges to be solved 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.

There is information that may help you and your partner enjoy a satisfying, intimate relationship despite physical changes or difficulties. Your doctor can advise you about using aids and medications, and can also refer you and your partner to other health professionals who specialise in the management of sexual problems. Sex after treatment may be different. However with the right advice and some patience and effort, it is possible for couples to find ways to continue a satisfying sex life. Sources of further information are listed below.

Sex after Treatment (Prostate Cancer)

Cancer Council Queensland www.qldcancer.org.au

Sexuality for the Woman with Cancer

American Cancer Society www.cancer.org

Sexuality for the Man with Cancer

American Cancer Society www.cancer.org

Information is also available on the Macmillan Cancer Support website www.cancerbackup.org.uk

“ I felt really hurt when we stopped having cuddles in bed. I mean I knew that sex was an issue but that didn't mean we couldn't enjoy a cuddle. 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. ”

“ 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. ”

“ Alison was very self-conscious at first and didn't want me to see the scars – she was scared I'd find her unattractive. So we got round it by her wearing pretty underwear until she felt more comfortable. Now she believes me when I say I love her, battle-scars and all. ”

Managing conflict

Conflict can emerge in a relationship during times of stress and 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.

Conflict doesn't necessarily mean a lack of caring – the person may care very much but be hampered by difficult feelings. However, the misunderstandings that result 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 that they don't go on to damage our relationships. To prevent this, it is important to take the time to work out what is happening and to agree on better ways to deal with it. Some ideas that people find helpful include:

- ▶ Take your time; don't try to solve the problem too quickly. Also, 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 your partner 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 (in private with no distractions) that suits you both.

- ▶ Allow each other the chance to be fully heard (without interrupting) 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.
- ▶ Really listen – and feed back what you think the other person is trying to say so they feel heard and know you understand (not necessarily agree with) their point of view.
- ▶ Seek solutions that respect each other's differences.
- ▶ 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.

Remember, 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 but because you hurt each other. 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. Perhaps you can reach out with hugs or touch. Or perhaps you can say something to let your partner know you love them and then let them come around in their own time.

Coping with uncertainty

Into the future

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

Rather than the expected period of relief and normality, you may find that your partner still feels anxious – perhaps even more anxious than he/she did during treatment. Without the demands of treatment, your partner finally has time to absorb the reality and implications of what they have been through. It is therefore not unusual for others (sometimes partners and often family or friends) to be ready and able to move forward more rapidly than the person who has had cancer. This mismatch can then lead to your partner feeling misunderstood and isolated in their experience. It is also not uncommon for patients and partners to miss the regular contact with the treatment team and 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', and this feeling of coping on your own can be heightened if you and your partner feel as though you are not working together as a team.

You and your partner may find that the people closest to you are less available to you for support. They may assume that everything is 'over' and 'back to normal' and may expect you both to be feeling on top of things without understanding the on-going challenges you may be facing. As well as getting less practical support, there may be less emotional support, with advice such as "be positive". Although this is a well-meaning response, it may be out of sync with how you and/or your partner are feeling and shuts off opportunities to express feelings and work through natural fears and concerns.

For both you and your partner, increased anxiety – often related to cancer reminders – will be a feature of the weeks and months following the end of treatment. Cancer reminders can take any shape but commonly 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 – from mild discomfort, irritability, or physical tension, to anxiety/distress, and sleeplessness.

At these times you may start to feel you are not coping or are moving backwards. Be reassured, these are completely normal responses to coming to terms with a very difficult life event.

The end of treatment can be a difficult and confusing time, and give rise to many conflicting emotions. Just knowing that this transition can be difficult can help you have more realistic expectations, allow yourself time, and make a plan to help yourself through this period.

“Finishing treatment was really hard. We’d focused so hard on reaching this moment, 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 from that. It’s taken time and understanding – from myself and others – to adjust and feel comfortable with the changes.”

“I feel a little bit afraid of planning for the future; I just want to focus on what we have here now.”

“Before I could only cope with the uncertainty by filling up my life, always keeping busy. I now know that the anxiety is normal and it can come and go without me having to try to push it away.”

“We speak positively about the future because that is how we choose to manage. It doesn’t mean that we don’t have the odd worrying moment, we can talk about those things too.”

A time of transition

It is helpful to think of this period as a time of transition for you and your partner – of moving from one stage in your lives (pre-cancer and cancer treatment) to another stage (after cancer). Making this transition takes time. The more difficult the cancer experience was for you both, the longer the transition to life after cancer 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 – your plans and goals both as a couple and as individuals – and require learning to live with greater uncertainty.

Use this time of transition to look after yourself well 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, like taking a holiday, or returning to activities you had stopped, now that cancer treatment has finished.

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 from time to time. Some ideas to help you manage living with uncertainty include:

- ▶ **Seek medical reassurance:** If your partner continues to be worried by any signs or symptoms, is very distressed, or has continuing medical difficulties, see your GP for help or reassurance.
- ▶ **Acceptance:** The future is always uncertain – when we make plans, we don’t usually acknowledge this fact. A cancer experience makes this more confronting. Learning to tolerate uncertainty, and living fully despite it, can help you move forward.

- ▶ **Finding direction:** (see section on page 42) Focusing on what is most important to you may help to guide you forward.
- ▶ **Balanced thinking:** Rather than using energy to constantly push away frightening thoughts, set aside time to deal with them or to acknowledge that they are there and that they are just thoughts. This will help you feel less overwhelmed.
- ▶ **Focus on the here and now:** When something triggers fear or anxiety, bring your attention back to the here and now. 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, as well as helping 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, also, that there are many people who have had a similar experience and understand how you are feeling. Your doctor, Cancer Council Queensland's website or the Cancer Council Helpline (see next page) may also be able to help you find out more about sources of information and support available to you.

Further information can be obtained from the Cancer Council Helpline on 13 11 20 or Cancer Council Queensland's website: www.cancerqld.org.au.

“Getting through cancer was one of the hardest things we've faced together. Even several years down the track now, there are still times when my partner feels worried. But you know, overall I think our life is great, we appreciate our family and friends more and enjoy life. I do think that after cancer the goal posts change, and you get more focussed on the things that really matter. That's one choice we do have.”

Finding direction

Accepting that you are in a time of transition allows you time and space – both individually and as a couple – to review your direction, the goals you had set, and whether these are still important or may 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 and 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 have had to be postponed. Returning to the things you value as soon as is practical can be beneficial for your long term health and well-being. You may want to reconsider aspects of your lifestyle. It is all too easy in a busy world for the demands of work, family, and children to take up most of our available time, attention and energy. Over 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, motivation, or freedom from other responsibilities to engage in 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 lead to limited opportunities for relaxation or personal space, which can increase tension.
- ▶ Communication – Limited time and opportunity for communication, especially when dealing with difficult topics, can lead to misunderstandings, hurt feelings, and loss of closeness.
- ▶ Shared couple/family activities – Extra demands on time and energy, particularly during cancer treatment, can limit shared activities and opportunities for respite, fun, and closeness.

- ▶ Social support – Reduced opportunities or energy to see friends may mean less chance for respite/fun, emotional release, communication, and/or extra help.
- ▶ Spirituality – Moving through cancer diagnosis and treatment with your partner may cause you to question your beliefs or to not make time for prayer, meditation or contemplation.

Neglecting these important activities can cause us to become stuck in a worsening cycle of stress and reduced wellbeing, leaving us feeling overstretched, dissatisfied and frustrated. Handling any extra demands and/or changes becomes ever more difficult and you are at risk of becoming physically and emotionally drained.

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

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

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

Deciding what matters

It can be helpful to spend some time thinking about what is **really** important to both you and your partner, and what you as a couple value most in life. These '**values**' provide a guide – a direction or path to follow. An important point to note is that a value is **not** a goal to be accomplished – although there may be **many** goals along the way

(see below). A value is like a compass setting, a constant star or lighthouse that helps you steer in a consistent direction. An example of a value might be supporting each other through difficult times. Or you might value your approach to family/parenting – being available to your children and being the best parents you can be.

Identifying what is important to you helps to clarify what gives purpose and meaning to your life together. It can also highlight the impact that cancer may be having on things that are important to you, for example whether you have stopped doing things that you value.

When you neglect or get side-tracked from your values, you can feel stressed, frustrated or lost. Once you are clear about what matters most to you, it is easier to identify your priorities and establish goals as a couple that will enable you to include meaningful activities in your life **despite** the obstacles that cancer might put in the way. For example, you may identify that doing enjoyable things together is an important value (i.e. gives your life meaning, helps you feel connected, helps you cope with stress), and that cancer/treatment has reduced your enjoyable time together. You are then able to work out if you can do anything to change this, such as putting 10 minutes aside every day for a cup of tea together no matter what else is happening.

A guide to identifying values and goals is included in Appendix 7.

Think of your values as a lighthouse, and you as the captain of a ship. The lighthouse helps to guide you on your journey, even when it's dark and a storm is raging.

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 that you can focus your precious time and energy on them. It may be that your current circumstances simply do not allow you to manage

your life as before. However, if a value (for example, 'looking after my health') 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 if required. 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 (for example, pleasant outings, activities with children/grandchildren, gardening, music, time to meditate or just 'chill') is helpful and can sustain your ability to cope over the long term.

Values guide us on our journey, and **Goals** keep us moving.

M. McKay et al (2010)

Committing to action

Staying focused on your values strengthens your commitment to the goals you set for 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 (page 29) may 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. Again, your values can be a guide to finding new ways to stay on track **despite** any difficulties you may 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.

Special issues

Helping children cope

At a time when your own emotions may be in turmoil, 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. However, 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, and their imaginations may well create fears that are much worse than the reality. They may also hear upsetting or inaccurate information from other people. Trying to hide the facts can cause them to feel hurt and isolated, unable to bring up the subject at home and cut off from one of their best sources of support, their parents.

Before you tell your children about the cancer, it can be helpful for you and your partner to work out together how you will deal with this as parents and a family. This is likely to include what you want your children to know, what treatment will involve, how you will try to keep family routines as normal as possible, and what changes can be expected. As a way to increase the support network for your children, it may also be useful to tell other significant people in your children's lives what is happening and/or enlist their help. These people may include extended family, people in the school community such as teachers or other parents, sports coaches, neighbours, and so on. However, it is advisable to ask these adults to manage this information sensitively. It's also important to ask each of your children who they would like to have on their support team. Under your leadership as parents, your family can continue working as a team with your children feeling 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 easily 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 and 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 and tell them about any changes to their normal routines. Involve them in how you intend to handle the situation, including who they may wish to tell (or not to tell).
- ▶ Be available – your children may need time to think about what you have told them, and 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 further if they don't want to.
- ▶ Tune in and really listen at other times (for example, bedtime, games, art, reading) to pick up on how they are feeling.
- ▶ Let them know that it is ok for them to still have fun and to engage with their normal activities – this can help children feel safe, more optimistic and assists them to cope.
- ▶ Finally, have confidence in your abilities – you know your children best.

More detailed information and advice can be found in the following publication:

When a parent has cancer: How to talk to your kids – A guide for parents with cancer, their family and friends (booklet).

Cancer Council New South Wales. Telephone 13 11 20.

www.cancercouncil.com.au.

There may still be times when you feel you need professional advice and this may be provided by a school counsellor, psychologist or counsellor, social worker, or a member of your treatment team.

The Cancer Council Queensland's Cancer Counselling Service is available to assist people affected by a diagnosis of cancer. This service can be accessed in Queensland by calling the **Cancer Council Helpline on 13 11 20 (toll free)**.

Being a carer as well as a partner

Sometimes the effects of cancer or the treatment may mean that your partner requires a much higher level of care than usual and 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, usually providing much more practical support, for example, coordinating medical appointments, taking over the running of the house, providing your partner with assistance with their daily activities such as bathing or dressing, preparing food, or advocating on their behalf within the medical system. You may feel that becoming a carer for your partner is a natural extension of your relationship. Alternatively, 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 and it can take some

time for both partners to adjust to the new dynamics in your relationship, particularly if your partner has previously been very independent. Adjusting to these new demands and changes can feel as if you are on an emotional rollercoaster ride and it's important for you to know that feeling afraid, angry, frustrated, lonely, guilty, tired or stressed are all normal in this situation.

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. Some of the rewards of caring can include learning new skills, being able to demonstrate your love and commitment, strengthening your relationship and gaining 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. This may be provided by other family members or friends. One of the options that may also be available to you is respite care. This allows you to have a break whilst 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 and it provides the opportunity for you to have some time out to look after yourself – for example, 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 about taking time out and leaving their partner in the care of someone else. **However, taking a break to safeguard your own health and wellbeing means that 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 will be required for admission to respite. This may take some months to organise so it is important to arrange the assessment in plenty of time.

Carers Associations exist in each territory and state to provide carers with information, support and advice. You can contact the Carer Advisory Service Centre on 1800 242 636 for help with referrals, counselling, support and resources on a wide range of topics, or visit the website <http://www.carersaustralia.com.au/>.

Also, Commonwealth Respite and Carelink Centres help to locate respite options in your local community and provide a one-stop shop for resources on community care and support services. They also offer a 24-hour emergency respite service. You can call them to find out about eligibility and services available on 1800 052 222 or visit their website at www.commcarelink.health.gov.au.

Fertility

Sadly, some treatments for cancer can lead to permanent infertility or there may be uncertainty about the possibility of having children after treatment. If you have not started or completed your family, this realisation can come as a shock. For some people, not being able to have children is devastating, involving losses of future hopes and plans. Infertility can also cause some people to feel differently about themselves as a woman or man, with other physical changes (such as early menopause, hormonal changes) adding to these feelings.

In the early days, when you are still dealing with the shock of diagnosis and fears for your future, it can be hard to think about issues such as fertility. However, if this is something that is *important* to you, then it is essential to discuss it with your doctors before cancer treatment starts. In some cases, there may be options to try to preserve fertility using techniques to store eggs, ovarian tissue, embryos, or sperm for future use. Even if this turns out not to be possible, knowing that you have explored the possibilities is likely to make a positive difference to how you feel later.

Although chemotherapy and radiation therapy may reduce fertility, you and your partner should be aware that 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 a period of time before trying to conceive (which may be from 3 months to 2 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 or ask about referral to a fertility specialist or counsellor. Other sources of information and support can be obtained from the Cancer Council Helpline.

“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 – all our plans, 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. It hasn't been easy, but we're starting to see, and even feel excited about, new prospects ahead.”

**Further information can be obtained from the
Cancer Council Helpline on 13 11 20**

When the outlook is poor

News that your partner has a cancer that is advanced can be devastating and very frightening. It is worth remembering that, although the cancer may not be curable, there may be treatments that can slow the disease and/or help to manage symptoms. You need not fear that you will have to cope alone. There are services available to support you and your partner now and during times to come. Even when cancer is not curable, 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 (such as dietary advice, equipment loan, physiotherapy, occupational therapy, counselling, social work services, spiritual support, and bereavement support) to both your partner, you and your family. Palliative care can be provided either at home or in a health facility (such as a hospice) depending on your partner's needs, preference, and the home environment. Ultimately, the aim of palliative care is to help your partner experience a good quality of life for as long as possible. Therefore, an early referral to palliative care can make the most of their extensive experience, reducing your and your partner's concerns, boosting your confidence, and allowing a smooth relationship to develop that will provide appropriate support to you and your partner as you need it.

You are likely to have many concerns, such as dealing with practical issues and potential loss and grief, which are outside the scope of this booklet. Details of further sources of information and support that may help you with these issues are available through the Cancer Council Helpline and website and the Palliative Care Helpline.

For information about palliative care and support in Queensland, call the Palliative Care Helpline on 1800 772 273 (9.00am-5.00pm Monday to Friday). The service can also be accessed via the website: www.palliativecarehelpline.org.au and email: info@palliativecarehelpline.org.au

Further information can be obtained from the Cancer Council Helpline on 13 11 20 or Cancer Council Queensland's website: www.cancerqld.org.au.

Appendices

Appendix 1

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
- Please accept there are some decisions I need to make on my own
- _____

- _____

- _____

Appendix 2

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 individually 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: take 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...

When you're ready... start to become aware of your surroundings and slowly return to your normal activities with a feeling of relaxation...

Appendix 3

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:

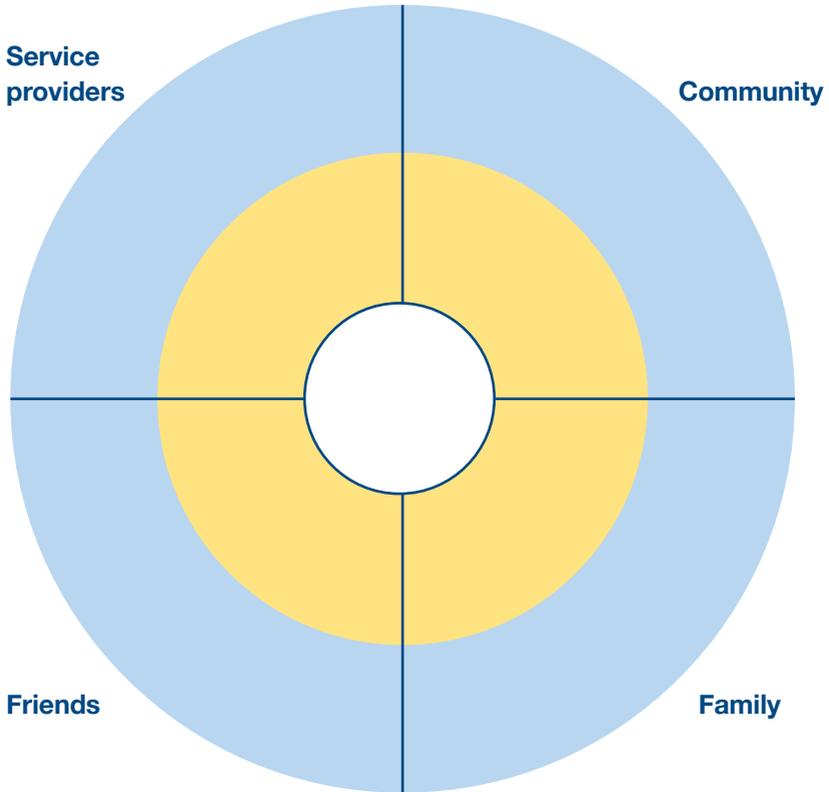
- ▶ Put the names of your *closest family members* in the white circle in the middle.
- ▶ Put the names of other people who are currently *supporting your family* in the yellow circle – people who know you or your family well and are willing to help in various ways (e.g., emotional support, practical 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 out 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?



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

Appendix 4

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 has 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 an unexpected 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. Then enjoy it!
- ▶ Give your partner a back rub 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 special card
- ▶ Have a shower together
- ▶ Make love in a way you know they will like
- ▶ Make a nice dinner

Appendix 5a

Steps for successful problem solving

- ▶ To start, **make a list** of all the challenges you are facing.
- ▶ Put the **problems into order** – list those that need immediate attention first followed by those that can wait for now.
- ▶ 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.
- ▶ **Brainstorm:** Take your most urgent problem, and **list all the possible options** for dealing with it. Make sure you include every idea, no matter how silly it may seem, as these ideas can lead to more flexible and creative thinking.
- ▶ **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 be useful to use a problem-solving worksheet to weigh up the advantages and disadvantages of each idea (see below).
- ▶ **Decide** upon the option or strategy (or combination) that seems best and then try it out. If it doesn't work then try your next idea!

Appendix 5b

Problem solving sample worksheet

Using the worksheet with your partner may be a helpful aid in solving problems together as a couple.

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 below.

STEP	NOTES
A. Attitude	
Take an optimistic attitude	Take a deep breath. Stop and think. There is no immediate catastrophe – think of this as a challenge. We can handle this problem.
Acknowledge the problem	
<ul style="list-style-type: none">State the problem and details	Loss of partner's income = difficulty meeting commitments = worry/poor sleep/irritability.
<ul style="list-style-type: none">What is a reasonable goal?	Find ways to balance income/outgoings.
<ul style="list-style-type: none">Can I change the situation?	Find other sources of income? Reduce expenses?
OR	
<ul style="list-style-type: none">Do I need to change my attitude?	Worry less about debt? Or, review our needs and make realistic plans.
B. Brainstorm	
Write down ALL your ideas	Find ways to reduce payments (talk to 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 2 – 4 of the best ideas:

Solution	Will it reach my goal?	Pros	Cons
Approach bank/utilities about temporary reduced payments	Yes	Reduces outgoings temporarily	Has to be paid eventually
Tighten budget	Yes	Identifies unnecessary expenditure and reduces outgoings	Impacts on lifestyle but temporary
Do extra work	Yes	More income, less financial worry	Less time at home/with partner, more strain/fatigue, less time for exercise, impact on own health and relationships
See financial counsellor	Yes	Objective, specialist advice about effectiveness of ideas plus maybe new ideas	None (use a free service, eg. Lifeline)

D. Decide

Decide on your best idea, put it in action, and rate the 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 with your second choice!

Example

Best idea: See a financial counsellor before we make any fixed 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, I can take better care of myself and, most importantly, we can spend time together.

Appendix 6

Tips for improving communication skills

As a speaker:

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.

Try to speak honestly about how you feel even if it is difficult. Most partners say that 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.

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.

There are always positive things that 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 that you let me know what was troubling you”.

To 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”.

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 listener:

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!).

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.

Notice the feeling/s 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.

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?*”

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.

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 usual ways of communicating can break old patterns and helps to reach new ground.

Appendix 7

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 that 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 below. Tick those that are most important to you and your partner as a couple.

Us

- Having a healthy lifestyle
- Doing our best for our children
- Being the best partner I can be
- Sharing retirement
- Focusing on what we have (rather than have not)
- Finding meaning and purpose in life

Our Relationship

- Having a close and loving relationship
- Making time for fun together
- Maintaining our individuality
- Being companions
- Respecting each other
- Solving problems together

Our Activities

- Sharing activities
- Making time for friends
- Enjoying music, art, drama
- Running a business together
- Having some individual time for my own things
- Being adventurous
- Being part of a community
- 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; what would it mean)
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 you focus on what gives your life meaning and what is most 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 acts as a 'guiding light' or 'compass 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.





Cancer Council
Helpline

13 11 20

For information and support call
Monday to Friday, 8am - 6pm

www.cancerqld.org.au