



**Cancer  
Council**  
Queensland



# Coping with cancer

**A guide for people with cancer, their families and friends.**

---

Cancer Council Queensland is a not-for-profit, non-government organisation that provides information and support free of charge 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 on 13 11 20 (toll free), Monday to Friday.**

---

# Introduction

In Australia, more than 100,000 new cases of cancer are diagnosed each year. For many people and their families, this is a very difficult time as they try to come to terms with the diagnosis, make choices about medical treatments, and face unexpected demands.

This booklet aims to provide a guide to help you through experiences that, for most people, are new and challenging. It explains some of the common reactions you, and those around you, may have after a cancer diagnosis. It also provides ideas about different ways of coping that can be helpful at this time. A cancer journey is not undertaken alone, so this booklet contains information to help you and your loved ones. It also looks at ways that you can build good working relationships with the health professionals involved in your care.

This booklet contains a lot of information which, for many people, may be too much to take in all at once, especially at such a demanding time. However, we hope that you will find time to skim through it so that you know what it can offer. Then you will be able to dip into it whenever you feel you need guidance, different strategies, or just reassurance that you're on the right track. Finally, this booklet provides details of further sources of information and support to help you on your cancer journey.

**“If I have seen further it is only by standing on the shoulders of giants.”**

*(Sir Isaac Newton) – with thanks to all those whose experiences, research, knowledge, and skills have provided the basis for the content of this book.*

# Contents

## **2** ..... **Understanding reactions**

- Diagnosis
- The cancer journey

## **6** ..... **Working with your treatment team**

- Working together
- Making the most of your appointments
- Getting a second opinion

## **10** ..... **Making decisions**

## **14** ..... **Tackling cancer problems**

## **18** ..... **Your coping toolbox**

- Gathering information
- Looking after yourself
- Getting support
- Relaxation
- Helpful thinking

## **38** ..... **The others in your life**

- Other people's reactions
- Talking it through
- Sharing with others

## **44** .... **Conclusion**

## **46** .... **Appendices**

1. Distress thermometer
2. Health professionals you may come across
3. Useful questions to ask when understanding your diagnosis or making treatment decisions
4. Problem-solving sample worksheet
5. Ways to show support
6. A relaxation exercise

## **60** .... **Further information**

- Other publications/ resources/websites

## **60** .... **Further support**

- Cancer Council Helpline
- Cancer Counselling Service
- Cancer Connect

*Hi, my name is Sam,*

*When I was diagnosed with cancer a few years ago, my emotions were in turmoil and I underwent many changes both physical and mental. It was really difficult to digest all the information I was given once told I had cancer. I needed brief factual information that could help me through my treatment, because initially I wasn't up to researching information from all different sources. I also needed strategies to help me face the challenges ahead.*

*This booklet provides a practical guide to dealing with the issues that come with a cancer experience. You can read it cover to cover or just focus on those pages relevant to the issues you are facing at the moment. It can be useful to re-read sections during and after your treatment and to also source more detailed information referenced in the booklet.*

*The great thing about this booklet is that it has given me tools and strategies that I can continue to use in my everyday decision-making and in my communication with family and friends.*

*Take care and I wish you all the best for the future.*

# Understanding reactions

## Diagnosis

Being told that you have cancer can come as a real shock. The thought of cancer is frightening in different ways. For a start, you can hear the word cancer and think: “How serious is this? Will it be cured? Am I going to die?” Cancer can also feel like a threat to your way of life and you may wonder: “Will I be the same person as I was before? Will I be able to do the things I usually do? How will my relationships change?”

In the time after diagnosis, you may experience many different feelings. Some people describe feeling like they were in shock or numb when their doctor told them the news. Other common reactions include feeling anxious and scared, or perhaps upset and emotional. Often people feel confused, particularly when trying to understand information or make decisions about medical treatments. Sometimes people feel angry - they may feel that it is unfair for them to get cancer at this time in their lives or wish that they had found out about the cancer earlier. Such strong emotions can make you feel like you are losing control of your emotions or your life. Sometimes people even say, “I felt like I was going crazy, like I was losing my mind!” You may never have felt this way before and it can be overwhelming.

**If you have these feelings, it is important to understand that you are not ‘going crazy’ and you are not ‘weak’, you are having a normal reaction to a difficult situation. Knowing this can help you to seek out ways to manage these feelings so they don’t overwhelm you.**

Over time, most people find that their strong feelings about cancer lessen. Although their life has changed in some ways, in other ways life goes back to a more normal pattern, and they feel more or less like their usual self. However, sometimes people find they continue to feel very worried or upset over a longer time and that this interferes with their lives. One way to check how you are going is to ‘take your emotional temperature’ using the Distress Thermometer (see Appendix 1 on page 46). If you score more than four or five on this scale, consider talking to your doctor or a health professional about how you are feeling and options for support. You can also call the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday, to find out about support available to you.

---

*“After I heard the word ‘cancer’ I was in shock. I didn’t hear another thing the doctor said that day. It really took a few weeks to sink in, before I stopped thinking that this wasn’t really happening to me.”*

*“At first I cried every time I thought about what would happen to my family if I died. Then I realised I was looking too far ahead – there was treatment that could help me and I needed to focus on that.”*

*“When I was first diagnosed, some mornings I would wake up feeling like I didn’t even want to get out of bed, that real ‘down in the dumps’ feeling. But once I got started, that feeling would kind of lift and things would seem ok. As time passes these depressing feelings are getting less.”*

## The cancer journey

It can be helpful to think of your experience with cancer as a journey. Rather than one stressful event, more often it is a number of different events that happen over time.

Your cancer journey probably started with medical appointments, tests, and test results. Having arrived at a diagnosis, what lies ahead can seem frightening. While it can be useful to plan for what lies ahead, worrying about the future can make you feel even more distressed. Breaking down the journey into stages or steps makes it more manageable. Instead of thinking of the future as a mountain to climb, it is useful to think of it as a series of stairs that you can climb one at a time, often with a breathing space in-between.

After diagnosis, the next stage of your journey is likely to be treatment – which may be one event, such as surgery, or a series of events such as surgery, radiation therapy and chemotherapy. Each of these events will have its own demands, including medical and hospital visits, tests, side-effects, and changed routines.

It makes sense to focus on the most immediate ‘step’, putting your effort into where it is needed right now. When you’ve dealt with what is happening now, then you can face the next step. Don’t forget to take advantage of ‘breathing spaces’, that is, the breaks between treatments, tests or appointments, or times when you are less troubled by the effects of treatment. These allow you to recharge your batteries (physical and emotional), spend time with those closest to you, and take time out for enjoyable activities.

You will then be better able to face the next step in your journey, perhaps finishing treatment, dealing with follow-up tests, getting back to a more normal way of life, and adjusting to life after or with cancer.

Although it is common for people to start to feel better in the weeks after a diagnosis, it is normal to experience an increase in distress at different points in your journey, particularly when things change, for example, starting or finishing treatment, having follow-up tests, or facing cancer reminders. People commonly feel anxious about these changes and it is important not to feel bad or worried about your reactions – they are part of the process of adjusting to cancer.

The following sections provide ideas for coping with challenges as you deal with cancer.

---

*“The secret of getting ahead is getting started. The secret of getting started is breaking your complex, overwhelming tasks into small, manageable tasks, then starting on the first one.” Mark Twain.*

# Working with your treatment team

During your cancer journey you are likely to be involved with various health professionals concerned with providing not only medical care but also emotional and practical care. These people may work individually or may be part of a multidisciplinary team who work together to discuss and plan your care.

**A list of different health professionals and what they do is included in Appendix 2 on page 48.**

## Working together

Most people see their GP (general practitioner) as the first person to turn to for information and support about medical matters. Even when you have been referred to a specialist, your GP is still a good source of support through treatment(s).

GPs may also take on a role of co-ordinating different types of care for you, particularly once you have completed hospital treatments. For these reasons, it is important to feel that you can talk with your GP openly about your concerns. Sometimes people do not have a GP they feel comfortable with or see regularly. If you need to find a GP, try asking family or friends if they can recommend someone in your local area.

It is also important to feel comfortable talking with your treatment team (specialists and other health professionals) so that they understand your concerns and needs. Your treatment team will be working closely with you for some time, so it is worth the effort to build a good relationship.

**Appendix 3, page 50, contains ‘Useful questions to ask when understanding your diagnosis or making treatment decisions’.**

If at any point you have problems that you find hard to handle, such as difficulty sleeping, low mood, high levels of stress or other issues, talk to your GP or specialist. It is likely that they will have seen people with similar problems and can reassure you, suggest options and make referrals if necessary.

---

*“Different people want different things from their medical teams. I think about it like a bus journey: Talk to people on a bus and you will find they have different ideas about their journey. One person may want to take the journey without knowing too much about the details, and simply look out of the window. A second person may, after discussion with the driver, decide the journey suits them and relax in the knowledge they are in safe hands. A third person may wish to plan the entire journey with the driver, be interested in the quality and comfort of the bus, monitor how the journey progresses and provide feedback to the driver, at the same time developing trust and admiration for the driver’s skill, knowledge, and care. Yet another person may want to drive the bus – if they have the skill, that is fine too.”*

*“I was so stunned initially that I didn’t feel I’d asked the right questions about the treatment being offered. Even though I was worried about bothering my specialist again, after a further consultation I was better informed and the final treatment approach suited me better.”*

## Making the most of your appointments

You will need information, guidance, and reassurance to help you manage your treatments and recovery. However, health professionals usually have limited time for each appointment, so it makes sense to prepare yourself to make the best use of this time.

- ▶ **Keep a diary of your medical consultations and treatments.** You will be seeing many health professionals and your records are likely to be in various places. Keeping your own record helps you to have accurate information at your fingertips, especially when looking back over time. This record could include dates, doctors/others seen, information/advice received, tests done, test results, details of diagnoses, treatments undergone, medications, symptoms or side-effects, etc.
- ▶ Before your visit, **write down your questions in order of importance** (if consultation time is limited, at least your most important questions will be answered). Be realistic and try not to have too many questions for a single visit.
- ▶ **Also write down information you want your doctor to know** (such as symptoms, side-effects, worries about treatments). Doctors may not always ask you about your feelings or other problems. This is not because they are not interested, but they often take the lead from what you tell them. It is therefore important not to wait to be asked but to tell your doctor if you are having difficulties coping. Clear communication **both ways** helps both you and your doctor.
- ▶ **Write down the answers provided.** This will help you later to review what the doctor said. Some doctors may tape, or allow you to tape, the consultation for you to listen to later.
- ▶ **Get answers you understand.** If you don't understand what your doctor is telling you, ask him/her to explain it further.

- ▶ **Take someone with you.** Having someone with you can help you feel better supported. Also, two sets of ears are better than one, and your support person can help you later to remember or make clearer what was said.
  - ▶ Ask your doctor for **sources of further information** (books, internet sites, organisations).
  - ▶ If you have a lot of questions or concerns to discuss, **ask if it is possible to book an extended appointment** (allowing the doctor to schedule more time with you).
- 

*“There is no such thing as a stupid question.”*

*“Knowledge is power.”*

## Getting a second opinion

There may be times when it helps to get a second opinion. This may be particularly the case for rare or more advanced cancers. A second opinion may provide another viewpoint about your illness, explore treatment options, reassure you about your choice of treatment, answer your questions, or allow you a choice of doctor (if seeing them privately). This is your right and most doctors (either your specialist doctor or your GP) will be happy to arrange this for you.

---

*“I felt that asking for a second opinion would make my specialist think I didn't trust him, but he just acted like it was normal. I guess, after all, nobody knows everything and different doctors do have different ways of looking at things.”*

# Making decisions

Over the course of your cancer journey, you are likely to be faced with the challenge of making difficult decisions. Difficult decisions that people face after a cancer diagnosis may include deciding between different types of treatment, whether or when to return to work, how to involve or care for family and what to do about finances.

Difficult decisions are made harder by the fact that there is sometimes no single right way forward. Different solutions often come with their own set of problems. Whereas some people prefer to have other people (like their doctor or partner) guide the decision, most people like to make the final decision themselves.

There are some useful tips that can help when making difficult decisions. You may have tried some of these and others may be new to you:

- ▶ **Take your time.** Often, even with a cancer diagnosis, there is time to consider your decision – check with your doctor about this. Generally, people make better decisions, and have less regret later, if they have:
  - ▶ Taken time to make sure they have enough information.
  - ▶ Considered all the possible consequences (now and in the future).
  - ▶ Thought it through to reach a decision that is right for them.

- ▶ **Seek good information.** Talk to people who have experience in the area (for example, medical specialists, your GP, financial advisers) and to people whose judgement you respect. When seeing your doctor, ask him/her to tell you which points about your cancer diagnosis or treatment are the most important to consider. This will help you focus on the key points at this time. Some people find it helpful to see their doctor more than once to allow themselves time to think about the information and return with their questions. It can also be useful to take someone with you to important appointments – they may help by taking notes, asking questions, and remembering complex information. Take care when getting information from websites and books that the information is accurate and relevant to you. Check with your doctor and/or call the Cancer Council Helpline on 13 11 20 (toll free) for reliable information.

**Tip:** A list of 'Useful questions to ask when understanding your diagnosis or making treatment decisions' is included in Appendix 3 on page 50.

- ▶ **Write it down.** Organising your thoughts on paper is easier than trying to do it in your mind (where it can feel like you are going round in circles). Make sure you have all the choices or options written down (for example, option one – have only surgery, option two – have surgery plus other treatment(s), option three – have only radiation therapy, option four – active surveillance). Considering every option

will make sure that you cover all angles. There are some useful guides to help work through difficult decisions. The Ottawa Health Research Institute has developed a decision support tool (the Ottawa Personal Decision Guide) and also has information on other patient decision aids (see website details on page 13).

- ▶ **List advantages and disadvantages and what is important to you.** Each option will have points for and against it – list these under each option and then underline the points that matter most to you. You might like to try rating how important each point is on a scale of one to five, with five being very important and one being not very important. Also, to give you some perspective on how important a point is, look at how it affects you and others both short-term and long-term. Weighing options up in this way will help you to see which option is best, on balance, for you.
- ▶ **Talk it over.** Talk through the options with someone close to you, like your partner or a close friend. As most decisions will affect other people in your life, it's also important to talk it through with people that will be affected and make sure their opinions are considered. For cancer issues, Cancer Council Queensland can help you with decision support or may be able to put you in touch with people who have faced similar sorts of cancer decisions. There are also cancer support groups around the state where patients and their partners can talk about their experiences and learn more about cancer and its treatment.
- ▶ **Get expert advice.** Review your options, and the points for and against each one, with people who have particular knowledge in that area (for example, someone in your treatment team, a financial or legal advisor or a counsellor).
- ▶ **Expect to experience doubts.** It is normal to wonder if you have made the right decision. Being unsure does not mean you have taken the wrong path. Reassure yourself that you have made the best decision you could with the information you had at the time.

## Useful websites:

Ottawa Health Research Institute:  
<http://decisionaid.ohri.ca/index.html>

Ottawa Personal Decision Guide:  
<http://decisionaid.ohri.ca/decguide.html>

Information on patient decision aids:  
<http://decisionaid.ohri.ca/AZinvent.php>

For information or support to make a decision, call the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday.

---

*“For a while I was just going round in circles: first I would think surgery was the way to go; then I would start to wonder if it would be better to have radiation therapy. Underneath it all I think I was wishing it would all just go away. So it took me a while to make a decision - writing down the options really helped with this. Talking it over with my partner helped as well, but in the end it was down to me. ”*

*“I took my time with my decision, read up about it on the internet, talked to lots of people and narrowed down the options with my doctor. By the time I made my decision I thought to myself, I know as much as I ever will so it is time to choose. I do feel that you come to a point when you just need to decide. ”*

*“I think it is important to remember that in the end the decision you make is the best one you can. No one can foresee the future, you just have to hear the options, consider the pros and cons, and make your best choice based on what matters to you. ”*

# Tackling cancer problems

Problem-solving is something that we generally do every day – working out what is causing the problem then looking at ways to deal with it. As this is just part of our daily lives, we don't usually think too much about how we do it. However, cancer can raise a whole lot of new problems which we have never had to deal with before. Difficult problems make us feel stressed, which can make it hard to think clearly about what to do.

*“It's not that I'm so smart, it's just that I stay with problems longer.”* Albert Einstein

Sometimes problems become more difficult to deal with because we see them as impossible to solve or change. Even if a problem itself may be unchangeable, there are things we can do to help ourselves cope or come to terms with it. Believing that we can do something to make a difference or that it is always possible to do something, even in the worst situations, is the first step in tackling any problem.

Armed with this optimistic attitude, we can then work through a set of steps for the problems we are facing. These steps include identifying the exact problem, brainstorming possible options, weighing up these options/alternatives, choosing an option or

strategy and trying it out. For simple or straight-forward problems these steps are not necessary – often we work out a solution automatically without much effort. But for difficult or distressing problems, or times when we become overwhelmed or stuck, working through the set of problem-solving steps can really help.

**Tip:** Remember, trying something is often better than doing nothing or doing more of the same. And if your first option doesn't work, you'll have more information than you had before.

---

*“I was so worried about losing my job and how we'd manage for money, so I didn't tell anyone at work at first. Finally, I had to tell my boss that I needed to have an operation and he was very understanding – in fact, they'd all wondered why I'd been so irritable! We worked out a plan that allowed me to start back on light duties and supervision, doing flexible hours if I needed, to work around further treatment. Now it's no longer a problem, and I can focus on getting strong again.”*

## 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) handling your fears about medical procedures.
- ▶ **Brainstorm:** Take your most urgent problem, and **list all the possible options** for dealing with it (look through the section, ‘Your coping toolbox’, on pages 18 to 37 for some ideas). 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 Appendix 4, page 54, for an example).
- ▶ **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!

**A sample problem-solving worksheet can be found in Appendix 4 on page 54**

*“ I couldn’t see how I could keep things running at home and focus on getting myself well again. Talking to a counsellor made me realise I don’t have to go it alone. We have good friends and a great community who will support me and make sure the kids feel secure. I just needed to be able to step back and see the possibilities... ”*

*“ I knew I had to have the treatment but it had got to the stage where I felt sick just approaching the hospital. My partner and I finally sat down together and came up with a list of strategies to help me get through it. Now I use my breathing and relaxation tape or music, I use coping statements, and I imagine how the treatment is helping fight the cancer. It’s still a bit of an ordeal, but it means I can keep going – and I make sure I give myself a decent reward after each treatment session! ”*

**Tip** Different ideas for coping with cancer problems can be found in the ‘Your coping toolbox’ section on the following pages.

# Your coping toolbox

When people are faced with a difficult situation, they will do a number of things to help themselves cope, usually without giving it too much thought.

*“Life is not what it’s supposed to be. It’s what it is. The way you cope with it is what makes the difference.”*

*Virginia Satir*

Most of us have ways of coping with difficult situations that we have learnt and practised over a lifetime. Different ways of coping might include seeking out information, trying to fix the problem, distracting yourself from difficult thoughts and feelings, having a laugh to try to feel better, or talking about things to try and make sense of what is happening. Our coping style depends on the type of situation we are facing, who we are, our upbringing, our role models and what has worked for us in the past. We may be very good at dealing with situations that are a ‘match’ for our style. However, our usual style of coping may not give us helpful ways of coping with all the different challenges caused by cancer. Relying on just one way of coping can also be limiting - it is useful to have a range of strategies to draw on when facing challenges and difficulties. In turn, finding more ways to deal with cancer issues can help you gain a greater sense of control and confidence.

An important question to ask yourself is: “Is my usual way of coping helping me?” If it is, then ask yourself, “Are there any negative effects or problems if I continue to rely on this way of coping?” If there aren’t any negative effects, then keep it up. If your usual way of coping is not helping or if there are negative consequences, the next question should be: “What other ways of coping could I use to help myself better?”

There is no single best or right way of coping. However, some ways of coping are likely to be more helpful than others depending on the situation, for example:

- ▶ Some ways of coping work best when the problem is a situation we can do something about (such as finances, childcare or organising a second opinion). These ways of coping include finding information and advice, getting help and trying different ways to fix the problem.
- ▶ In situations that we can't change (such as facing up to bad news or having to have a medical test) we can still help ourselves by finding ways to manage our feelings and/or thoughts. Examples include relaxation, exercise, art, writing, talking with others, having a laugh, and thinking in a helpful way.

Think of different ways of coping as being tools in your toolbox. Different jobs generally need different tools. If one tool doesn't fit the job, you need to try another one, so you are better off having many different tools. In the same way, if you are flexible about using different ways of coping to manage different cancer challenges, you are likely to do better.

**Tip:** It is important to note that there are some strategies that are generally unhelpful for any situation if used too much over time, for example avoiding the problem entirely, self-blame, alcohol or drug use, over-eating, or gambling.

The following sections can be thought of as tools for your coping toolbox. Some of these tools will help you to make changes that solve or ease a difficult situation. Other tools will help you get through difficult situations that can't be changed. You will already be using some of these tools, and it is useful to remind yourself of the things that are working well and the efforts you are making. Exploring these ways of coping may reassure you that you are on the right path, as well as giving you some fresh ideas.

## Gathering information

The chances are that your cancer journey is taking you into unknown waters. Gathering good information can help you to:

- ▶ Understand more about your diagnosis.
- ▶ Understand the words and terms used by your doctor and treatment team.
- ▶ Explore what treatment options may be available.
- ▶ Ask informed questions.
- ▶ Find support services.
- ▶ Be prepared for the next step in your journey.

In the beginning there can be a lot of information to take on board, and well-meaning family and friends may give you information they have found. Too much information can leave you confused about what to do. Rather than getting more information, you may need more helpful information or a way of dealing with the information that you already have. The following tips will help you to get the most from the information available to you.

- ▶ Get organised: Start a filing system of the various types of information and records you want to keep.

- ▶ Keep a diary of your medical details to help you keep track of events and highlight where information may be missing (see 'Working with your treatment team – Making the most of your appointments', page 8). This will also be a useful, accurate record into the future (especially if seeing different professionals in different locations).
- ▶ Take some time to work out what specific information you need. It can help to write down your questions and to put them in order of how important they are right now. For example, you may know what treatments are available to you but you may not know the specific pros and cons of each treatment for your situation.
- ▶ Involve other people. Two heads are often better than one, especially when it comes to gathering and making sense of new information. Of course it is important that you trust this person to help you out, rather than to add to your confusion.
- ▶ Consider different sources of information such as websites, books and different organisations. Care should always be taken with information about cancer, some of which may not be accurate as it may refer to things not available in Australia or may not be relevant to your situation – check with your doctor. **Call the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday, for reliable information.**
- ▶ If you are unsure about information or it is confusing, it can be helpful to talk to your doctor (specialist or GP) about it. Doctors are usually happy to explain things for you and point you in the right direction.
- ▶ File away information that may be useful in the future, but is not needed right now.

- ▶ If you have all the information you need but are still unable to make a decision about treatments, working through the decision in a structured way can help – see the section ‘Making decisions’ on page 10 for more information.

Reliable sources of information are available on Cancer Council Queensland's website [www.cancerqld.org.au](http://www.cancerqld.org.au) or by calling the Cancer Council Helpline on 13 11 20. Your doctors or other health professionals may be able to provide further sources of information. Care should be taken about how medical or statistical information (especially internet information) is interpreted - remember that the best source of information about your specific diagnosis is your oncologist and/or specialist surgeon.

**Searching the internet can leave you with massive amounts of information, much of which is of poor quality or irrelevant to your situation. It can be helpful to limit your search to sites that are credible – that is, they come from well-known organisations that are updated regularly.**

## Looking after yourself

When times are tough and there are many things to deal with, it can be easy to forget to take good care of yourself. However, not looking after yourself is likely to leave you feeling worse - more stressed, sleeping poorly, overreacting – and turning to less helpful ways of coping such as over-eating, using alcohol and/or withdrawing from family and friends.

Think of your wellbeing like a bank account. Your account stays in credit if you look after yourself well ('deposits' in your account). However, the demands of cancer and treatment mean that you are taking more out of your account than usual. If, at the same time, you are putting less into your account by not looking after yourself, your wellbeing account will soon be drained and in debt.

Ways of looking after yourself and boosting your wellbeing include:

- ▶ **Healthy eating:** Eating healthily gives your body better fuel to help it cope with the stresses of illness and treatment. Try to ensure your diet is balanced, with plenty of vegetables and fruit, healthy carbohydrates that are low in fats and sugar (bread, pasta, rice, cereals), and protein (lean meat, eggs, milk, beans/lentils). Keep alcohol and caffeine (in coffee, soft drinks, and tea) to a minimum. If cancer or cancer treatment is affecting your appetite and ability to eat well, talk to your doctor or a dietician about how to manage. If you are thinking about making extreme changes to your diet, talk to your doctor first. Also, if you are having cancer treatments and you are taking (or considering) supplements or natural medicines, discuss these with your doctor as some substances can interfere with the effects of treatment.

- ▶ **Being active:** Making time for physical activity is hard at the best of times and is even harder when your energy is low. However, physical activity has been shown to be an effective way to lift low mood, lower blood pressure, improve sleep and reduce stress. Contrary to what we might think and how we feel, physical activity is also the most important way to manage fatigue - helping you to feel more energetic and less tired. Research also shows that physical activity can help with the side-effects of chemotherapy. Try to maintain regular physical activity as part of your routine. Be active at a level that is comfortable for you – even small amounts of activity can help. If you are changing your usual pattern of physical activity, it is a good idea to talk with your doctor about this first.
  
- ▶ **Making time for you:** Even though things may be very busy, it is important to create spaces in each day just for relaxation and enjoyment. Think about things you do (or have done in the past) that help you to relax and feel good. It might be reading the newspaper, being in the garden, reading a good book, or listening to relaxing music. These activities are not luxuries, they are an important way to prevent the build-up of stress.
  
- ▶ **Dealing with feelings:** Some people believe that showing emotion is a sign of weakness, or may lead to them breaking down, and that keeping a ‘stiff upper lip’ is the best way to manage. Unfortunately, this approach can put people under extra pressure and lead to increased frustration and anxiety. Some people find that they need to do more and more to distract themselves from these difficult feelings and even find they withdraw from loved ones. Some people find themselves using drugs or alcohol to avoid the pain. Instead of blocking out or avoiding unpleasant thoughts or feelings, it is safer (reducing pressure build-up), less tiring, and more effective in the long run to find ways to process them. Talking about the problem with your

partner or friends can help make sense of your feelings and lighten your load. Another way to process your feelings is to write about them. This can often help you to make sense of difficult thoughts and emotions, and put things into perspective.

- ▶ **Staying connected:** Although a lot of your attention will be focused on dealing with cancer, it is draining to do this all day long. Staying connected with the world around you can help you see a life outside of cancer and give you time out from your worries. For some people, this may involve staying at or returning to work. For others, this will mean continuing with enjoyed hobbies/activities/interest groups or spending time with friends and family.
- ▶ **Tapping into spiritual beliefs:** A sense of meaning and purpose is an important part of many people's lives. Some people find great comfort from their faith and spiritual practices such as meditation or prayer. For others, spirituality may be experienced more generally, such as feeling connected with nature or feeling part of a 'circle of life'. For many people, working on this connection helps them to cope, increases their sense of strength, brings comfort and helps them to find meaning in what is happening. However, sometimes the experience of cancer can challenge beliefs, blocking the spiritual connection and/or causing distress. In this case, seeking support to deal with spiritual concerns may play a helpful role in your self-care.

**Need to talk to someone about how cancer is affecting you? Call the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday.**

## Getting support

In our daily lives, we have a network of people around us. The give and take of being around others can make life easier and more meaningful. Sometimes we give more and sometimes we take more but, over time, things tend to balance out.

While you are on your cancer journey, the balance of support may change as you need more support from others than you can give in return – at least for the moment. However, even though family and friends may be there to help, many of us still find it hard to ask for and accept support. One way to look at it is: If someone you loved had a problem, how would you feel if they did not let you help? Not surprisingly, family and friends can feel helpless and shut out if they are not allowed to provide support. When you are facing the extra demands of cancer, your support network can make an enormous difference, if you use it.

Be aware that not everyone will be able to help in the same way. Some people will be comfortable talking about the cancer and comforting you if you are upset. However, other people may not be good with words or strong feelings. They might prefer to support you in practical ways such as helping with meals or transport or helping out with work around the home. Let people know what they can do to help and allow them to choose activities that match their abilities. Different ways that people can help might include:

- ▶ Giving practical help (for example, sharing an after-school roster, driving to appointments, providing company, shopping, making meals, helping you exercise).
- ▶ Keeping others informed, screening calls/emails, acting as a support co-ordinator.
- ▶ Listening without trying to solve your problems.
- ▶ Having fun, not talking about your worries.

- ▶ Getting you out and about.
- ▶ Someone close to you may be able to help by getting information (for example searching the internet or exploring services), giving advice or helping to make decisions.

**Tip:** For a more detailed list of ways to show support look at the list in Appendix 5 on page 56. It may help to put a mark next to the things that your partner or family member or friend can do that would be most helpful and show it to them.

Letting others share in your journey allows them to feel useful, caring and supportive. It is also worth remembering that the more supporters you have, even in small ways, the less load there is on any one person. Think about other supports that might be available to you outside your normal circle. These may include:

- ▶ Health services such as your GP, hospital services, home nursing, respite care, community health services.
- ▶ Government services such as Centrelink, home help, child care assistance.
- ▶ Community groups and organisations: For example, Meals on Wheels, neighbourhood centres, cancer support groups and organisations.
- ▶ Formal or informal school-based assistance such as the school counsellor or chaplain, outside school hours care, parent groups.
- ▶ Church/religious groups.
- ▶ Counselling services.

**Tip:** Asking for help or support does not mean you are weak, it means that you are using the tools you have in your coping toolbox.

**Remember to go easy on yourself. Having cancer is tough. Give yourself permission to feel upset about it and to ask for, and accept, support.**

---

*“ We have no trouble putting together a wedding gift list so that we don’t end up with eight toasters – so it makes sense to do the same now with cancer and put together a ‘helpful things you can do’ list to let people know what you really need. ”*

*“ Thinking about what really would help me, and then being ready with ideas if people offered help, actually increased my sense of control – rather than just being on the receiving end of well-meant gestures that weren’t always what I needed. ”*

## Relaxation

**“The time to relax is when you don't have any time.”**

*Franklin D. Roosevelt.*

Have you noticed that at different times (like when you visit your doctor for test results, or when you have been thinking a lot about your cancer) you get body sensations like a sick feeling in your stomach or feeling tense or uptight? These feelings are most likely to be a result of stress.

Stress is your body's natural response to threat or change – so it is to be expected at times on your cancer journey. This stress reaction is sometimes called the ‘flight or fight’ response – when your mind sees a threat, it prepares your body to deal with the situation by either running away or fighting. Your body releases adrenaline, your heart beats faster, your blood pressure goes up, you breathe shallow and fast, your hands get sweaty, and your mouth gets dry. These are normal responses and very useful when dealing with emergencies, but they are not very helpful in dealing with cancer. Learning strategies to reduce these reactions can help you feel calmer.

Relaxation is the practice of skills that calm the mind and body, and it can be as simple as slowing your breathing down. Like any other skill, it needs to be learnt and practised. Relaxation can increase your sense of control in a situation, reduce worry and tension, calm you down, and provide some protection from the effects of stress. Relaxation can be used to cope with all types of situations (for example, to calm yourself before a visit to your doctor or to let go of worry before going to sleep).

**Relaxation is not mystical or magical and the only secrets are: (1) finding the right type of relaxation to suit your personality and lifestyle, and (2) regular practice.**

There are many different proven ways to relax. Meditation and self-hypnosis are special forms of relaxation that require dedicated practice to be effective. Easier and more common types of relaxation are:

- ▶ **Slow breathing:** helps you to become aware of your breathing and to relax by taking slow, deep breaths. By regulating your breathing, you can begin to manage stress reactions and produce a calming effect. Slow breathing by itself is an effective way to relax quickly in a difficult situation. It can also be used with other techniques to enhance the relaxation effect.
- ▶ **Muscle relaxation:** involves systematic, progressive relaxation of the muscles in the body. This can be done by consciously letting go of tension in the muscles or by gently tensing each muscle first before letting go. By relieving muscle tension in this way, the body becomes more relaxed and comfortable. Stretching different muscle groups is another quick and effective way of relieving muscle tension.
- ▶ **Mental relaxation (imagery):** is the use of concentration and imagination to visualise relaxing images. It is like day-dreaming, only more deliberate. The aim is to use all your senses (sight, hearing, smell and touch) to create as vivid and powerful an image as possible. The principle behind imagery is that your body responds to mental images in the same way as it does to real events. By using pleasant images, you can help your body feel calm and relaxed. The image you use can be anything that is pleasant and relaxing. Examples include the beach or a rainforest, a holiday destination, or pleasant memories. Mental relaxation can also be used as positive imagery, to see yourself coping successfully in a difficult situation. For example, you might picture yourself feeling calm and confident and then visualise coping successfully with having an MRI scan or other difficult medical procedure.

**Tip:** Relaxation is best practiced:

- ▶ In a quiet place, free from distractions (but not in bed unless you are using it to get to sleep).
- ▶ At regular times (but not immediately after food or exercise).
- ▶ In a comfortable sitting or lying position (if you tend to fall asleep, sitting is best).

**Tip:** Practice is the key – why not try the short relaxation exercise(s) included in Appendix 6, page 58.

**To find out more about relaxation, call the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday.**

## Helpful thinking

*“Man is not disturbed by things, but by the views he takes of them.” Epictetus*

What we think has a direct effect on how we feel and behave. This explains why two people may feel and behave very differently in a very similar situation. Consider the example below:

**John, 53 years old, diagnosed with bowel cancer two months ago:**

**Feelings:** Upset and guilty.

**Thoughts:** I have let my family down by getting cancer. They are upset and it is my fault.

**Michael, 61 years old, diagnosed with bowel cancer last month:**

**Feelings:** Concerned but ok.

**Thoughts:** My family are upset that I have cancer - but then I would be upset if it happened to any of them. Feeling concerned about each other at a time like this is part of being a family. Cancer can happen to anybody and blaming myself only makes it harder on all of us. The important thing is to support each other through this.

It is a fact that in highly stressful situations, thoughts happen very quickly and you may not even be aware of them. Your thoughts at this time can be unbalanced and unrealistic – that is, they may be overly negative, exaggerate your problems and underestimate your ability to manage. Such thoughts are unhelpful – they leave you feeling more upset and finding it even harder to cope.

The following steps can help you better manage unhelpful thoughts so that you can get your problems into perspective, rather than just worry about them:

- ▶ **Notice your thinking:** This is not always easy because thoughts are often quick and automatic, and because we are not used to stopping to consider how we are thinking. The best way is to notice whenever you are feeling upset, then ask yourself, “What has triggered this feeling? What am I thinking that might be making me feel bad?”
- ▶ **Write down your thoughts:** Writing down your thoughts is helpful because it slows down your thinking and makes it easier to focus.
- ▶ **Test your thoughts:** If your thoughts are making you feel upset, ask yourself:
  - ▶ What is the evidence that this thought or view is totally true and correct?
  - ▶ Is this thought in proportion to reality? Is this really likely to happen?
  - ▶ Is thinking in this way helpful for me right now?
- ▶ **Find helpful alternatives:** If the answer to any of the last three questions above is “NO”, then replacing the thought with a more helpful one might help you to feel calmer and less worried.

- ▶ **Be realistic:** A common belief is that the most important thing in coping with cancer is staying positive. Although an optimistic attitude can be helpful, this doesn't mean denying the reality that cancer is serious or frightening. Trying to put on a brave face all the time, and avoiding anything negative (such as fear, anger, sadness) is hard work, drains energy, and generally doesn't work well (the negative thoughts keep coming back). Fears or problems do not go away by pretending they don't exist, and in fact are likely to get worse. An over-emphasis on having to be positive all the time can lead to people being afraid to discuss fears and feelings, which actually increases problems. What is important is to be realistic about what is happening and to be able to voice your fears and concerns so you can better deal with them. Explaining this to those around you (especially to those well-meaning supporters who urge you to "think positive") can help to promote understanding and enable you to get the support you need.
  
- ▶ **Coach yourself:** For thoughts to be helpful they need to be balanced and believable. You need to encourage or coach yourself through difficulties, rather than be critical and undermine yourself. In this sense, you need to learn to be a good friend to yourself. For example, ask yourself: "If a good friend of mine was thinking this way, what would I say to him/her? How would I help him/her to challenge this thought?"

An example of identifying and challenging unhelpful thoughts is described below.

**My feelings:** Anxious and teary. I just want to curl up in a ball.

**My initial thoughts:** It's all too much. There's no way I can get through surgery and chemotherapy. How can I keep everything else going?

**Challenge the thought:** Is this really true? Is this way of thinking helping me? If a good friend was thinking this way, what would I say to him or her to challenge this thought?

**My helpful thought:** This is hard, but I don't have to do it alone – my family, friends and treatment team will help. I can make a plan to deal with one thing at a time. I need to let some things go and just focus on what's most important. Other people get through this and so can I.

## Unhelpful thoughts that keep coming back

Unhelpful thoughts are a fact of life, especially after a cancer diagnosis. It is not uncommon for people affected by cancer to find themselves going over and over the same distressing thoughts about the past or future. Ignoring the thoughts or trying to distract yourself may work well in the short term but they will often pop up again when you are not distracted, for example in bed at night or early in the morning. Sometimes the fact that you keep on having the same thoughts is a hint that you need to stop and face a difficult issue that you might have been avoiding.

Facing up to difficult thoughts often brings up strong negative feelings. However, struggling against the thoughts can make things even worse. The following tips can help to lessen the power of strong negative thoughts:

- ▶ When you next notice unwanted thoughts, instead of pushing them away, just allow them to be there. Notice what your thoughts are telling you and how they make you feel.
- ▶ Practice standing back and seeing your thoughts as just thoughts. See your thoughts as if they are words on a karaoke screen or clouds passing through your mind.
- ▶ Make some room for the feelings and sensations that come with the thoughts. Notice what is going on in your body. Is there somewhere in your body that knots up? Are there tears? Do the thoughts and feelings change as you watch them?
- ▶ Having noticed your thoughts, ask yourself if it is possible that you are jumping to conclusions or exaggerating the negatives. If not, is there something you can do to change the situation or improve it using problem-solving?

It is important to realise that distressing thoughts will come up from time to time. They are a part of life - just like other things in life that we don't like (certain people, embarrassing moments, chores), we're never going to welcome them but neither can we (always) run away from them. Life is full of things we don't like – but they are only a part of life, not all of it. Similarly, if we can see our distressing thoughts as just thoughts, then they are more likely to come and go rather than hang around. This calm acceptance can replace the continual struggle to block such thoughts, giving us the freedom to make the most of things we do enjoy.

---

*“Life does not consist mainly, or even largely, of facts and happenings. It consists mainly of the storm of thought that is forever flowing through one's head.”* Mark Twain

**Tip:** If I'm feeling upset, it's a signal to look at what I'm telling myself.

### How I'm feeling

---

---

---

---

### Unhelpful thoughts

---

---

---

---

### More helpful thoughts

---

---

---

---

### How do I feel now?

---

---

---

---

# The others in your life

## Other people's reactions.

Sometimes you may come up against reactions from other people, even those close to you, that seem insensitive or uncaring. Some people may avoid or withdraw from you, some may appear too positive ("You're so strong, you'll get through this") and some others may make light of your situation (for example, compare you with other, 'worse' cases). These reactions may make you feel hurt, angry, or frustrated.

**It is worth remembering that people usually don't mean to make things worse. Their reactions are likely to come from their own difficulties in handling feelings such as fear and anxiety, or from uncertainty about what to do or say.**

Because all people use different strategies to cope with difficult situations, these differences can be reflected in how they respond to you after cancer. For example, many people cope with problems by trying to fix them. They are often resourceful, practical people - but if they can't fix the problem, they may be left feeling helpless and not knowing what to do. Others may try and cope by not thinking about the cancer and by keeping busy or distracting themselves. They can remain focused and can be a source of strength or give you a break from dealing with cancer - but they may avoid dealing with important issues and can sometimes seem aloof or uncaring. Others cope by talking and sharing their feelings. This can be very helpful in showing caring and understanding - but it may not always be well-timed or may feel one-sided. Understanding and respecting that we are all different and have different strengths can help prevent frustration and conflict.

People are often unaware that their efforts - either to help you or to hold things together themselves - are making things even harder for you. If the relationship is important to you, consider making the effort to let them know how their reactions are affecting you. If you find you are having communication difficulties, further information is available from the Cancer Council Helpline on 13 11 20.

Despite our best efforts to understand the responses of others, sometimes we find ourselves deeply disappointed by their reactions. However, we might also find that other people - and sometimes unexpected people - have stepped up to provide a great deal of wonderful support. These people can become lifelong friends. Focusing on those people who are providing valuable support can help balance some of the disappointment about former friends.

---

*“I’ve met some amazing people along the way who have guided and helped me – a couple at least are likely to continue to brighten my future. Sadly, some old friendships didn’t meet my expectations, but I can accept now that sometimes paths take different directions as people face their own challenges.”*

## Talking it through

Even with those closest to us, talking about how we are feeling can be difficult. On top of that, people often think that talking about cancer and other difficulties will only upset them (or the other person) and make things worse. In fact the opposite is usually true – talking, and even crying, with one another is a way of sharing the journey, understanding each other, getting support, relieving tension, and getting things out in the open. Even when people don't know what to say, the value of listening or just being there should never be underestimated – and, most of all, it shows you care.

It is natural to want to understand how our loved ones feel and why they are acting in a particular way. When we avoid talking about difficult issues, we still try to work out what is going on and tend to try and 'mind-read' the other person. Unfortunately, we often get it wrong, resulting in misunderstandings and hurt feelings.

Good communication can take the guesswork (and the heat) out of situations and help to make sure that everyone feels heard, understood, and respected. The following tips can help to reduce the risk of misunderstanding and give you a better chance of having your support needs met:

---

*“I think that in the beginning Jude thought that I was hiding my feelings from her when - frankly - I was just struggling to keep things together. It was important for me to feel that our routine wasn't going to change and I worked hard to keep it like that. Jude and I were bickering because she was always at me to talk. Things only improved when we sat down one day and I told her what I was trying to do and why.”*

## Tip:

- ▶ **Make time to talk.** Don't wait for the 'right' time, it may never come.
- ▶ **Talk openly** about what is happening and what you need.
- ▶ **Be honest** about your thoughts and feelings - even if it is upsetting.
- ▶ **Listen** to what the other person has to say. Put aside your own thoughts so you can really listen.
- ▶ **Try to understand** what he/she might be saying and why.
- ▶ **Don't try to solve the problems.** Solving the problem is not as important as showing that you understand.

## Sharing with others

You will need to decide who, of your extended family, friends, and other contacts, you want to tell about your cancer. For most people, telling others about the cancer diagnosis is likely to be a difficult time. A little preparation can help to pave the way – decide what you want to disclose and answers to possible questions. Choose a quiet time and place, and accept that the person you are telling may get upset.

**Tip:** Repeated telling (to different people) can be emotionally draining for you and, in this case, it may be helpful to ask a trusted friend or family member to pass on the information.

For some people, having others know what is happening to their health can feel like an invasion of their privacy and independence. However, telling others what is happening can help to prevent misunderstandings, put you in control of what information is given out, and allow those who care about you to be involved. As well, family and friends can form part of a network of support for both you and your loved ones.

Sometimes you may switch between wanting to talk about things at one time and then wanting to avoid difficult thoughts and feelings at another time. It is worth remembering that it is okay to say no – whether it is to discussing your personal concerns or to an offer of help that you do not wish to accept. Being prepared to say no in an assertive but respectful way will help to avoid bad feelings on either side. You might do this by suggesting a different way or another time they could help you, or by expressing thanks for their concern but explaining it is not the right time/place for you to talk. At times when you don't feel up to taking phone calls or seeing visitors, it can be helpful for your partner or another family member to be a 'gatekeeper', handling enquiries or rearranging calls/visits for more suitable times.

---

*“It’s okay to say no – I just worked out some ways to say it that respected the other person’s feelings and gave me a polite way out, but still left the door open.”*

**Taking the lead in letting people know what is going on allows you to guide them in how you would like to handle the situation.**

# Conclusion

We hope that the information provided in this booklet will give you tools to help you through the challenges of dealing with cancer. The topics covered are based on the experiences of many people who have faced these challenges, and they aim to guide you through the unfamiliar territory. Knowledge can give you confidence in your abilities - both to cope personally, and to take the lead in guiding the other people in your life in how to best support each other.

While this booklet has aimed to cover issues that most people who are diagnosed with cancer will face, there will always be topics that relate only to some groups of people. Cancer Council Queensland has a wide range of information resources available from the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday.

**Further details of Cancer Council Queensland publications, resources and services can be found on pages 60-61.**

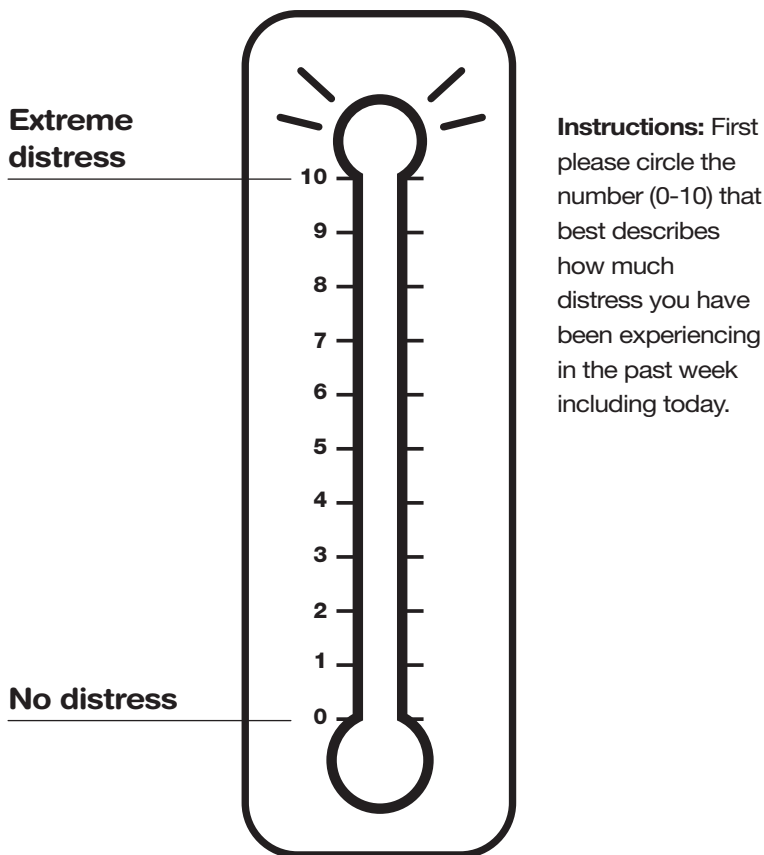
**It is important to remember that there is no right or wrong way to feel when you are faced with cancer – just as there is no one right way to cope. Use this booklet to remind yourself of the things you are doing well and to give you fresh ideas on ways of moving forward.**

**Most importantly, be kind to yourself. No cancer experience is easy – congratulate yourself for your efforts, forgive your mistakes, and recognise what you have learnt and gained along the way.**

# Appendices

## Appendix 1: Distress thermometer

NCCN Practice Guidelines in Oncology – v.1.2010



**Extreme distress**

**No distress**

**Instructions:** First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Version 1.2010, 01/22/10 © 2010 National Comprehensive Cancer Network, Inc. All rights reserved. These guidelines and this illustration may not be reproduced in any form without the express written permission of NCCN.

Reproduced with permission from The NCCN 1.2010 **Distress Management** Clinical Practice Guidelines in Oncology. ©National Comprehensive Cancer Network, 2010. Available at: <http://www.nccn.org>. Accessed 03/17/2010. To view the most recent and complete version of the guideline, go online to [www.nccn.org](http://www.nccn.org)



## Appendix 2

### Health professionals you may come across

**General practitioner (GP):** Your family doctor who provides your general medical care, referring you to specialists when necessary. GPs have completed a medical degree, hospital internship, and three-year 'Australasian General Practice Training Program'.

**Surgeon:** a doctor who specialises in procedures and treatments that involve surgery.

**Medical oncologist:** a doctor who specialises in chemotherapy and hormone therapy to treat and manage cancer.

**Radiation oncologist:** a doctor who specialises in the use of radiotherapy and radioactive substances to treat and manage cancer.

**In public hospitals there are different levels of doctors:** A Consultant is a senior specialist qualified to provide unsupervised medical care in one or more specific areas, for example, a haematologist (blood), dermatologist (skin), gynaecologist (female reproduction). A Registrar is a registered doctor (has completed a medical degree and one or two years of hospital internship or residency) who is undertaking further training in a specialist area, which takes about six years to complete. An Intern/Resident has completed their degree and is undertaking training within a hospital internship.

**Radiologist:** a doctor who specialises in using medical imaging techniques to see inside the body. Some forms of imaging include X-ray, MRI, ultrasound and CT scans.

**Pathologist:** a doctor who examines samples of body tissue or fluids under microscope to assist with the diagnosis and staging of cancer.

**Nursing staff:** may specialise in a particular area, for example, oncology (cancer) nurse, breast care nurse, stoma nurse. They provide care to people when staying in hospital or attending outpatient clinics and may

also work in the community. They may assist in co-ordinating other services for people and can be good sources of support and information.

**Dietician/Nutritionist:** specialises in nutrition and dietetics. They can provide food and nutrition advice to meet individual health and lifestyle needs of people with cancer. Accredited dietitians have university qualifications. A nutritionist may be a qualified nutrition scientist. This term is also used by naturopathic nutritionists and qualifications may vary (e.g. diploma or other qualification from a college of naturopathy).

**Physiotherapist:** provides physical therapy, information and exercises to help with recovery and mobility. Some physiotherapists specialise in treating lymphoedema which can occur after cancer treatment.

**Occupational therapist:** provides practical strategies and information to help overcome difficulties with daily living.

**Social worker:** provides support and information about emotional and practical issues such as financial difficulties, home help, childcare. They may also provide counselling such as family or bereavement counselling.

**Counsellor:** provides support and general counselling to help cope with challenges in life. Training varies from certificate to university level qualifications.

**Psychologist:** provides counselling and therapy to help people cope with emotional challenges and improve quality of life. Psychologists must be registered to practice, by completing four years of psychology studies followed by either two years' applied studies or two years' supervised practice. Clinical psychologists do more specific training and additional supervision. Psychologists cannot prescribe medications.

**Psychiatrist:** a medical doctor who has specialised in mental health (e.g. depression, anxiety) and the medications used to treat such conditions. They may also provide counselling and therapy.

## Appendix 3

### Useful questions to ask when understanding your diagnosis or making treatment decisions

Select relevant questions off this list to ask your doctor. It is unlikely that you will want to ask all the sample questions below, and you may want to ask different questions at different points in your journey. To make the most of your medical consultations, it is useful to make a note of those questions that are relevant for you and take these with you when you see your doctor.

- ▶ What treatments are used to treat my type of cancer? What are my options?
- ▶ In your opinion, what treatment(s) would you advise for me?
- ▶ What is the purpose of this treatment (e.g. cure, control, prevent cancer spreading, prevent recurrence, relieve symptoms)?
- ▶ How effective is this treatment likely to be for my type of cancer:
  - a) In general?
  - b) In my particular case?
- ▶ What effect will the treatments have on:
  - a) The cancer's progression?
  - b) Chances of recurrence? How much does this treatment/ each treatment change the risk of recurrence? (You may want to ask for this as a percentage).
  - c) Chances of cure/survival? How much does this treatment/ each treatment add to the chance of cure/survival? (You may want to ask for this as a percentage).

- ▶ What will happen if I don't have treatment/this particular treatment?
- ▶ What happens if the treatment does not work?
- ▶ Are there any other treatments available in other states or overseas?
  - a) If so, are they better than those offered here?
  - b) If so, can I access them? How?
- ▶ Are there costs involved? If so, is there any financial assistance available?
- ▶ What, exactly, will the treatment involve (e.g. medical procedures, hospital visits or admission(s), number of treatments, total period of treatment, length of recovery)?
- ▶ What side-effects could the treatments cause?
  - a) Are these temporary or long-term/permanent?
  - b) Can they be prevented or controlled?
  - c) What are the risks? Are there 'late' effects of this treatment? (side-effects that may occur a long time after treatment)
- ▶ What effect will treatment have on my life/quality of life (e.g. work, ability to drive, managing the home, childcare, leisure activities, sexual function)?
- ▶ Is there anything I could do (before, during, or after treatment):
  - a) To make treatment more effective?
  - b) That would make treatment less effective?

- ▶ Who would be in charge of my treatment, do they specialise in my type of cancer, and how much experience have they had with treating my type of cancer?
- ▶ Who will be members of my treatment team?
- ▶ Are there other services (e.g. physiotherapy, dietician, counsellor) available to help/support me?
- ▶ Will I be treated by a multidisciplinary team (that is, will the doctors and other health professionals involved liaise with each other about my treatment)?
- ▶ Who should I contact if I have a problem - is there one member of the team (for example, my treatment manager) who can co-ordinate my treatment and be my point of contact?
- ▶ Is there liaison between my treatment team and my GP? What information is forwarded to my GP?



## Appendix 4

### Problem solving sample worksheet

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
<b>A. Attitude</b>	
Take an optimistic attitude	Take a deep breath. Stop and think. There is no immediate catastrophe – think of this as a challenge. I <b>can</b> handle this problem.
<b>Acknowledge the problem</b>	
▶ State the problem and details	Getting to treatment (40-minute drive; expensive parking; no direct public transport; feeling unwell).
▶ What is a reasonable goal?	Find an inexpensive, comfortable means of travel.
▶ Can I change the situation?	No – I have to attend treatment.
or	
▶ Do I need to change my attitude?	I might have to accept the expense of parking (if well enough to drive) or taxi (if unwell). I might have to ask family/friends for help.
<b>B. Brainstorm</b>	
Write down ALL your ideas	Drive myself; catch a bus; take a taxi; ask Mum to drive me, ask others to drive me, move house...

## C. Consequences

Predict the likely outcomes of 2 to 4 of the best ideas:

### Solution

	Will it reach my goal?	Effect on others	Time/effort needed
Drive self	Yes	No burden Worry about me	Convenient Hard when feel unwell Expensive parking
Bus	Yes	No burden Worry about me	Inconvenient Hard when feel unwell
Taxi	Yes	No burden or worry	Expensive
Ask others	Yes	A burden for one person Convenient, cheaper Much easier for several people Comfortable	Have to ask for help

## 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!

**Best idea:** Asked family/friends if they could a take turn to drive me to treatment, organised a roster, and tried it for a week.

**Outcome:** Very satisfied – people were happy to help, it didn't ask too much of any one person, and I could relax about getting to treatment.

## Appendix 5:

### Ways to show support

Look through the list and mark those things that would MOST help you to manage over the next few weeks. These might be things that are already happening and/or things you think might help.

- Ask me how I'm feeling
- Listen to me talk about my feelings
- Share your thoughts and feelings with me
- Ask me about my plans for coping and how you can help
- Let me know what helps you cope
- Express an understanding of my mood and feelings
- Give me encouragement
- Don't try and solve my problems
- Discuss important decisions about my illness with me
- Keep me informed
- Speak positively about the future
- Don't avoid talking to me about the difficult things
- Tell me that you love me just the way I am
- Give me a cuddle
- Keep me company
- Give me some time alone
- Take care of me if I feel unwell
- Help me to think of other things besides cancer

- Arrange for family/friends to visit
- Limit visiting times
- Take messages or return phone messages for me
- Keep other people informed about what is happening
- Come with me to doctors' or clinic appointments
- Exercise with me or encourage me to exercise
- Joke or use humour to cheer me up
- Rub my feet/shoulders or back
- Take me on an outing
- Help me with transport
- Make me a snack or drink
- Help me with the shopping
- Do household tasks
- Cook or help prepare meals
- Help out with the kids
- Take the kids to/from school
- Get the kids to help around the house
- Organise a roster of people to help out
- Let me sleep in or take naps
- Get library books or rental DVDs for me
- Help me with my hobbies

This list is adapted from J.L. Scott (1995) – Helping Women Cope with Cancer.

## Appendix 6:

### A relaxation exercise

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 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...

# Further information

## **Other publications/resources/websites**

There is a wide range of booklets and DVDs, available free of charge, providing information about cancer, treatment options and the possible effects of those treatments. These can be obtained by contacting the Cancer Council Helpline on **13 11 20** (toll free), Monday to Friday.

**A comprehensive list of useful websites and publications can be found at the Cancer Council Queensland website [www.cancerqld.org.au](http://www.cancerqld.org.au).**

# Further support

## **Cancer Council Helpline**

The Cancer Council Helpline is a free service of Cancer Council Australia. Connecting to the local State or Territory Cancer Council, the Cancer Council Helpline is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specially trained staff. The staff can also send you written information and can put you in touch with appropriate services in your area.

**The Cancer Council Helpline can be contacted on 13 11 20 (toll free), Monday to Friday.**

## **Cancer Counselling Service**

Cancer Council Queensland has a dedicated Cancer Counselling Service which provides free, short-term cancer counselling by psychologists to people with cancer and those close to them. Telephone counselling is available to anyone in Queensland affected by cancer. Face-to-face counselling is also available to people who can access our offices in Brisbane and selected regional offices.

**The Cancer Counselling Service can be accessed by calling the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday.**

## **Cancer Connect**

Cancer Connect is a free and confidential service that puts people in touch with trained volunteers who have had a similar cancer experience. Volunteers provide information and emotional support by telephone and can be especially helpful for people who feel isolated by their cancer experience or who live in rural or remote communities.

**The service can be accessed by calling the Cancer Council Helpline on 13 11 20 (toll free), Monday to Friday.**

# Notes

# Notes



For information and support call  
Monday to Friday

[www.cancerqld.org.au](http://www.cancerqld.org.au)