



coping together

A PRACTICAL GUIDE FOR COUPLES FACING CANCER

MAKING YOUR TREATMENT DECISION

The challenges addressed in this booklet...

- We need help with the decision making process
 - We feel overwhelmed by options
 - We feel we don't have enough options
- We feel that we don't understand enough to decide
 - We want more of a say in the decision
 - We feel pressured to make decisions
- We feel anxious due to treatment related delays

Note to reader

This booklet is not intended as a substitute for consultation with your health care professionals. Patients or partners with health care questions should call or see their health care professional promptly and should not disregard professional medical advice, or delay seeking it, because of information encountered in this booklet. Before commencing any health treatment, always consult your doctor.

All care has been taken to ensure that the information contained here is accurate at the time of publication. All names of patients and partners have been replaced to protect their anonymity. ***Coping-Together*** is not responsible for any injury or damage to persons or property arising out of, or related to, any use of the booklets, or to any errors or omissions.

MAKING YOUR TREATMENT DECISION

Deciding on a treatment plan is a common issue couples face following a diagnosis of cancer.

This booklet provides practical ways to address the issues many couples face when making cancer treatment decisions.

Meet the experts

Every **Coping-Together** booklet has sections where health care professionals have been invited to discuss the information and strategies that are presented. Each expert is easy to identify – their picture is included next to their input, and you will recognise some of their faces from the **Coping-Together** DVD.

In this booklet, **Making Your Treatment Decision**, our experts are Dr Peter Chong, Associate Professor Fran Boyle, and Associate Professor Jane Turner.



Dr Peter Chong is a Urological Surgeon working at John Hunter Hospital, Royal Newcastle Centre and Lake Macquarie Private Hospital. His areas of practice include urological oncology, urinary stone disease and lower urinary tract dysfunction. He is active in post-graduate training and advocates for patients to be well-informed before deciding on treatment.



Associate Professor Fran Boyle is a Medical Oncologist at North Sydney's Mater Hospital, where she is Director of the Patricia Ritchie Centre for Cancer Care and Research, and Associate Professor of Medical Oncology at the University of Sydney. Her main areas of practice are breast cancer and melanoma. Fran's areas of interest include improving doctor-patient communication and decision making.



Associate Professor Jane Turner has worked as a Consultation-Liaison Psychiatrist in oncology for over 20 years. She has extensive experience in the design and delivery of health professional education, and has taken an active role in the development of consumer resources and educational initiatives for people affected by cancer, and their families.

The following flowchart shows some common concerns couples have when deciding on cancer treatment. Navigate your way through the chart until you recognise your own concern and choose the strategies recommended on the right. Go to the relevant pages for more detailed information.



We need help with the decision making process

👏👏 I felt like I was overwhelmed by uncertainty, there was so much I didn't know and yet I had a decision to make, one that my life literally depended on. 🙏🙏

Grahame, diagnosed with prostate cancer.

👏👏 We found it very challenging to make a decision regarding Loretta's treatment. I wanted to know everything but she found all the information very confronting. There were times when I felt I had no idea where to start, what was the best option for us? 🙏🙏

Trent, husband of Loretta, diagnosed with breast cancer.

Decisions regarding cancer treatments are more complicated than the types of decisions we make on a day-to-day basis. This is because the decision you make involves some degree of uncertainty and making trade-offs between positive and negative outcomes. As a result, you might find you're having a hard time making a decision about your treatment, even if you're generally a decisive person.

Suggestions for making treatment decisions

1. Work out **what sort of decision maker you are**.
2. **Use the DECIDE strategy** as a guide to the decision making process.



Suggestion 1: Work out what sort of decision maker you are

People have their own ways of making decisions about their health, but most are likely to find that they use one of three decision making styles. Look at the decision making styles described in the following table and think about how you prefer to make decisions about your health. It may then be helpful to discuss this with your partner and highlight any differences that may exist between you.

Top Tip: There's no right or wrong decision making style – what's important is that your decision making preferences are accommodated when making a decision about your treatment.



When you work out the sort of decision maker you are, think about how you can create a positive decision making environment with your partner and your health care team. Here are some strategies you may find useful.

Decision making style	If this doesn't match your partner's style ...
Active A decision making style where you make the final treatment decision. This may or may not include seriously considering your doctor's and partner's opinions.	<ul style="list-style-type: none"> • Consider how failing to consider your partner's wishes might impact on your relationship. • Try to discuss why your partner prefers a different approach. • If you've considered your partner's opinions, tell them. • Consider how you can support your partner, even if you disagree with their decision.
Collaborative or shared A preference to share decision making with your doctor and partner.	<ul style="list-style-type: none"> • Try to discuss why your partner prefers a different approach. • Encourage your partner to join in the decision making process at any time. • If they want to, encourage your partner to ask questions. • Share relevant information with your partner, so they have what they need to help make decisions.
Passive A preference to leave all treatment decisions to your doctor.	<ul style="list-style-type: none"> • Explain to your partner why you don't wish to be involved in decision making. • Discuss whether you're comfortable with your partner taking a more active role. If you are, make sure your doctor knows this. • Don't push your partner to be more involved – they may feel pressured and become resistant to having a say.

Adapted from Denger et al. (1997) and Kremer, Ironson, Schneiderman and Hautzinger (2007).

Decision making style	If this doesn't match your health care professional's style ...
<p>Active</p> <p>A decision making style where you make the final treatment decision. This may or may not include seriously considering your doctor's and partner's opinions.</p>	<ul style="list-style-type: none"> • Consider getting a second opinion. • Try to explain the reasons behind your decision to your health care professional – it's your decision to make, but explaining the thoughts behind your decision may help your health care professional understand and reassure them that you've considered the necessary factors. • If you've considered your health care professional's opinion, tell them how you've factored it in.
<p>Collaborative or shared</p> <p>A preference to share decision making with your doctor and partner.</p>	<ul style="list-style-type: none"> • Clearly communicate to your doctor your desire to be involved in treatment decision making. • Ask for more information so you can better understand your treatment options. See the section 'we don't know what to ask' in the <i>Getting What You Need From Your Health Care Team</i> booklet for tips on asking questions. • If your health care professional seems unwilling to include you in the decision making process, consider getting a second opinion.
<p>Passive</p> <p>A preference to leave all treatment decisions to your doctor.</p>	<ul style="list-style-type: none"> • Explain to your doctor why you're happy for them to make the final decision. • Communicate any concerns you and your partner have to your doctor for their consideration.

FACT: Cancer treatment decisions often have what's called high decisional conflict. Decisional conflict occurs when there's a high level of uncertainty and you have to choose between options involving risk, loss and challenge to your life values (e.g. health, family, relationships, career).









Which one
suits me best?



Suggestion 2: Use the DECIDE strategy as a guide

Sometimes it's important to apply a systematic approach when making important decisions involving high decisional conflict. It's a way of ensuring you consider the relevant information and take your preferences into account.

The **DECIDE** model helps to break the decision making process down into smaller components and highlights what's important. What follows is the **DECIDE** model in action, using the example of John, who has been recently diagnosed with prostate cancer, and his wife Betty – a farming couple living in rural NSW.

Step	Description	Example
 <p>Define the problem</p>	<p>This involves being able to clearly state what decision needs to be made. Consider:</p> <ol style="list-style-type: none"> 1) What is the problem/ decision? 2) Why should anything be done at all? 	<p>John and Betty consider their situation and determine that:</p> <ol style="list-style-type: none"> 1) The urologist has suggested surgery or radiation therapy. 2) If nothing is done, the cancer will most likely spread and be more difficult to treat. 3) The cancer must be treated to maximise John's chance of survival.
 <p>Establish the criteria</p>	<p>This involves figuring out what factors need to be considered when making the decision. Consider:</p> <ol style="list-style-type: none"> 1) What do you want to achieve? What is the goal? 2) What do you want to preserve? 3) What problems do you want to avoid? <p><i>If you need help establishing the criteria – see the Four Box method on page 13.</i></p>	<ol style="list-style-type: none"> 1) John and Betty want to maximise John's chances of survival. 2) They want to preserve a high quality of life and spend as much time as possible on the farm. 3) As much as possible, John wants to avoid problems with incontinence and impotence. Betty believes that they can be managed if they occur.

Step	Description	Example
 <p>Consider the options</p>	<p>This involves considering the pros and cons of each treatment option.</p> <p>When considering your options, it's important to have ample information with which to make your decision. The first step is to seek information from your health care team. You may also see the 'we need more information' section in the Getting the Support You Need booklet.</p> <p><i>The table on page 14 may help you weigh the pros and cons of your decision.</i></p>	<p>John and Betty consider the pros and cons of surgery and radiation therapy.</p> <p>Radiation therapy: little pain or discomfort, treatment five days/week, for nine weeks, will have to leave the farm for this period and pay for transport and accommodation, risk of bladder inflammation, diarrhoea and impotence.</p> <p>Surgery: tumour removed, hospital stay of two to four days, general risks associated with major surgery, more likely to have issues with incontinence and erectile dysfunction.</p>
 <p>Identify the best option</p>	<p>Select the best option. This may be based on discussions between you as a couple and with your health care team, but also on your individual opinions, the criteria you set and your feel for each option.</p> <p><i>The table on page 14 can help you identify your best option.</i></p>	<p>John and Betty have identified surgery as their best option. Maximising the likelihood of survival is most important to them, despite the odds of disruption to their everyday quality of life (through incontinence and erectile dysfunction).</p>

Step	Description	Example
 <p>Develop and implement a plan of action</p>	<p>It's now time to figure out how your decision is going to be implemented. This involves thinking about the resources required and how this will impact on your day-to-day life.</p>	<p>John and Betty discuss their preference for surgery with the urologist who puts them in contact with a Prostate Cancer Care Nurse. The nurse provides pre-surgery information, as well as some information about what to expect post-surgery. John and Betty start making plans for who can help on the farm while John is hospitalised. As Betty doesn't drive, they also arrange for their daughter to help with transport to and from the hospital and for their neighbours to take Betty grocery shopping with them.</p>
 <p>Evaluate and monitor the decision</p>	<p>This involves troubleshooting your decision – planning to avoid problems and addressing them if they arise. Consider:</p> <ul style="list-style-type: none"> • What could go wrong? • What can be done to correct the problem? 	<p>Incontinence and erectile dysfunction could be more severe than expected. John and Betty have discussed several incontinence management techniques with their health care team. For erectile dysfunction, various medications and penile aids that can help to manage this in the longer term, if required, were also explored.</p>

Adapted from Guo (2008).

By applying the **DECIDE** model to their treatment options, John and Betty were able to break down and evaluate the impact of each treatment on their life. When making important treatment decisions, it is essential to integrate the information and advice from your health care team with your own thoughts and needs.

Exercise: If you need help to establish the criteria for your decision, try the Four Box method

MEDICAL FACTORS

What's the diagnosis and prognosis?
What are the goals of each treatment option?
What are the probabilities of success?
What's the 'back-up plan' if this option doesn't work?
What impact might treatment have on other health conditions?

OUR CRITERIA:

PERSONAL PREFERENCES

How do the treatment options match our values and beliefs?
What experiences do we have with medical issues that might help make this decision?
What were our gut reactions to hearing the treatment options?
Are there any legal issues that need to be addressed (e.g. organ donation)?

OUR CRITERIA:

QUALITY OF LIFE FACTORS

What are the prospects, with or without treatment, for a return to normal life?
Will we be able to adjust to the necessary changes during and after treatment?
What lifestyle factors might we need to change to maximise treatment success?
Will we still be able to do the activities we enjoy after treatment?

OUR CRITERIA:

SITUATION FACTORS

Are there family issues we need to consider?
What other factors (e.g. finances, employment) do we need to consider?
Are there issues with our health care professionals that might influence our decision?
Is there any clinical research involved?
Are we comfortable with that?

OUR CRITERIA:

Exercise: Use this table to weigh the pros and cons of treatment options

- 1. List each treatment option in the table.
- 2. Discuss the pros and cons of each option, considering the medical, personal, quality of life and situational criteria you established earlier.
- 3. Rate whether the treatment option is generally positive (put a '+' in the column) or generally negative (put a '-' in the column) with respect to each criterion. Options might have both positive and negative elements for each criterion. Try to determine whether the positives outweigh the negatives or vice versa. If they're balanced, put a '0' in the column.

Treatment option	Medical Factors	Personal Preference	Quality of Life
Example – John and Betty			
Radiation therapy:	0	-	+
Surgery:	+	+	+

Adapted from Nezu (1998).

- Consider the short-term and long-term effects of the treatment option.
Overall, are they generally positive, negative or balanced?
- Consider whether the treatment is likely to work and whether you could go through with it. You can complete these columns using '+', '-', percentages or 'yes'/'no'.
- Rank each option in order of preference, with your most preferred option ranked 1.

	Situation factors	Short-term effects	Long-term effects	Likelihood of success (will it work?)	Likelihood of implementation (can I do it?)	Overall rating
	-	-	-	0	No	2
	+	-	-	+	Yes	1

What others say about being involved in decision making

👍👍 I spent lots of time thinking about my options and I discovered that there was good news and bad news. The good news was that by taking an aggressive treatment option the cancer might be gone, but the bad news was that I would probably have some side effects, and some of those were very serious. It was a process of me figuring out what was acceptable to me, considering what might be lost and whether I could handle that. 🗨️🗨️
Larry, diagnosed with prostate cancer.

👍👍 Margie was happy for her doctor to make decisions for her, but I was like 'Hang on a minute, this is important, we need to decide this'. We talked about it and she was happy for me to get more information and to talk things through with the doctor more. In the end, she appreciated that I had done this and she did have her say. We did decide on what the doctor had originally suggested, but at least I was sure it was the best decision for Margie. 🗨️🗨️
Leon, husband of Margie, diagnosed with breast cancer.

Why using these suggestions can help decision making – What the experts have to say

Although we all make decisions every day, few are as complex as the decision you make regarding cancer treatment. The **DECIDE** model helps you think through your decisions systematically by allowing you to work out what's important for you, what the advantages and disadvantages are of each option and what's required to put the decision into practice. Using a structured decision making process is linked to more effective and confident decision making.



– **Associate Professor Fran Boyle**

FACT: Matching your decision making preference to your level of involvement in decision making is important. Research has shown that people who play the role they desire in decision making report lower levels of depression and anxiety, greater satisfaction with their care, greater adherence to treatment and a higher overall quality of life.



Key Points: The decision making process

1. People have differing decision making preferences – the important thing is to ensure you have the level of input into the decision making process that you desire.
2. When making treatment decisions, it's important to establish the criteria that are important to you. These will guide your decision making and make sure the issues important to you are considered.
3. Effective decision making involves weighing up the pros and cons of all options.



We feel overwhelmed by options

👂 There just seemed to be so much at stake. I mean, if I got this decision wrong there could be major implications. All of the treatments had positives and negatives, there was no clear cut 'best option'. There were moments where I wished I didn't have to choose. 🗨️

Marta, diagnosed with breast cancer.

A big question for you and your partner might be: *"how do we treat this?"*. The answer is rarely straightforward. It's common for couples to feel overwhelmed by the choice, wondering which option is best for them and worrying that they might regret their decision.

Some things you'll need to consider when deciding on a course of treatment are:

- ✓ What do we know about the cancer (e.g. type, stage, effects)?
- ✓ What treatments are available for this type of cancer?
- ✓ What treatment path does my health care team advise?
- ✓ How effective are these treatments?
- ✓ What are the potential side effects of these treatments?
- ✓ What are my prospects if I choose this treatment over another (e.g. does it give me a better chance of recovery)?
- ✓ What are the expected benefits of each kind of treatment?
- ✓ How is my current state of health (i.e. how well can I cope with this treatment)?
- ✓ How easily can I access these treatments (e.g. distance, expense)?
- ✓ How much time do we have to decide on a course of action?
- ✓ Do we need more information (e.g. further explanation or a second opinion)?

Top Tip: If you're faced with a number of treatment options, it might help to ask your doctor to give you a short summary of each, so you can see them 'in a nutshell'. Taking someone along to the appointment when you discuss treatments, and even recording your discussion, can also help you to go over what you've been told.



Suggestions for choosing between a number of treatment options

1. Think about **what's most important to you** at this time.
2. **Talk to your health care professional** about your concerns.
3. **Try using a decision aid** to guide your choice.

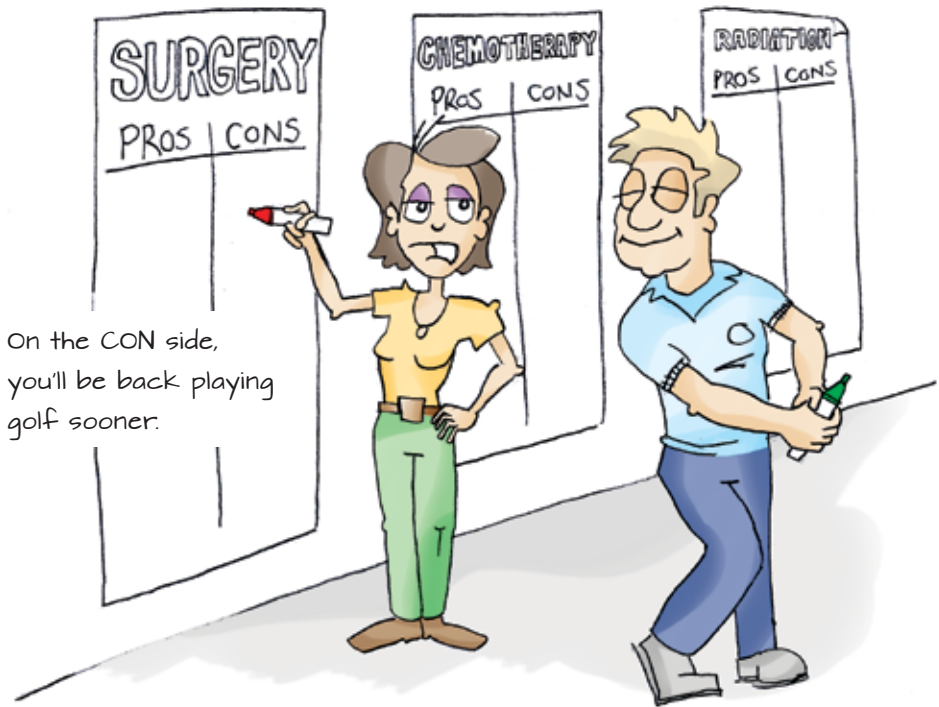


Suggestion 1: Think about what's most important to you at this time

Think about your priorities and values before deciding how to proceed with treatment. This might mean weighing up the potential benefits of a therapy against the potential costs. How much time are you prepared to commit? What side effects are you willing to put up with?

The exercise on establishing your decision criteria in the '***we need help with the decision making process***' section of this booklet may help you identify what is most important to you.

Always discuss both sides of any treatment decision
- it helps to highlight what's most important to you.



On the PRO side,
I'll be back playing
golf sooner.

Suggestion 2: Talk to your health care professional about your concerns

The most important health care professional to talk to about treatment decisions is the specialist (e.g. surgeon, medical oncologist or radiation oncologist), who is likely to be overseeing your treatment. But if you're not getting the guidance you need, you can also try talking to:

- ✓ **Your GP**, who might be able to help you consider your options or, if it comes to it, might be able to refer you to another specialist.
- ✓ **Your oncology nurse**, who might have answers to questions about different treatments.
- ✓ **Your cancer care coordinator**, who might be able to steer you towards the help you need.
- ✓ The **Cancer Council**, which has counsellors and information that might help you decide between options. Contact their Helpline on 13 11 20 or go to www.cancer.org.au to access your State Council's website.

Top Tip: For tips on how to talk to your health care professionals, try the ***Getting What You Need From Your Health Care Team*** booklet. For further information on how to get the help you need, try the '***we need extra help from the right health care professionals***' section of the ***Getting the Support You Need*** booklet.



Suggestion 3: Try using a decision aid to guide your choice

A decision aid is a tool designed to help you think through your treatment options. The aid might be anything from an audio tape of your consultation, to a flowchart, interactive DVD or online program.

A decision aid can help you by:

- ✓ Recording the details of a medical consultation.
- ✓ Grouping and summarising different treatments, side effects and expected outcomes.
- ✓ Defining terms and clarifying complex information.
- ✓ Stepping you through different courses of action.
- ✓ Navigating to information relevant to you.

The availability, nature and quality of decision aids may vary between doctors and other facilities.

Top Tip: Your doctor may have a decision aid available for you. If not, ask your doctor if there are any tools to help you consider your options. You can also try specific cancer organisations such as the National Breast and Ovarian Cancer Centre (<http://canceraustralia.nbocc.org.au>), Bowel Cancer Australia (www.bowelcanceraustralia.org) or contact the Cancer Council (13 11 20 or www.cancer.org.au) for advice or links to relevant sources.



Here are some examples of decision aids.

Brochures, pamphlets or booklets

Breast cancer: <http://canceraustralia.nbcc.org.au>. Go to the 'resource library' tab, and then click on 'resources for women, family and friends' to find a variety of booklets.

Colorectal cancer: www.bowelcanceraustralia.org. Treatment options and treatment pathways can be found in the 'just diagnosed' section under the 'bowel cancer' tab.

Prostate cancer: www.prostate.org.au. Click on the 'diagnosis' tab for information.

Melanoma: www.melanomapatients.org.au/home?subSiteId=1
Click on the 'information tab', and select 'about melanoma'.

Workbooks

A good workbook will help you apply information to your own situation and to consider options alongside your own values and priorities.

The Michigan Cancer Consortium's workbook "*Making the Choice: Deciding What to do about Early Stage Prostate Cancer*" is a good example (a PDF version can be found at www.prostatecancerdecision.org).

Taped consultations

You can ask your doctor if it's okay to record your consultations. A recording allows you to go over what was discussed, with the benefit of hearing it in context and noting how the information was given (e.g. tone of voice).

Information DVDs and audio recordings

DVDs and audio recordings can present a complex set of options in an easily digested 'show and tell' format.

The Cancer Council SA has a "*Cancer: What Now?*" DVD, which uses information from health professionals and cancer survivors to help with decision making. It's available at www.cancerwhatnow.com.au.

The National Breast and Ovarian Cancer Centre has several audio and video recordings relating to breast cancer. Go to <http://canceraustralia.nbcc.org.au> and search for "*What Every Woman Should Know About Breast Cancer*" and "*When the Woman you Love has Early Breast Cancer*" in the resource library.

Interactive computer-based programs

These may be online or CD-ROM tools that lead you through a questionnaire, which leads to concluding advice or recommendations. However, the results are only as good as the program's capacity to assimilate and process all possible answers.

"Prostate Cancer: Your Decision Notebook" or "Breast Cancer: Your Decision Notebook" CD-ROMs can be found at <http://sbir-cancercontrol.cancer.gov/sbir/>.

Question checklists

An example of a question checklist for making treatment decisions is provided in the **'we feel we don't understand enough to decide'** section of this booklet.

Top Tip: Asking the right questions is an important part of your decision making. See the section **'we don't know what questions to ask'**, in the **Getting What You Need From Your Health Care Team** booklet, for information on using question checklists.



Top Tip: Use glossaries

Web-based glossaries or dictionaries, in which you can search for user-friendly definitions of medical terms and other jargon, are good tools for making sure you fully understand all aspects of the treatment options you're considering.

Glossaries can be found on many reputable cancer sites, including the Cancer Council (www.cancer.org.au) and the American Cancer Society (www.cancer.org/cancer/cancerglossary/index).

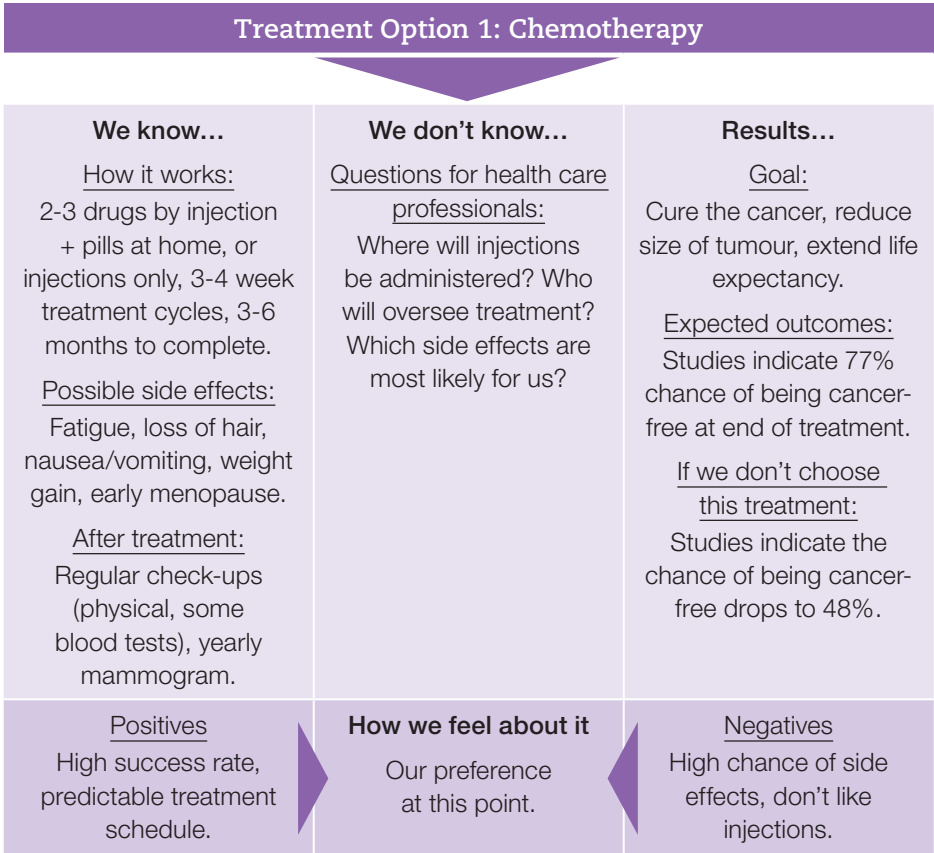
For more information on cancer-related sites and information, see the **'we need more information'** section of the **Getting the Support You Need** booklet.



Example: Using a decision aid

The decision board below can help you consider a range of information about your treatment options.

Example decision board: Treatment options



Adapted from Whelan and Loprinzi (2005).

Step 1: Use the blank decision board on the next page. You'll need to complete a board for each option you're considering. It may be time consuming, but it can help you clearly consider all options available to you and may raise some interesting issues to discuss with your health care team.

Step 2: Take the notes you've made to your doctor and discuss your thoughts. You might have found, during the process, that you need some questions answered or some more information. Or, you might have reached a definite decision. Either way, your doctor will be able to talk it through with you.

Sources: Cancer Council NSW (2011); National Breast and Ovarian Cancer Centre (2009).

What others say about using these suggestions for choosing between treatment options

👍👍 I was still trying to digest the fact I had breast cancer and would need surgery, so it was almost too much when I was told I had a choice of what kind of surgery I could have. The doctor could see I was rattled and said the breast care nurse would give me some web links and a video to look at and would see me in a couple of days to go through it all. I felt the pressure lift a bit then. 🙏🙏

Lucy, diagnosed with breast cancer.

👍👍 I run workshops for a living, so it was quite an experience for me to have a doctor stand there with a flipchart and go through possible treatment plans. He even had a little summary on paper for me to take home, which gave me something to think about. 🙏🙏

Charles, diagnosed with bowel cancer.

Our decision board: Treatment options

<p>We know...</p> <p><u>How it works:</u></p> <p><u>Possible side effects:</u></p> <p><u>After treatment:</u></p>	<p>We don't know...</p> <p><u>Questions for health care professionals:</u></p>	<p>Results...</p> <p><u>Goal:</u></p> <p><u>Expected outcomes:</u></p> <p><u>If we don't choose this treatment:</u></p>
<p><u>Positives</u></p>	<p>How we feel about it</p>	<p><u>Negatives</u></p>

Why these strategies for choosing between treatment options can help

– What the experts have to say

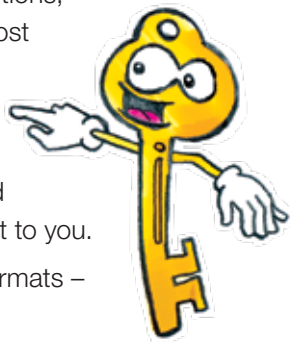
There are few certainties in cancer treatments. Outcomes aren't guaranteed, side effects vary and many factors can affect how you respond to treatment. All of this means that decision making can be a fraught process. Decision aids have been shown, in many cases, to empower couples dealing with cancer to share in the decision making process. Some patients have found that decision aids increased their confidence about making the best decisions and helped reduce their anxiety about making a decision.





– **Dr Peter Chong**

Key Points: Choosing between treatment options

1. When considering a number of treatment options, start by thinking about the things that are most important to you – your priorities and values.
2. A good decision aid helps you and your partner work through your options by providing you with additional information and helping you consider factors that are relevant to you.
3. Decision aids come in different forms and formats – find one that suits you.



We feel that we don't have enough options

 I was beginning to wonder whether the fact I was a not particularly well-to-do farmer from the bush had anything to do with what the doc was telling me I needed to do next. It wasn't like he was giving me much choice. 

Roger, diagnosed with bowel cancer.

While an array of treatment options can make decisions difficult, some couples are shocked to find their choices to be quite limited. Depending on the type and stage of cancer, there may only be one or two options available. The treatment options you are offered may also be influenced by your doctor's experience and preferences.

The first thing to ask your doctor is why you've been given such a limited choice of treatments. If you're not satisfied with their answer, read on...

Suggestions for seeking more options

1. Seek a second opinion from another health care professional.
2. Find more information resources.
3. Consider joining a clinical trial or using complementary therapies.



Suggestion 1: Seek a second opinion

Most doctors understand that patients may want a second opinion and may encourage it. Another doctor may give you more options or might put your mind at ease by reinforcing what your doctor has already told you.

Top Tip: If you feel uncomfortable about telling your doctor you want a second opinion, ask your partner to be there with you to help you explain, or speak to another member of your health care team (e.g. cancer care coordinator or GP) about how to manage this.



...and in my opinion that would be the best course of action at the moment.



Thank you doctor. We really appreciate your advice. Now before making a final decision, we'd like to get another opinion - is there someone you can recommend?

Here are some hints for seeking second opinions:

- ✓ Before you act, think about why you feel you need to get another doctor's advice (e.g. is it worth the extra time and expense?)
- ✓ Tell your principal doctor you intend to seek a second opinion – they usually appreciate the courtesy and might even refer you to someone.
- ✓ Be honest with your doctor about your reasons for asking another doctor's opinion – they're likely to understand your need to be as fully informed as possible.
- ✓ It can take some time to get your second opinion, so ask your doctor if they can help facilitate the process. If you want a second opinion for a specific concern, they might know someone who has expertise in dealing with that particular issue.
- ✓ Ultimately, couples want a well-informed team looking after the treatment. If you let your doctor know you are seeking a second opinion, they can ensure that you have all the information you need to take to your consultation to get an accurate second opinion. A referral for a second opinion also means that letters will be sent between doctors so that everyone is kept informed.
- ✓ Be sure the second opinion comes from a credible source – check with your doctor, the hospital or the Cancer Council.
- ✓ Be wary of using websites to find a second opinion.
- ✓ If you're considering a second opinion from outside your location, include travelling to treatment and possible impact on follow-up care as factors to consider in your decision making process.
- ✓ Let your principal doctor know what you've gleaned from a second opinion so they have a chance to discuss the information and offer their views.
- ✓ Make sure you let both doctors know who you've decided to go with for treatment. Keeping everyone in the loop makes sure you don't slip through the cracks or get overlooked on busy treatment schedules.



– Dr Peter Chong

FACT: You're fully entitled to seek another doctor's opinion.
You also have the right to choose which doctor provides treatment.



Suggestion 2: Find more information resources

There is a lot of useful information on treatment out there. You can try:

- ✓ The **Cancer Council** (13 11 20 or www.cancer.org.au), which offers a variety of written resources, directories and counselling services.
- ✓ **Other people who have been diagnosed with cancer and their partners**, who are likely to have many experiences to share with you. You can contact others through support groups (which can be found through cancer agencies, hospitals and doctors' surgeries) or through online forums, chat rooms or social networking sites such as Facebook (many of which you can find through cancer-specific organisations). Also, the Cancer Council has a one-to-one support program called Cancer Council Connect, where you can talk to a trained volunteer who has gone through similar cancer experiences (call 13 11 20 for more information). See the **'we need more emotional support'** section of the ***Getting the Support You Need*** booklet for more detailed information on connecting with others affected by cancer.
- ✓ Academic **research and studies** into different cancers, treatments and patient experiences. You can find these resources via the Internet, through cancer organisations (such as the Cancer Council or cancer-specific bodies) or through libraries. See the **'we need more information'** section of the ***Getting the Support You Need*** booklet for more details on how to find these resources.

Top Tip: Be sure to check that any information you find on other treatment options is credible and worthwhile. The following box has some hints to help you with this. Also, talk to your health care professionals about what you find. This is especially important if any of the information worries you, seems to contradict what you've been told, or is influencing your treatment decisions.



To check that information is worthwhile, ask yourself:

1. Is it from a credible source? Make sure it comes from a reputable organisation, such as a recognised medical institution or government agency, and be wary of information that is sponsored by someone with a commercial interest. Discuss the information with your health care professionals.
2. From which institutions have research papers and articles originated? Are they recognised universities or other research organisations?
3. Do you fully understand the language used?
4. Is the information the most recent you can find?
5. Do you know the full story behind the accounts of other people with cancer or their partners? This will help you decide how relevant the information is to your circumstances.
6. Who gave you the information or referred you to it? What might be their motivation for doing so? For example, is it from a pharmaceutical company with a product to sell?
7. Does the information sound incredible or too good to be true? If so, it probably is.

Suggestion 3: Consider clinical trials or using complementary therapies

Clinical trials are studies into new medical techniques to test how they work in practice. Trials rely on the willingness of patients to participate. Your doctor might not recommend a course of clinically unproven treatment, but may suggest cancer treatment trials if you're interested in finding other treatment options.

FACT: Many clinical trials are 'randomised', which means that participants are randomly chosen to receive either the study treatment or the best standard treatment available. Depending on the study, participants often don't know which treatment they're receiving until the study is completed.



Some questions you might want to ask your doctor when considering a clinical trial are:

- ☒ What's involved in this trial treatment?

- ☐ How does it compare with the best standard treatment for my cancer?

- ☐ Who has reviewed and approved the trial?

- ☐ What are the possible benefits / side effects / risks?

- ☐ What are the risks of not undergoing the treatment recommended by my doctor?

- ☐ What can I do if the treatment doesn't work or the trial doesn't work out for me?

- ☐ Will my doctor still be involved in my care?

- ☐ What extra tests or procedures, if any, will I be expected to undergo?

- ☐ Are there any costs involved for me?

- ☐ How much time do I have to think about it?

- ☐ Will study staff communicate with my doctor at all?

- ☐ How could being part of the trial affect my day-to-day life?

Adapted from Australian Cancer Trials (2010); and National Cancer Institute (2008).

Where to find clinical trials

You can ask your doctor about clinical trials that might be suitable for you, or check with the oncology department of your hospital. You can also try the Cancer Council (www.cancer.org.au or 13 11 20) or specific cancer organisations such as the National Breast and Ovarian Cancer Centre (www.nbocc.org.au); Colon Cancer Alliance (www.ccalliance.org); Melanoma Institute Australia (www.melanoma.org.au); or the Prostate Cancer Foundation of Australia (www.prostate.org.au).

Other sources of information on clinical trials include:

- ✓ Australian Cancer Trials (www.australiancancertrials.gov.au)
- ✓ Cancer Trials Australia (www.cancertrialsaustralia.com)
- ✓ Australian New Zealand Clinical Trials Registry (www.anzctr.org.au)
- ✓ Cancer Institute of NSW (www.cancerinstitute.org.au/research-grants-and-funding/clinical-trials)
- ✓ The Coalition of Cancer Cooperative Groups' Cancer Trials Help website (www.cancertrialshelp.org)
- ✓ The American Cancer Society (www.cancer.org/acs/groups/cid/documents/webcontent/003006-pdf.pdf)
- ✓ The US National Cancer Institute (www.cancer.gov/clinicaltrials/education/questions-to-ask-about-participating)

Complementary and alternate treatment options

For some couples, incorporating complementary therapies as part of the treatment regime gives them a sense of control and helps them feel that they are doing all they can to ensure a positive outcome. It is essential that you discuss any complementary or alternate therapies with your doctors prior to starting them.

Top Tips for making decisions about complementary or alternative treatments

Some therapies can be undertaken in conjunction with your mainstream treatment – these are known as **complementary therapies** and include treatments such as massage and acupuncture. Others can be undertaken in place of your mainstream treatment and are known as **alternative therapies**.

These therapies come in all forms and can be good or bad for you, depending on your health, what they are, who provides them and how they are administered. Regardless of how ‘harmless’ you think the therapy might be, you should always check with your health care professional before you undertake any non-mainstream forms of treatment.



Here are some questions to ask yourself and your health care professionals before you try a complementary or alternative therapy:

- ☒ Could this therapy interfere with other planned cancer treatments (like chemotherapy)?
- ☐ Does the provider have the appropriate qualifications and training?
- ☐ What are the possible motivations of the provider (e.g. do they make the product they sell)?
- ☐ Is there credible information or research to back up any claims made by the provider regarding treatment outcomes?
- ☐ Is the product or therapy (and the claims it makes) recognised by any medical authorities?
- ☐ Does the therapy come with any warnings about possible side effects? Most reputable ones do.
- ☐ How does the therapy fit into your lifestyle and, where applicable, with your current treatment?
- ☐ How much does it cost, and can you claim any rebates through Medicare or your health fund?
- ☐ How will the cost of the treatment impact on your ability to pay for ongoing doctors' appointments/conventional treatment? Can you afford both?

Adapted from National Coalition for Cancer Survivorship (2011).

FACT: Many complementary therapies are promoted through anecdotal patient evidence and not scientific evidence. If there is solid scientific evidence behind a complimentary treatment it is usually taken up by conventional medicine.



What others say about seeking more options

👤 I was a little bit surprised when the oncologist told me that my choices were chemo or nothing. I didn't realise it was usually that black and white. My GP said I should try another oncologist, just to be doubly sure. I felt a bit bad about that, but it was worth it because the second one said he could try to remove the tumour first and that might limit the amount of chemo I needed. 🙌

Anka, diagnosed with breast cancer.

👤 I was a bit sceptical about surfing the Internet, because I'd read about people who wrongly self-diagnose and that doctors hate it. I mentioned this to the nurse at the hospital, thinking she'd agree, but the next time I saw her, she had a list of websites I could look up if I wanted to do some of my own research. It was kind of like I had 'official permission' to do it. 🙌

Pieter, diagnosed with melanoma.

👤 Our niece is a naturopath so she suggested a range of herbal supplements we could try to help with healing and tiredness during Cole's radiation. However, she also stressed that we should discuss this with the radiation oncologist before we started, and even wrote a letter that we could take to him. Our radiation oncologist was very happy to discuss this with us. 🙌

Sherilynn, wife of Cole, diagnosed with prostate cancer.

Why seeking more options can help – What the experts have to say

Research shows that couples facing cancer are more likely to be satisfied with treatment if they feel they've contributed to the decision making process. If the options your doctor presents are limited, the danger is you might feel you have little choice, and therefore not much of a say, in how to treat the cancer. Finding information from other sources may help to put your mind at ease. You might find some new leads to follow-up with your doctor, or your research might reinforce your doctor's reasons for offering limited options.



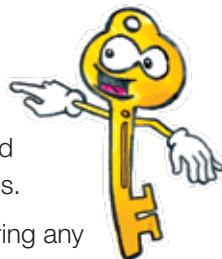
– **Associate Professor Fran Boyle**

Top Tip: Sometimes a treatment decision needs to be made urgently, but in most cases, there is time to gather information and make a decision. Check with your doctor about recommended time frames for treatment decisions.



Key Points: Seeking more options

1. It's always important to ask doctors why treatment choices are limited.
2. Most doctors understand and encourage your need to seek a second opinion or other treatment options.
3. It's important to check with doctors when considering any other treatments.



We feel that we don't understand enough to decide

👂👂 Well, the trouble is in ignorance, you don't know how one choice is better than the next... if I was offered choices, I would try and rely on the information I got from the doctor, the specialist. 🧠🧠

Eric, diagnosed with prostate cancer.

Dealing with a cancer diagnosis often means being given a lot of new and complex information to digest. This can become a problem, particularly when it's not clear enough to make decisions.



Don't worry dear. As soon as he's back with us, I'll ask him what all this **really** means.

Suggestions for making sense of information

1. **Ask questions** of health care professionals.
2. **Seek clarification** if you don't understand.



Suggestion 1: Ask questions

People often feel that there's no time to ask further questions during a consultation, or that they're bothering their busy doctor with queries. Another common concern is asking a stupid question. However, most doctors say that they prefer patients and partners to speak up if they need to know anything, and that there's no such thing as a stupid question.

A good way to make sure that you ask everything you need to ask is to **be prepared**. You can do this by:

- ✓ **Preparing a list of questions before your appointment.** This is called a *question checklist* and is a tool health care professionals often advise people to use. Read on in this section for more information on question checklists.
- ✓ **Booking a longer appointment.**
- ✓ **Giving your doctor a 'heads-up'.** Prepare your doctor for your questions by providing them before your appointment (i.e. ask the doctor's assistant if it's okay to email a list of questions or give your list to the receptionist when you arrive).
- ✓ **Taking someone with you.** A second or third person can offer the moral support you need to speak up and they can also help with asking questions (e.g. they might think of things you've forgotten, or take notes so you can concentrate on what the doctor is saying).

For more information on preparing for appointments, see the **'we leave our appointments feeling we didn't get what we wanted'** section of the ***Getting What You Need From Your Health Care Team*** booklet.

Question checklists

A question checklist can help you get all the answers you need to make an informed decision about your treatment. Here is an example of a question checklist relating to treatment.

FACT: Research shows that people who use checklists remember what they hear, feel less anxious and are more likely to get the information they need to gain some control over cancer. More detailed information on, and examples of, question checklists can be found in the **'we don't know what to ask'** section of the ***Getting What You Need From Your Health Care Team*** booklet.



Questions about treatment (general)

Who to ask: Medical oncologist, surgeon, specialist

- ☒ Why should I have treatment right now? What will it do?
- ☐ What are the benefits and risks of having treatment?
- ☐ What is your recommendation? Why?
- ☐ What can I expect from this treatment?
- ☐ How well established is the treatment you're recommending?
- ☐ How much time do I have to think about this? Should I get a second opinion?
- ☐ What is the treatment schedule (how many, how often, how long)?
- ☐ What medication do I require?
- ☐ What does the treatment involve (how is it done, where)?
- ☐ How does it work? How long should it take the treatment to work?
- ☐ Will I need to spend time in hospital? If so, for how long?
- ☐ Will treatment affect my quality of life (e.g. sex, work)?
- ☐ What are the side effects and can these be controlled?
- ☐ What happens if I react badly to treatment and need to stop?
- ☐ Who should I call if I experience side effects, or have questions?
- ☐ How can I expect to feel during treatment?
- ☐ What happens if I miss a treatment?
- ☐ How often should I be seen for follow-up appointments?
- ☐ What other health care professionals will I need to see for treatment?
- ☐ How will my condition be monitored after my treatment?
- ☐ What should I do to help myself stay healthy?

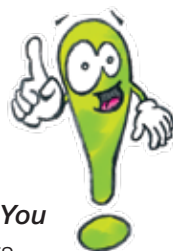
Adapted from Cancer Council South Australia (2007), Cegala (2001) and University of Sydney Medical Psychology and Research Unit.

Suggestion 2: Seek clarification

Here are some ways to follow-up and clarify the information you're given about treatment.

What to do	How to go about it
Ask your doctor to explain further.	<ul style="list-style-type: none">✓ Make your questions specific. For example, "Did you mean I should try [a particular treatment]?" rather than "What should I do?"✓ Ask the health care professional if there's another time or another way (e.g. telephone) that you can discuss it in more detail.
Repeat what you've heard in your own words.	Get it clear in your own mind by rephrasing it, using words such as "So, what you mean by that is..." or "From what I understand, you're suggesting..."
Ask the doctor to present information differently.	People process information differently, for instance, some people are more 'visual' and more likely to understand pictures and diagrams. Others might find it easier to work with numbers and statistics. If you're finding it difficult to grasp something in one form, ask your doctor to try it another way (e.g. using different words, using analogies, drawing diagrams or noting down key points).
Ask for supporting information.	Ask your doctor, nurse, GP or hospital about brochures, pamphlets, websites and other supporting literature that presents the details of your treatment options clearly and simply. You can also try the Cancer Council and other reputable organisations; these resources are often available at no cost.

Top Tip: If you're unable to ask further questions of your doctor, think about other members of your health care team who might be able to help. Depending on the nature of your questions, these could include your GP, oncology nurse, social worker or cancer care coordinator. See the **'we don't know who to ask'** section of the **Getting What You Need From Your Health Care Team** booklet for more hints.



What to do	How to go about it
Ask for a summary.	At the end of your consultation, ask your health care professional to summarise the most important points from your discussion. Not only does this help you to remember details, but you might also find that health care professionals use simpler terms when summarising.
Follow-up consultations.	Most doctors will invite you to contact them if you have any concerns or questions that arise after your consultation. Some will be happy to call you back when they're available. At your first consultation, ask about the best way to communicate with the doctor between appointments.
Get it from the horse's mouth.	If you're trying to grasp exactly what you can expect from specific therapies, it might be possible to speak to those who administer the treatment. Ask your principal doctor if they can provide contacts or set up appointments for you to speak to therapists, specialists or nurses who work at the 'coal face' of treatment.
Take your partner or other trusted person to consultations.	<p>Taking in new information can be tough for people dealing with the stress of a cancer diagnosis, so it can help to have someone accompany you to consultations to help take notes, ask questions and talk through the details with you.</p> <p>See the <i>'we leave our appointments feeling we didn't get what we wanted'</i> section in the <i>Getting What You Need From Your Health Care Team</i> booklet for further tips on working together during consultations.</p>

See the ***'we don't always understand what the doctor is telling us'*** section of the ***Getting What You Need From Your Health Care Team*** booklet for more details about clarifying information.

Example: Clarifying information

Tristan is attending his first appointment with his medical oncologist since a biopsy confirmed his diagnosis of melanoma. During the appointment, the doctor refers to the ‘Clark level’ and ‘Breslow’s depth’ before going on to explain that Tristan’s case would be treated as ‘high risk’. She also says “The biopsy appears to have excised the tumour, but we may need further surgery, probably a wide local excision, to make sure it does not recur”. The doctor adds that ‘adjuvant treatment’ may also be needed. Tristan is overwhelmed – and just a little bit sick at the thought of being a ‘high risk’ case – so, even though the doctor has spent a lot of time outlining different plans of attack and has asked if he has any questions, Tristan is feeling confused and ill-equipped to go away and consider his options.

Using the information and tips in the table on pages 42–43, note down how Tristan can clarify his understanding of the information he was given.

Possible strategies – Tristan could:

- ✓ Take along a question checklist.
- ✓ Ask the doctor for pamphlets explaining the terms she has used.
- ✓ Ask the doctor to draw a diagram of what the Clark level and Breslow’s depth represent.
- ✓ Ask questions such as “What exactly do you mean by high risk?”, “What does that mean in terms of my prognosis?”, “What does adjuvant treatment involve?”.
- ✓ Send a follow-up email to the doctor asking for further explanation of terms he did not understand (only if he has checked emails are acceptable to his doctor beforehand),
- ✓ Take his partner to the consultation so they can share what they each heard and understood.

What others say about using these suggestions to make sense of information

👍👍 My doctor thought it was funny when I walked in one day with a set of coloured Textas and a sketch pad out of my son's art box. I'm a pretty 'visual' person and I'm always asking him to draw a picture of whatever he's trying to describe, and he was always scrabbling around looking for a scrap piece of paper and trying to find a pen that worked. 🎨🎨

Denise, diagnosed with colon cancer.

Why increasing your understanding to make sense of information can help – What the experts have to say

Couples who ask questions and seek clarification have been shown to take a more active role in making decisions about treatment and, as a result, are often more satisfied with their care. Confusion and a lack of understanding can not only cause you to reach the wrong conclusions and possibly fear the worst, they can also leave you feeling frustrated, or even depressed at the idea that your treatment is out of your control. Health care professionals often report that they prefer patients to speak up when they don't understand something. It helps them to know how much their patients understand and what they need to do to ensure that their patients are happy with their treatment.



– Dr Peter Chong

Key Points: Making sense of information

1. The more you understand about your treatment options, the more likely you are to participate in the decision making process and be satisfied with your care.
2. Asking for clarification and more information is your right as a patient, and is usually encouraged by doctors.
3. For people dealing with any kind of medical condition, there is no such thing as a stupid question.



We want more of a say in the decision

👍👍 I had great anxiety regarding my treatment. I had done some reading and wanted to consider a different treatment option to what my doctor had recommended. But I couldn't say 'Hey, what about this?' I didn't want him to think I was telling him how to do his job. But, I was really worked up about not knowing whether the right decision had been made 🤔🤔

Martina, diagnosed with breast cancer.

FACT: Most doctors prefer their patients to participate in decision making. It's also your **right** to choose or reject any form of treatment.



Suggestions for having more of a say in the decision

1. **Assert yourself** in the decision making process.
2. If you still feel left out, **seek a second opinion**.



Suggestion 1: Assert yourself in the decision making process

Being assertive is quite different to being aggressive. It means respectfully speaking up for yourself and letting your health care professionals know you wish to be involved in decisions about care and treatment.

Assertiveness comes more easily to some than others, so we've provided a possible plan of action for you, in case you need some tips.

Assertiveness plan

Step 1: Tell your health care professional how you like to interact.

e.g. "I tend not to say a lot, but I do like to have a say in all decisions."

Step 2: Discuss with your health care professional how you can best get involved.

Talk about being provided with all options and relevant information, for example, set a question time or contact the practice via email.

Step 3: Discuss concerns with your health care professional.

Tell your health care professional how you feel about your involvement in the decision making process. Be specific about the problem and what you need. The exercise on the next page on making assertive statements, takes you through a technique you can use to help make your position clear to your health care team.

Step 4: Talk to others.

If you're still not happy with your level of involvement, try talking to your cancer care coordinator, social worker or nurse about your options. You are also entitled to ask for another doctor or a second opinion. See Suggestion 2 in this section for more information about seeking a second opinion.

See the ***'we leave our appointments feeling we didn't get what we wanted'*** section of the ***Getting What You Need From Your Health Care Team*** booklet for more information on being an active and assertive participant in decisions about your care.

Exercise: Making assertive statements

Think about the next time you'll be talking to your doctor about treatment options, or remember a consultation at which you weren't satisfied with your involvement in the decision making.

1. Decide what you hope/hoped to achieve during that discussion with your doctor.

Setting a specific goal for communication with your doctor can help you to be assertive. Assertiveness is about saying what you want in a clear and effective way and it's difficult to be clear with others when you're unsure what you want. A specific goal might be: "To find out if there are any treatment options beyond what my doctor seems to prefer."

Your goal:

2. Work out how to clearly state where you stand.

Once you're clear about your goal, you need to think about how you can set out a clear picture of your position for your doctor, as misunderstandings occur when others don't get the full story. Make sure you cover three key pieces of information:

- i. What you think about the situation – "We think..."
- ii. How you feel about the situation – "We feel..."
- iii. What you want to do, or would like to see done, about it – "We want/would like..."

An example of how you might state your position assertively is:
"We think we need to look at more options before a decision is made about treatment. We feel that we don't know enough about what else might be on offer. We'd like it if you could give us some information on what other options might be available to us, even if you don't particularly prefer them."

Your assertive statements:

We think

We feel

We want / would like

Adapted from Davis, Paleg and Fanning, (2004).

Suggestion 2: Seek a second opinion

If you feel excluded from the decision making process because of the way in which your health care professional works with you, it's your right to ask for a second opinion. Most doctors understand if you explain why you feel you need to see someone else. In fact, many are happy to provide a referral.

FACT: You are entitled to seek another doctor's opinion on how to treat the cancer. For more information on seeking a second opinion, see the section '*we feel that we don't have enough options*' in this booklet.



Okay doc, we think we'll go
with chemo. Do you think
that'll get us to our goal?



What others say about asserting themselves in the decision making process

👍👍 At first I was a little uncomfortable telling my doctor I wanted to choose my treatment. I simply told him that choosing what was best for me was important because I would know my needs had been fully considered. 🗨️

Kenneth, diagnosed with prostate cancer.

👍👍 The biggest hurdle for me was overcoming the fear of all this new information, and a whole new, scary situation. But I decided I couldn't just sit there and be told what to do, so I said to my doctor, 'Hey, you know, I'm one of those people who needs you to tell me everything about what is going on, so I can go and do some of my own research and help myself out a bit. Sorry if I'm your worst nightmare!' In fact, I think he appreciated my honesty and was pretty good about answering my questions and giving me more detail than perhaps other patients might ask for. 🗨️

Allen, diagnosed with bowel cancer.

Why asserting yourself in the decision making process can help – What the experts have to say

People who feel that they're not active enough in the decision making process are often shown to be dissatisfied with their treatment and care. In some cases, patients reduce their communication with their doctor because they feel helpless or frustrated. This only makes the problem worse as the doctors don't not know about their patient's concerns. It makes all the difference for you to let your health care professionals know how you're feeling and how much you want to be involved in making decisions about treatment.



– **Associate Professor Fran Boyle**

FACT: Studies show that patients whose perceived levels of involvement in the decision making process match their preferences are more satisfied with their treatment and less likely to feel depressed. The outcomes are poorer for patients whose perceived level of involvement falls short of their expectations.



Key Points: Asserting yourself in the decision making process

1. Every person has the right to make the final decision about what treatments to use.
2. It's easy for busy doctors with good treatment systems in place and proven track records in cancer treatment to fail to realise that you're being left out of the decision making process.
3. Being assertive is about respectfully speaking up for yourself and letting your doctor know what you need.



We feel pressured to make decisions

👍👍 People should have some time to think and do some research before having to make decisions about treatment. This is one of the biggest decisions of your life. You tend to go along with what is suggested by your doctor, because that is what you always do. It is blind trust. Then you find out about the long-term consequences. 🗨️🗨️

Anshula, diagnosed with breast cancer.

Settling on a cancer treatment plan is probably one of the biggest decisions you will make and few couples have the luxury of making this decision without the presence of additional pressures.

Top Tip: Those around you usually have only the very best of intentions in guiding your decisions about treatment, and may not realise how the pressure of conflicting advice affects you. If you're feeling pressure from your loved ones, let them know, and ask them to give you some time and space to consider your options.



Suggestions for making treatment decisions under pressure

1. **Be open, honest and assertive** with those around you.
2. Focus on the **ISSUE**.



Suggestion 1: Be open, honest and assertive

Some of the pressures on treatment decision making may be unavoidable. However, you can alleviate some of the pressure by identifying and working around it. Following are some tips for dealing with different sources of pressure.

Pressure source	What you can do
I'm distressed by my diagnosis and can't get my thoughts straight.	Tell your doctor how you're feeling and ask for important information in forms you can easily digest (e.g. summarised notes, lists of things to remember or diagrams). Also ask if you can clarify anything you're not sure of via email or telephone. You might spend some time with your partner, who you can talk things through with, or seek a consultation with a social worker or psychologist who can help you work through your thoughts. Remember that if you have a GP it can be very reassuring to talk things over with him/her. Techniques such as relaxation strategies (see the 'I feel tense, angry and/or stressed' section in the Dealing with Stress and Worry booklet) can help you to feel calmer and more able to make a decision.
The cancer is advancing and we need to act quickly.	<p>Discuss with your doctor the medical reasons why you need to make a quick decision. Weigh up your priorities; the consequences of not hurrying your decision against the consequences of making the wrong decision (for you) in a rush. Ask your doctor to help you make a pros and cons list to make sure you consider all the relevant issues. Avoid being pushed into important decisions on the spot.</p> <p>See the 'we want more of a say in the decision making process' section of this booklet for information on being assertive with health care professionals. The DECIDE model, in the 'we need help with the decision making process' section of this booklet, may also help.</p>
The doctor is available only at limited times.	Take your consultations with doctors when you can get them, but ask if there's a standby list and if there are other ways you can stay in touch while you're considering your decision. Your doctor may be happy for you to ring back at an agreed time, or may even suggest other health care professionals with whom you can discuss things.





Pressure source	What you can do
My doctor believes this treatment is the best way to go, but I'm wondering if I need a second opinion.	<p>Explain to your doctor that while you value and trust their opinion and expertise, you need time to consider all the information about treatment options and weigh them against your own values and priorities. You also might like to seek a second opinion or talk to another member of your health care team.</p> <p>See the sections <i>'we feel that we don't have enough options'</i> and <i>'we feel that we don't understand enough to decide'</i> in this booklet for information on dealing with limited options and seeking second opinions. Also, see the <i>Getting What You Need From Your Health Care Team</i> booklet for more tips.</p>
My family and loved ones would prefer me to undergo this treatment, but I'm not so sure.	<p>Make time to talk to those around you – listen to what they have to say and explain that their concerns and opinions matter to you and you'll consider them in your decisions. Be honest about how you're feeling and what you need (e.g. "I'm feeling a bit burdened by all these different ideas at the moment. I just need a bit of space to go away and think about it all."). Ask them to do their best to understand that no matter what decision you make, you'll still need their support; which involves accepting your decision.</p> <p>See the sections <i>'I'm having trouble talking to my partner'</i> or <i>'I don't know how to talk about the hard stuff'</i> in the <i>Supporting Each Other</i> booklet.</p>


Top Tip: Consider other ways to ease the pressure that you're feeling. Try engaging in pleasant activities or using relaxation techniques. See the ***Dealing with Stress and Worry*** booklet for more information about these suggestions.



Suggestion 2: Focus on the ISSUE

ISSUE is an acronym for a thinking process you can follow to gauge your readiness to make a decision.

	If you answer 'NO', what can you do?	
 <div> <input type="checkbox"/> YES <input type="checkbox"/> NO → </div> <p>Do you feel <u>informed</u> enough to make a decision?</p>	<ul style="list-style-type: none"> • Ask your health care professionals for more information or to clarify the specific issues you're unsure about. • Get information from other credible sources (see the 'we need more information' section in the <i>Getting the Support You Need</i> booklet). • Get a second opinion. 	
 <div> <input type="checkbox"/> YES <input type="checkbox"/> NO → </div> <p>Are you <u>sure</u> which choice is best for you?</p>	<ul style="list-style-type: none"> • Work through the decision making process or the decision aid outlined in this booklet (see the 'we need help with the decision making process' and the 'we feel overwhelmed by options' sections). Make sure you think about which criteria are most important to you. • Discuss your choices with your health care team and other people who are close to you to get their ideas. Be careful that you don't let their views add to your pressure. 	
 <div> <input type="checkbox"/> YES <input type="checkbox"/> NO → </div> <p>Are you <u>satisfied</u> with the decision you have made/are going to make?</p>	<ul style="list-style-type: none"> • Identify which aspects of the decision make you uncomfortable/dissatisfied. Can these be changed? • Voice your concerns with your health care team to see if there is information you need to allay your concerns. 	
 <div> <input type="checkbox"/> YES <input type="checkbox"/> NO → </div> <p>Were you <u>unpressured</u> in the decision making process?</p>	<ul style="list-style-type: none"> • Speak directly with whoever is making you feel pressured and ask them to give you some space to make the decision. • If the pressure is coming from your doctor, seek a second opinion. 	

	If you answer 'NO', what can you do?	
 <div> <input type="checkbox"/> YES <input type="checkbox"/> NO → </div> <p>Were you encouraged or did you have enough support to make your decision?</p>	<ul style="list-style-type: none"> Consider what sources of support you'd like to help you make your decision and work out how to access them (e.g. information from a source other than your doctor, talking to couples who have experienced this type of cancer). 	

If you and your partner answer “yes” to the questions in this table, you’re most likely ready to make a decision, if you haven’t done so already. If you answer “no” to a question, it might be that you need a bit more time to work through the decision making process, to ensure that you make the right decision for you.

What others say about using these suggestions when making decisions under pressure

👍👍 I could tell Paula was a bit panicky about whether she should have the surgery or the chemo but she’s always prided herself on being so capable and under control, and she wasn’t really admitting it to anyone. So I sent an email to her doctor’s secretary, and a couple of days later the doctor kindly rang her ‘out of the blue’ to see how she was coping and she suggested a couple of people that Paula could talk to, which I think made her relax about it a bit more. 🙌🙌

Donald, partner of Paula, diagnosed with breast cancer.

👍👍 When you hear the word ‘cancer’, your mind starts thinking of some beast eating through your body like a Pac Man. Well, mine did anyway. I kind of felt like I needed to start blasting away at it straight away and it didn’t help that the doctor was saying we needed to get on to it ‘sooner rather than later’. The best thing I did was ask him what he meant by that, and he set out a timeline for me that showed me his idea of ‘sooner’ was measured in weeks, while I had been thinking in days. Phew! 🙌🙌

Kai, diagnosed with melanoma.

Why using these suggestions when making decisions under pressure can help

– What the experts have to say

Feeling pressured to make a treatment decision can increase your anxiety and make you feel less confident that the correct choice has been made. You need time to consider your options and in most cases, there is no need to rush or make an immediate decision.



It's important that you have an opportunity to consider the available options, talk to others and consider the consequences of each choice. This will give you reassurance that your views have been considered and increase your belief that you have some control over what's happening.

– **Dr Peter Chong**

Key Points: Making decisions under pressure

1. The pressures on couples faced with treatment decisions include their own feelings, conflicting ideas from others and the circumstances (e.g. time constraints).
2. Health care professionals and loved ones may inadvertently exert pressure, even when they think they're doing or saying what's best for you.
3. Being open and honest with those around you can help to alleviate some of the pressure.



We feel anxious due to treatment-related delays

👍👍 I kept telling myself that it was okay and I should use this time to arrange meals and sort out domestic arrangements. But I didn't. I couldn't focus. I felt like I was in a daze and sometimes I couldn't even think. Once treatment started I thought 'Okay, here we go, let's get on with it'. Waiting is a nightmare. 🤔🤔

Jane, diagnosed with breast cancer.

Once you've settled on a cancer treatment, there may be several types of delay that emerge. Some delays are unavoidable, and could be due to any number of reasons (e.g. the availability of your surgeon, the sequence of treatments). The length of any delay in beginning treatment will vary from case to case, and you should discuss this possibility with your health care team.

It's normal for patients and partners to feel worried or anxious when dealing with treatment-related delays. Often couples describe this as feeling like they are 'in limbo' and may experience helplessness. Fortunately, there are things you can do to manage your worries and uncertainty. For a full recap, be sure to review the ***Dealing with Stress and Worry*** booklet.

Suggestions for coping with the stress of waiting

1. **Change your self-talk** to get rid of unhelpful thoughts.
2. **Confine your worries** to a set time.
3. **Seek social support** and pleasant distractions.




Suggestion 1: Change your self-talk

During stressful times, we may feel overwhelmed and it can become difficult to separate thoughts from feelings, and fears from reality. Negative and unhelpful self-talk can make it hard for you to think clearly about things. The steps set out below might help you to tone down some of your self-talk so you can manage your worries with a clearer mind.


Step 1: Pay attention to your feelings.

What are they? What has triggered these feelings?




Step 2: Pay attention to your self-talk (your thoughts).

Are the thoughts realistic? Is there any evidence they might be true?



Step 3: Challenge the unhelpful self-talk.

Is there a chance these thoughts are overly negative?
Do these thoughts underestimate your coping ability?



Step 4: Find helpful replacement self-talk.

Try to be realistic, rather than overly positive or putting on a 'brave face'.

Example: “I feel like my cancer is only getting worse while I wait for treatment to start.”

Step 1:

Think about the feelings behind this thought and what might be causing them. Is it anxiety about the unknown (e.g. you don't know enough about how your cancer is likely to progress)? Is it panic caused by stories you have heard or read?

Step 2:

Is the thought realistic? You might like to talk to your doctor or nurse about whether a delay in treatment can cause any harm.

Step 3:

Challenge this negative self-talk by bringing some perspective to it. For instance, your doctor or nurse might explain that most patients experience this delay and the outcomes are usually unaffected.

Step 4:

Having ‘analysed’ your negative self-talk in the previous steps, you might replace it with something like “I feel like the sooner I start my treatment, the quicker I can get on the road to recovery. But I know this sort of wait is pretty normal, and everyone is doing their best for me, so I'll put my faith in them, and in the fact the doctor says the wait is not likely to change anything.”

For a more in-depth discussion on dealing with self-talk, see the ***‘I feel worried or uncertain’*** section of the ***Dealing with Stress and Worry*** booklet.

Suggestion 2: Confine your worries

A constant stream of worrying thoughts can make it hard for you to think clearly and sort problems out. While it's often unrealistic to expect you to simply put those thoughts out of your head, one thing you can try is a technique referred to as 'worry postponement'. This involves limiting your worry time, by allocating a specific time during the day (say, half an hour), to get your worrying done. The trick is to make a point of setting a time, 'assigning' any worrying thoughts that pop into your head during the day to that time, and then sticking to the time limit when it comes to doing the actual worrying.

Following are some tips for making your worry time work.

When a worrying thought arises:

- ✓ As soon as a thought pops into your head, acknowledge it and then postpone it. You might do this by saying to yourself "Yes, that is a worry, but I'm not going to waste any time on it now. I'll think about it [at the allocated time], and get back to what I am doing now".
- ✓ Jot down the thought, if you think that might help you later, and then put it aside.
- ✓ Actively turn your mind to what you were doing when the thought came up. This might mean reciting the steps you were going through, or asking yourself a question about what you were doing.
- ✓ Do something practical, physical and/or nurturing (i.e. a 'feel-good' activity) to distract yourself from worrying thoughts.

During your worry period:

- ✓ Stick to your time limit.
- ✓ Find a dedicated 'worrying spot' (e.g. another room) that you can go to for the allocated time, then leave (or close the door) when you are finished.
- ✓ Don't feel you necessarily need to solve your problem, especially if what is worrying you is treatment delay. There's nothing you can do to make the days go faster. Sometimes, giving yourself permission to stress over something for a little while can be a form of release.
- ✓ If you feel you need emotional support or help with solving a problem, you might ask your partner to join you during your 'worry time'.
- ✓ Keep paper and pen with you, so you can note anything you need to remember or follow up.

Top Tip: If you find it difficult to 'banish' a worrying thought on the spot, try not to be too hard on yourself. Sometimes, you just need to let the thought run its course. But if you're finding that such thoughts are taking over your life, or causing you undue stress, it might help to speak to a health care professional. See the resource directory in the ***Dealing with Stress and Worry*** booklet for suggestions.



Example scenario

Petra's problem: *"It's not the treatment itself I'm worried about; it's the waiting that really bothers me. I can't stop thinking about it."*

Petra has been diagnosed with cervical cancer, and is anxious to start treatment. She decides to tackle the problem, using the 'worry postponement' technique:

- ✓ She looks at her diary and allocates herself a 30-minute 'worry time' for the day, when she knows she will be able to concentrate on her problems without other distractions.
- ✓ She allocates a space for her 'worry time' – usually her reading room.
- ✓ Whenever she catches herself musing about the waiting time for treatment during the day, she first acknowledges the thought by saying to herself, "Yes, this is stressful, but I'm wasting my time thinking about this now. I'm 'parking' that thought until [the allocated time]".
- ✓ She then turns her attention back to what she was doing; trying to actively engage herself by talking herself through a process (e.g. the steps involved in opening up a document on the computer, or in starting up the washing machine), or by focusing on a mental task such as a crossword.
- ✓ At her allocated 'worry time', she goes to her 'worry space', where she sets an alarm for 30 minutes. Some days she spends the time thinking through the problem, writing thoughts and feelings down, and thinking up ways to distract herself during her delay. Other days she lets the worry flow over her as a form of 'release'.
- ✓ Petra sometimes asks her partner James to join her during her 'worry time'.
- ✓ When the 30-minute alarm sounds, she physically leaves her 'worry space', and mentally leaves her worries behind in that space, until next time.

Top Tip: When you find yourself expending energy on worrying about waiting for treatment, it can help to redirect your energy. You might try making a list of small jobs that need to be done around the house or at work, and onto which you can easily swing your attention. Other distractions can be mental tasks, such as doing a puzzle or remembering the lyrics to a song.



Suggestion 3: Seek social support and pleasant distractions



Staying connected with others, and the outside world in general, can help to pull you away from your own thoughts and anxiety, even if only for a short while. Doing activities you enjoy, with people whose company you enjoy, can also be a pleasant way to pass the time while you wait for treatment to start. You might not feel like socialising with others, or you might think you won't be very good company, but here are some tips to help you find the social support that might suit you.

Activity	How you might go about it
Exercise with, or around, others.	Even light exercise can help to ease your anxiety. You can ask a friend to join you, or simply walk or do other forms of exercise where others are (e.g. a gym, a park).
Get out of the house.	If you're feeling edgy or anxious but still need to get through your day's to-do list, think about what you can achieve in a different environment (e.g. shopping), where you can become absorbed in the bustle around you.
Phone a friend.	A chat over the phone might be enough to distract you from your worries (or a good chance to talk them through with someone you trust).
Do one of your favourite things.	This might be a good time to go to the library to seek out that book you've been meaning to read. Or, if you like cooking, perhaps have a go at that recipe you've been meaning to try. The secret is to give yourself permission to 'indulge' in one of your favourite pastimes.
Accept social invitations.	Your first instinct when you're feeling anxious may be to say 'no' to invitations from others. It's worth taking up the occasional offer – you might enjoy yourself more than you think. Having said that, don't be afraid to say "no" if you're really not up to it, you don't need the anxiety of trying to meet a commitment you're struggling with.
Accept offers of help from friends and family.	You may be reluctant to rely on others, or worried about appearing helpless, but offers of help are sometimes a good way of staying connected with your friends and family. Asking a friend or family member to come to an appointment with you, for instance, means you can enjoy each other's support and company.



Activity	How you might go about it
Seek out a support group.	<p>Joining a cancer-specific support group can remind you that you're not alone in your concerns, and can give you a forum for talking about how others have coped with the anxiety of waiting for treatment to start. The Cancer Council (13 11 20) can help you find an appropriate group in your local area.</p> <p>For more information on cancer support groups, see the 'we need more emotional support' section of the <i>Getting the Support You Need</i> booklet.</p>

To read more about seeking social support, see the **'I feel sad, down and/or isolated'** section of the ***Dealing with Stress and Worry*** booklet.

What others say about using these suggestions to deal with treatment-related delays

 I was a bit sceptical about the whole idea of 'controlling' your anxiety. I mean, it's easy for others to say you should just not worry about, or put that thought out of your head. I don't know about you, but my brain doesn't work that way. But then I tried it, and I was surprised how much it reduced my worry during the day. There were times that it was hard to keep my worries to the set time, but I stuck to it and overall it did make things feel less anxious. 

Lou, diagnosed with bowel cancer.

 I found it very nerve-racking when I was waiting for test results. I could feel the worry in the pit of my stomach and whenever I was on my own that was all I could think about. But I did notice that doing things I enjoyed with family and friends helped to distract me; painting with my other art society friends, playing with the grandkids, doing yoga with my husband. I would suggest to anyone in a similar situation to spend as much time out and about with others as you can manage. 

Kathleen, diagnosed with breast cancer.

Why using these suggestions for dealing with treatment delays can help

– What the experts have to say

Everyone encounters worrying situations, and what we think and say to ourselves (self-talk) about these has a direct impact on how we feel and behave.

Sometimes our thoughts are far more negative than they should be, which makes problems seem worse than they are. Aim for establishing realistic self-talk that acknowledges the anxiety and frustration you may have in relation to treatment delays, but also acknowledges that you have the capacity to deal with your current anxiety.

Researchers have found that the worry postponement technique allows people to ‘compartmentalise’ their worry so it doesn’t take over their day. This seems to reduce the impact on their overall mental and emotional wellbeing, and can reduce levels of anxiety and depression. Research has also shown that, for some people, the simple act of realising they’re worrying, and identifying what is worrying them, is enough to reduce their anxiety levels.

Spending too much time alone can make you feel disconnected from the world, and can create more opportunity for your worries to take over. Connecting with friends and family can increase confidence, enhance wellbeing, reduce tension, increase motivation and create opportunities for participating in enjoyable activities. Seeking support via a cancer-specific support group can give you a forum for talking about specific concerns related to cancer, and maybe pick up tips for handling treatment-related delays.

– **Associate Professor Jane Turner**



Key Points: Treatment-related delays

1. It's common to feel anxious about delays in the treatment process.
2. Challenging negative self-talk to make it more realistic can help you to manage your worries and anxiety.
3. If anxiety is affecting your everyday life, ‘worry postponement’ can help you to limit the amount of energy you spend on worrying.
4. Social support and pleasant ‘distractions’ (e.g. staying busy and spending time with others) can help you to keep anxiety at bay.



Support organisations and resources

Throughout this booklet we have provided you with lots of information and contacts for support organisations. The following list summarises many of the sources used to create this booklet.

Australian organisations	
Australian Cancer Trials	02 9562 5333 www.australiancancertrials.gov.au
Australian New Zealand Clinical Trials Registry	02 9562 5333 www.anzctr.org.au
Bowel Cancer Australia	02 9923 8269 www.bowelcanceraustralia.org
Breast Cancer Network Australia	1800 500 258 www.bcna.org.au
Cancer Australia	1800 624 973 www.canceraustralia.gov.au
Cancer Council Australia	02 8063 4100 Helpline (all States) 13 11 20 www.cancer.org.au/home.htm
Cancer Institute NSW	02 8374 5600 www.cancerinstitute.org.au
Cancer Trials Australia	03 9342 7306 www.cancertrialsaustralia.com
Melanoma Institute Australia	02 9911 7200 www.melanoma.org.au
National Breast and Ovarian Cancer Centre	1800 624 973 http://canceraustralia.nbocc.org.au/
Prostate Cancer Foundation Australia	1800 220 099 www.prostate.org.au

International organisations

American Cancer Society (US)	www.cancer.org
The Coalition of Cancer Cooperative Groups' Cancer Trials Help (US)	www.cancertrialshelp.org
Colon Cancer Alliance (US)	www.ccalliance.org
National Coalition for Cancer Survivorship (US)	www.canceradvocacy.org
The US National Cancer Institute (US)	www.cancer.gov/cancerinformation

Booklets, publications, audio resources and websites

Cancer dictionary, Cancer Council Victoria, 2011,
www.cancervic.org.au/glossary/default.asp

Cancer glossary, American Cancer Society,
www.cancer.org/cancer/cancerglossary/index

"Cancer survival toolbox", National Coalition of Cancer Survivorship, 2011,
www.canceradvocacy.org/toolbox/

"Cancer: What now", DVD, Cancer Council South Australia,
www.cancerwhatnow.com.au

"Clinical trials: What you need to know", American Cancer Society,
www.cancer.org/acs/groups/cid/documents/webcontent/003006-pdf.pdf

"Communicating with your doctor: The PACE system", D.J. Cegala, 2001,
<http://patcom.jcomm.ohio-state.edu>

"DECIDE: A decision making model for more effective decision making by health care managers", K.L. Guo, 2008, www.nursingcenter.com/library/static.asp?pageid=800371

"Guide for women with early stage breast cancer", National Breast and Ovarian Cancer Centre, 2010, <http://canceraustralia.nbocc.org.au/download-document/ebc-guide-for-women-with-early-breast-cancer>

"Making the choice: Deciding what to do about early stage prostate cancer", Michigan Cancer Consortium, www.prostatecancerdecision.org

"Melanoma", Melanoma Patients Australia and B. Grace, www.melanomapatients.org/images/stories/information/general_melanoma_information.pdf

"Participating in a trial: Questions to ask your doctor", National Cancer Institute, 2008, www.cancer.gov/clinicaltrials/education/questions-to-ask-about-participating

"Physician/patient decision aids for adjuvant therapy", T.J. Whelan and C. Loprinzi (2005), <http://jco.ascopubs.org/content/23/8/1627.full.pdf>

Question prompt lists, Australian Cancer Trials, 2010, www.australiancancertrials.gov.au/about-clinical-trials/question-prompt-lists.aspx#anchor52

"Questions you might like to ask your doctor", Cancer Council South Australia, 2007, www.cancersa.org.au/resource_library/3/17/Questions_doctor_May2007.pdf

"Self-advocacy: A cancer survivor's handbook", National Coalition of Cancer Survivorship, 2009, www.canceradvocacy.org/assets/documents/self-advocacy-publication.pdf

"So you have cancer: Questions to ask your medical or radiation oncologist", University of Sydney – Medical Psychology Research Unit, www.psych.usyd.edu.au/cemped/docs/comms_Booket2.pdf

"Tips for making decisions about treatment", National Breast and Ovarian Cancer Centre, 2009, <http://canceraustralia.nbocc.org.au/breast-cancer/treatment/tips-for-making-decisions-about-treatment>

Treatment pathway, Bowel Cancer Australia, www.bowelcanceraustralia.org/bca/images/pdf/BCA%20Treatment%20Pathway%20Flowchart_final.pdf

"Understanding your rights: A guide for people with cancer, their families and friends", Cancer Council New South Wales, 2011, www.cancercouncil.com.au/wp-content/uploads/2012/03/Understanding-Your-Rights-NOV-2009.pdf

"What every woman should know about breast cancer", National Breast and Ovarian Cancer Centre, 2009, <http://canceraustralia.nbocc.org.au/our-organisation/video-resources/what-every-woman-should-know-about-breast-cancer>

"What is prostate cancer?", Prostate Cancer Foundation, www.prostate.org.au/articleLive/pages/What-is-Prostate-Cancer.html

"When the woman you love has early breast cancer", CD (Boys Do Cry), National Breast and Ovarian Cancer Centre, 2009, <http://www.canceraustralia.gov.au/publications-resources/cancer-australia-publications/when-woman-you-love-has-early-breast-cancer>

Other resources

"Prostate Cancer: Your Decision Notebook", CD-ROM

"Breast Cancer: Your Decision Notebook", CD-ROM

An interactive CD-ROM that presents evidence-based information about treatment options for patients recently diagnosed with prostate or breast cancer. The program can be ordered from <http://sbir-cancercontrol.cancer.gov>

The best cancer care starts with getting the cancer information you need. Well-informed patients and partners are their own best advocates and invaluable partners for health care providers. **coping together** puts the focus on the patients and their partners, providing the practical information they need to learn new coping skills and build confidence in using them. **coping together** has been put together by a team of researchers and clinicians, including psychologists and nurses, with expertise in helping people cope with cancer.

👤👤 All I wanted was good information about what I had, what my treatment options were, what efficacy rates for those treatment options were. 🗨️

Jesse, diagnosed with prostate cancer.

👤👤 You get a kick in the guts when you're told you've got cancer. Then all you want to do is 'okay, I've got cancer, what are my options? What am I looking at?' You know? That's your primary concern, and making sure you consider all your choices. 🗨️

Lydia, diagnosed with breast cancer.

👤👤 At first I was hesitant to let Betsy know my views on her treatment options, I mean, this was her body, she had to decide. But she made it clear she wanted my support and that this was 'our' decision. We tackled this choice together. 🗨️

Clive, husband of Betsy, diagnosed with bowel cancer.

